**Drive inclusion and equity for children and young people with disability**

**Pre-Budget 2021-22 Submission**

**Children and Young People with Disability Australia**

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# Summary of recommendations

**Recommendation 1: Involve and engage children and young people with disability across all government portfolios impacting their lives**

Children and young people with disability often face barriers to participating in consultative activities that inform policy and service development. This breaches children and young people’s rights and risks government investing in actions that will not work or failing to provide targeted supports where most necessary. Funding is required to develop and implement a National Child and Young Person with Disability Engagement Framework.

**Recommendation 2: Drive and fund transformational change to ensure inclusive education**

Australia’s education system is inequitable and does not adequately support the learning and full inclusion of children and young people with disability. Segregation of students with disability in special schools and classes continues and is growing, despite compelling evidence that inclusion in regular schools leads to better short and long-term outcomes. A National Inclusive Education Plan is required to guarantee compliance with Australia’s international human rights obligations, consistent policies and practice across the country, educational outcomes are monitored and improved, and responsibilities across jurisdictions are clear.

**Recommendation 3: Develop and implement a targeted National Youth Disability Employment Strategy**

Young people with disability experience high rates of unemployment and underemployment. They experience the intersectional disadvantage of being a both young person and a person with disability in the labour market – with this disadvantage expected to be entrenched as a result of the COVID-19 economic down-turn. A targeted National Youth Disability Employment Strategy which spans the career planning and support required in secondary school and the transition to post-school options is required.

**Recommendation 4: Develop a COVID-19 youth recovery response that includes the voices and needs of young people with disability**

Young people are disproportionately affected by the immediate and long-term economic and social impacts of the COVID-19 global pandemic. Within the youth cohort, young people with disability face increased marginalisation. Development and implementation of a COVID-19 youth recovery response is required to address inequities and mitigate negative, enduring consequences.

**Recommendation 5: Ensure young people with disability are not living in poverty**

Nearly half of young people with disability are reliant on income support as their main source of income. The income payments are inadequate for a dignified standard of living – with young people receiving varying rates of payment on an inequitable basis. A review and amendment of the social security system is necessary to ensure that young people with disability are not living in poverty.

**Recommendation 6: Ensure the National Disability Insurance Scheme is fit-for-purpose for children and young people**

The National Disability Insurance Scheme (NDIS) model and service delivery does not take into account the holistic needs of children and young people, including their development, social and emotional needs, and interactions with mainstream services and community life. Additionally, the NDIS does not effectively interface with other service systems, resulting in children, young people and their families experiencing negative outcomes. It is recommended that a NDIS practice framework for working with participants aged 0-25 is developed and rolled out to ensure service improvement and consistency across the country.

**Recommendation 7: Fund outcomes monitoring for children and young people with disability**

The available data and outcomes reporting for children and young people with disability is lacking. While the National Disability Data Asset (NDDA) is a welcomed initiative to help address this issue, an 18-month pilot is too short to monitor or understand any medium or longer-term impacts and outcomes. A full investment and extension of the NDAA is required to ensure its value and effectiveness.

**Recommendation 8: Ensure the Royal Commission into the Violence, Abuse, Neglect and Exploitation of People with Disability can meet its terms of reference**

The terms of reference of the Royal Commission into the Violence, Abuse, Neglect and Exploitation of People with Disability are vast and complex. As such, the Commissioners have called for the Royal Commission to be extended to September 2023. CYDA urges the Government to sufficiently resource this extension so the Royal Commission can effectively identify system failures, recommend change and prevent future incidents of violence and mistreatment.

**Recommendation 9: Adequately resource the new National Disability Strategy’s actions and strategies**

The previous National Disability Strategy 2010-2020 lacked a coordinated approach across policy areas and jurisdictions. As a result, it fell flat on many of its intended outcomes. To ensure that history does not repeat, and the new National Disability Strategy under development can live up to its potential, there must be sufficient resourcing of the proposed actions and strategies. A particular focus on children and young people with disability, which will have lifelong impacts, is also needed.

**Recommendation 10: Boost funding for systemic and individual advocacy for children and young people with disability for better outcomes**

Individual and systemic advocacy organisations are vital mechanisms to support and protect the rights of children and young people with disability. Currently, these organisations are under resourced and unable to meet the high demand, despite the return on investment being well established. Increased funding for disability advocacy services and supports is urgently required.

# 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 5,000 young people with disability, families and caregivers of children with disability, and advocacy and community organisations.

Our vision is that children and young people with disability are valued and living empowered lives with equality of opportunity; and our purpose is to ensure governments, communities, and families, are empowering children and young people with disability to fully exercise their rights and aspirations. We do this by:

* Driving inclusion
* Creating equitable life pathways and opportunities
* Leading change in community attitudes and aspirations
* Supporting young people to take control
* Calling out discrimination, abuse, and neglect.

CYDA welcomes the opportunity to provide a 2021-22 Pre-Budget Submission. The Australian Government, through the Federal Budget, has the power to fund initiatives that will lead to vast improvements in the lives of children and young people with disability. By investing in interventions and strategies that will protect and empower this cohort, the Australian Government can support children and young people to thrive – now and as they transition into adulthood.

When children and young people are given equal opportunities to engage in a quality education, employment, make friends, and enjoy community life, we all benefit – culturally, socially and economically.

# Drive inclusion and equity for children and young people with disability: our recommendations

## Recommendation 1: Involve and engage children and young people with disability across all government portfolios impacting their lives

The rights of children and young people with disability to express their views, and have these views listened to, are articulated in the Convention on the Rights of Persons with Disability (CPRD) and the Convention on the Rights of the Child (CRC), and recognised through a range of legislation and policy in Australia at federal and state levels, including the Disability Discrimination Act (1992), various State Disability Acts, and the Disability Standards for Education (2005).

Article 7(3) of the CRPD states “*Children with disabilities have the right to express their views freely on all matters affecting them, their views being given due weight in accordance with their age and maturity, on an equal basis with other children, and to be provided with disability and age-appropriate assistance to realize that right*”. Article 12 of the CRC states “*States Parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child.”*

However, there are currently few mechanisms to implement these rights in Australia in practice. Children and young people with disability are too often overlooked in policy and service development – including in the previous budget where mention of the group was largely absent.

Children and young people with disability and their distinct needs are regularly missed in government policy. “When children’s rights are considered, children with disabilities tend to be forgotten. When the rights of people with disabilities are considered, children with disabilities tend to be forgotten. Their rights, therefore, are at risk of being marginalised.”[[1]](#footnote-2)

This risks governments investing in interventions and strategies that will not be effective for the almost one in 10 Australian children and young people who experience disability [[2]](#footnote-3) and/or failing to provide targeted supports when and where most necessary.

Children and young people with disability often face barriers to participating in consultative activities that inform policy and service development. The processes are often inaccessible (including inadequate information delivery, meeting structures, interpreters, assistive technology), and we have seen scant evidence that government consultative processes are responding to these needs adequately. This was noted in the recent report commissioned by the Department of Social Services, which confirmed young people with disability “do not find current mechanisms used by governments to engage on these issues appealing, suitable or easy to access.”[[3]](#footnote-4)

At the national level, policy impacting children and young people with disability sits across multiple policy portfolios, including:

* *Education policy and programming* – Services Australia, Department of Social Services (DSS) and Department of Education, Skills and Employment (DESE)
* *Employment policy, services, income support* – DESE
* *Youth policy* – DESE
* *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.

For policy to reflect the needs of children and young people with disability and for the respective departments to follow through on effective service and strategy delivery, governments need to meaningfully consult with, involve and engage children and young people with disability and their families/ caregivers in policy development. This inclusion must be genuine and built on co-design principles.[[4]](#footnote-5)

Disability representative organisations have diverse and engaged networks and specialised knowledge that can promote genuine and safe engagement opportunities for different communities and cohorts; however, they are often not called upon by governments to support in facilitating consultative processes. This risks governments, despite their best intentions, delivering sessions that are not meaningful, accessible or inclusive for target audiences. In contrast, an example of good practice is the Youth Advocacy Support grants program, whereby government has utilised existing organisations to meaningfully engage with different communities of young people. This method of leveraging representative organisations’ expertise should be used consistently across portfolios.

CYDA recommends funding and implementing a National Children and Young People with Disability Engagement Framework for genuine inclusion, built on co-design principles[[5]](#footnote-6). The Framework should be used to input into the National Disability Strategy and other policies and systems that intersect with the children and young people with disability across the multiple portfolios. This framework needs to be developed and implemented in partnership with young people with disability and Disability Representative Organisations, including CYDA, the only national representative organisation focusing solely on the rights and needs of children and young people with disability aged 0-25.

## Recommendation 2: Drive and fund transformational change to ensure inclusive education

Having a quality education helps set us up for life. On an individual level, quality education and levels of educational attainment are linked with increased employment outcomes, higher wage earnings, and reduced reliance on income support as a main source of income later in life.[[6]](#footnote-7) [[7]](#footnote-8) The skills, attributes and knowledge we gain through getting a good education also support us to be active citizens in our community.

The benefits of quality education for society are also widespread. Modelling by Deloitte Access Economics[[8]](#footnote-9) has shown that quality education outcomes for Australian students has spill over effects at the whole-of-economy level, and investment in quality education pays large dividends in the future.

Students with disability do not currently experience quality education on the same basis as their peers. Despite academic reviews revealing there is a lack of evidence to suggest any benefit of segregated education, enrolment in special schools in Australia is increasing.[[9]](#footnote-10) For students in mainstream settings, many are separated from their peers in segregated classes and units and/or are not receiving adequate support to foster their learning and participation in their school community.[[10]](#footnote-11)

These inequitable opportunities have consequential impacts on students’ experiences of education and educational outcomes. A 2019 national youth survey found that compared with those without disability, twice the proportion of respondents with disability reported that they were either dissatisfied or very dissatisfied with their studies.[[11]](#footnote-12) Students with disability leave school before the age of 16 at a rate nearly three times higher[[12]](#footnote-13) than that of their counterparts and are less likely to complete year 12 or attain a tertiary education, such as a gaining a bachelor’s degree or higher.[[13]](#footnote-14)

In contrast to the current education system, inclusive education – whereby all students experience equitable and full participation and membership within the school community – “has positive benefits for everyone”[[14]](#footnote-15), including students with and without disability, 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.[[15]](#footnote-16) 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.”[[16]](#footnote-17)

The Australian Government holds many of the levers for ensuring students with disability are fully included in school. Most importantly, they hold the funding and legislative levers under the *Disability Discrimination Act 1992* and the *Disability Standards for Education 2005*, that have been widely criticised as being ineffective, including by the Committee overseeing the Convention on the Rights for Persons with Disabilities for not providing the [impetus for schools to provide inclusive education](https://www.afdo.org.au/wp-content/uploads/2019/09/UN-Outcomes-Report-on-Australia.pdf).[[17]](#footnote-18) The intent of the legislation to safeguard and uphold the rights of children and young people to an inclusive education is currently failing, with strong inconsistencies in the access and implementation of inclusive practices throughout Australia. A review of policies and practices found that there was a lack of systemic coherence about what inclusive education means and what is required to achieve inclusive education.[[18]](#footnote-19)

The Australian Government plays a critical role in preventing students from bearing the burden of systemic failures and ensuring they can reap the immediate and ongoing benefits of a quality education. A National Inclusive Education Plan is required to guarantee policies and practice are consistent across the country, educational outcomes are monitored and improved, and responsibilities across jurisdictions are clear.

The Australian Coalition for Inclusive Education (ACIE), chaired and co-convened by CYDA and All Means All, 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*](https://acie105204494.files.wordpress.com/2020/11/acie-roadmap-final-26-october-2020.pdf)) to help realise inclusive education and prevent the violence, abuse, neglect and exploitation of students with disability. This plan has been endorsed by disability advocacy and youth-led organisations across the country.

Our roadmap has six key pillars to ensure Australia’s compliance with Article 24 of the CPRD:

* Ensure inclusive education
* Phase out segregated education
* Increase educational outcomes
* Stop gatekeeping and other discrimination
* Eliminate restrictive practices
* Prevent suspensions and expulsions



A nationally agreed Inclusive Education Plan developed with states and territories together with students with disability and their representative organisations would transform education and drive inclusion.

## Recommendation 3: Develop and implement a targeted National Youth Disability Employment Strategy

While it is encouraging to see the investment in youth employment initiatives in the 2020-21 Budget and the recent announcements and development of the Australian Public Service Disability Employment Strategy 2020-25 and the National Disability Employment Strategy – young people with disability, and strategies to address the multi-faceted barriers they face in the workforce, remain largely absent in national policy.

Young people with disability are one of the most disadvantaged cohorts in the labour market. They experience the intersectionality of systemic disadvantage and oppression of both being a person with disability and a young person – with this disadvantage being even further amplified by other demographic factors, such as socio-economic status, ethnicity, gender or sexual diversity, or living in a regional or rural area.

Young people[[19]](#footnote-20) with disability in the labour force are more than twice as likely to be unemployed than older adults[[20]](#footnote-21) with disability (24.7 per cent compared to 7.9 per cent).[[21]](#footnote-22) Young people with disability are also more than twice as likely to be underemployed[[22]](#footnote-23) — meaning they have the capacity and desire to work more hours than what they are currently employed.

According to the Productivity Commission[[23]](#footnote-24), those who experience negative shocks in the labour market, such as those caused by economic down-turn, go on to have ‘scarring’ effects on their longer-term employment and earnings prospects. While the previous Budget acknowledges that young people are disproportionality impacted by the COVID-19 economic crisis, the strategies do not factor in the increased systemic and structural disadvantage in the labour market experienced by young people with disability compared to their peers without disability.

To ensure employment strategies and policies are designed to address the distinct causes of unemployment and underemployment of young people with disability, particularly during the current economic period where they face increased vulnerability, the development of a targeted, fit-for purpose National Youth Disability Employment Strategy is required. As the disadvantage experienced by young people with disability in the labour market is so complex and distinct from other cohorts, a generalised employment strategy for people with disability, which is not co-designed with young people, will not be effective.

This strategy should be planned, implemented and eventually evaluated with the meaningful inclusion of young people. It needs to consider the crucial careers guidance provided at school, and transition between education and post-school options, as recommended in the Senior Secondary Pathways Review.[[24]](#footnote-25) The strategy should also include targeted approaches for young people within the disability community that risk experiencing increased marginalisation in the workforce, such as young Aboriginal and Torres Strait Islander peoples, gender diverse young people and different disability groups.

## Recommendation 4: Develop a COVID-19 youth recovery response that includes the voices and needs of young people with disability

Young Australians are – and will continue to be – disproportionately affected by the economic and social impacts of the COVID-19 global pandemic. The crisis exacerbated existing labour market inequities and acted as a catalyst for a severe reduction in entry-level opportunities and jobs in industries that are dominated by young people.[[25]](#footnote-26) As result, the underemployment and unemployment rates of young Australians surged – more so than for any other cohort.[[26]](#footnote-27)

This economic burden experienced by young people has had consequential impacts on their health and wellbeing. As reported by the Youth Affairs Council Victoria[[27]](#footnote-28), presentations to emergency hospitals with self-harm related injuries rose by 33 per cent. Data collected by the Melbourne Institute at the University of Melbourne[[28]](#footnote-29) demonstrated that nearly one quarter (23 per cent) of young people aged 18 to 24 years reported they were experiencing high mental distress – 14 percentage points higher than in 2017.

The COVID-19 crisis will also have enduring impacts on the financial and social security of the current generation of young people. Negative experiences in the labour market – particularly at such a pivotal life transition – will have long-term impacts on earning and job prospects throughout the lifetime. Young people will also experience a higher tax-burden throughout their careers to bear the costs of government-spending for recovery for all cohorts.[[29]](#footnote-30) Housing stress and unaffordability for young people is also likely to grow – worsening an already inequitable housing market.

Within the youth cohort, some communities and groups, such as young people with disability, are increasingly marginalised and are more vulnerable to inadequate policy responses. A recent research report[[30]](#footnote-31) prepared for CYDA demonstrated how children and young people with disability are more at-risk during the global pandemic, not because of their impairment, but because of discriminatory, limited, or inappropriate policy strategies. The research respondents reported a high rate of uncertainty and lack of necessary supports in areas such as education, employment and access to health services. The authors concluded that these experiences of uncertainty were enhanced for people with disability and their families and that targeted support and information was lacking for this group.

CYDA’s 2020 Education Survey[[31]](#footnote-32) also found that students with disability not were not adequately supported throughout the COVID-19 crisis and the shift to remote learning. Nearly three in five (or 61 per cent) of respondents said students with disability were not received adequate education support during the pandemic, with some students unable to engage in online learning entirely. The survey also found that nearly three quarters of respondents reported that students with disability felt socially isolated from their peers – with this isolation then having significant impacts on their mental health.

In addition to immediate COVID-19 crisis responses, young people with disability also face increased barriers in accessing appropriate supports that would help mitigate the longer-term impacts of COVID-19. This includes appropriate educational, mental health, employment, income and housing supports.

A COVID-19 recovery response for young people is urgently needed. Not only to respond to the financial and social crisis we are currently experiencing, but to ensure that young people do not endure the ongoing negative impacts across their life course. This recovery response must include a lens and plan of action for groups of young people who face increased marginalisation, such as young people with disability. The strategy must be developed alongside young people to ensure it appropriately meets their needs.

Any other COVID-19 response or recovery plans governments develop should also include a youth-lens. As young people are most impacted in the long-term, creating a plan without their distinct needs and strengths factored in risks further disadvantaging the cohort.

## Recommendation 5: Ensure young people with disability are not living in poverty

The social sector[[32]](#footnote-33) has long advocated for an increase in income support payments, with current payments being so inadequate that those who rely on them are overrepresented in living below the poverty line[[33]](#footnote-34). Young people with disability are forced to live on these inadequate payments at a disproportionate rate. Nearly half of young people with disability aged 15 to 24 years (49 per cent) rely on income support payments as their main source of income compared to 14 per cent of those without disability.[[34]](#footnote-35)

While many young people with disability rely on income support, the type of payments they receive has shifted considerably in the last decade. From 2012, policy reforms have been introduced to restrict the growth of Disability Support Pension (DSP) payments, payments for working age people with medical conditions and disability that bring restricted capacity to work.[[35]](#footnote-36) These reforms include most applicants needing to demonstrate they have actively participated in job searching activities for 18 months prior to applying, as well as meeting stringent eligibility requirements against impairment tables.

The complexities of the application process have created additional administrative burden for individuals and in turn, created inequitable impacts for those receiving the payments. People who have less ‘human capital’, such as an education, money, psychological resources or social networks, are less likely to access resources that may help them overcome the administrative burden.[[36]](#footnote-37) Research has also demonstrated that applicants who receive support to complete their DSP form are more likely to have their claim granted than those who do not have assistance.[[37]](#footnote-38)

The change in DSP eligibility and work capacity requirements has subsequently driven many young people to instead access the JobSeeker or Youth Allowances Payments which provide significantly lower rates of pay than the DSP. [[38]](#footnote-39),[[39]](#footnote-40),[[40]](#footnote-41)  Data obtained by CYDA from the Department of Social Services shows that:

* The number of Jobseeker (known as Newstart prior to 2020) recipients aged between 20 and 25 years with partial capacity to work has increased by 372.8 per cent in the decade from 2009, growing from 5,308 in 2009 to 25,096 in 2020
* The number of Youth Allowance recipients under 19 years old with partial capacity to work has increased by 174.9 per cent, from 2,299 in 2009 to 6,319 in 2020
* The number of Youth Allowance recipients aged between 20 and 25 years with partial capacity to work has increased by 970.3 per cent, from 936 in 2009 to 10,018 in 2020
* The number of DSP recipients under 19 years old has decreased by 20.4 per cent, from 18,414 in 2009 to 14,662 in 2020
* The number of DSP recipients aged between 20 and 25 years has increased by 12.6 per cent, from 36,128 in 2009 compared to 40,690 in 2020.

## Figure 1: Trends from 2009 to 2020 of Newstart/Jobseeker Allowance, Youth Allowance with partial capacity to work and Disability Support Pension recipients aged 20 to 25 years

|  |  |  |  |
| --- | --- | --- | --- |
| **Year** | **Newstart/Jobseeker – Partial capacity to work** | **Youth Allowance (Other) – Partial capacity to work** | **Disability Support Pension** |
| **2009** | 5308 | 936 | 36128 |
| **2010** | 6667 | 1318 | 38016 |
| **2011** | 7709 | 1432 | 40133 |
| **2012** | 8905 | 1878 | 41554 |
| **2013** | 9133 | 4708 | 42970 |
| **2014** | 11551 | 5728 | 44451 |
| **2015** | 13428 | 6547 | 44634 |
| **2016** | 15226 | 6857 | 42004 |
| **2017** | 16107 | 6649 | 41216 |
| **2018** | 17685 | 6745 | 40638 |
| **2019** | 19017 | 7681 | 40092 |
| **2020** | 25096 | 10018 | 40690 |

Source: Department of Social Service data provided to CYDA

## Figure 2: Trends from 2009 to 2020 of Youth Allowance with partial capacity to work and Disability Support Pension recipients aged 19 years and under

|  |  |  |
| --- | --- | --- |
| **Year** | **Youth Allowance (Other) – Partial capacity to work** | **Disability Support Pension** |
| **2009** | 2299 | 18414 |
| **2010** | 2754 | 19814 |
| **2011** | 3235 | 20704 |
| **2012** | 3589 | 20317 |
| **2013** | 4246 | 19001 |
| **2014** | 4752 | 18838 |
| **2015** | 4829 | 16978 |
| **2016** | 4649 | 15201 |
| **2017** | 4014 | 14050 |
| **2018** | 4136 | 13601 |
| **2019** | 5100 | 13843 |
| **2020** | 6319 | 14662 |

Source: Department of Social Service data provided to CYDA

For the young people who have successfully gained access to the DSP, the strict eligibility requirements have also created increased barriers to gaining employment, with rates of DSP recipients receiving earnings dropping by 1.7 percentage points between 2009 and 2018 (from 9.3 per cent to 7.6 per cent).[[41]](#footnote-42) CYDA has heard from our membership that young people are reluctant to obtain paid employment as the risk of losing their access to the DSP, which is ultimately their safety net. This is a particular concern of young people with episodic or fluctuating disability.

CYDA urges the Australian Government to review and amend the social security system to ensure that young people with disability are not living in poverty and are adequately supported to find and maintain meaningful employment. This includes:

* increasing the rate of payments to a dignified standard of living that factor in the extra living costs that are associated with living with disability,
* reviewing and amending the eligibility requirements for the DSP to ensure different groups and disability types are not disadvantaged,
* amending the DSP requirements to support recipients to engage in paid employment, and
* ensuring that there is timely and appropriate information and support available for young people to assist them to secure income support payments.

## Recommendation 6: Ensure the National Disability Insurance Scheme is fit-for-purpose for children and young people

Children and young people experience a myriad of biological, psychological and social changes in the first 25 of years of their lives. Along with these individual changes, children and young people also rapidly transition through different life stages and encounter new systems. How they experience these life transitions – and whether there are safeguards in place – then have flow-on impacts on the trajectory of their lives and the opportunities they can access.

Factoring how important and influential these early years are, services and systems must have the capacity to understand and support the distinct needs of children and young people. Despite 57 per cent of all participants being aged 25 years or younger[[42]](#footnote-43), the National Disability Insurance Scheme (NDIS) does not currently have a framework about what it is trying to achieve for young people, or a framework to ensure optimal outcomes across this crucial developmental period. Currently, the NDIS offers the same support system – with the same workforce – to all participants aged seven years and older.

This approach is not supported by neurodevelopmental theory and does not acknowledge the importance of middle childhood and the life transitions that occur for children and teens. While the Early Childhood Early Intervention (ECEI) model does offer a separate service system for participants aged six years or younger, the outsourcing of the service has resulted in children across Australia receiving inconsistent levels and quality of support. The current NDIS process, including the ECEI stream, often does not consider the role of families/caregivers in supporting the development of children and young people, and their inclusion in community and mainstream services.

At a governance level, research has identified that there is a lack of clarity around the boundaries of the NDIS and how it interfaces with different services and systems, including education, health, justice, and child protection.[[43]](#footnote-44) This results in systems ‘passing the buck’ on who is most responsible for providing supports and care. This not only creates increased stress and added time and administrative burden for children, young people, their families and caregivers, but it also risks individuals falling through the gaps between systems.

The NDIS is also intended to provide many young people with employment supports. As at June 2018, nearly half (44 per cent) of young[[44]](#footnote-45) NDIS participants had employment as one of their goals in their plan.[[45]](#footnote-46) However the link between the employment supports young people are accessing through the NDIS and employment outcomes is tenuous, with NDIA figures[[46]](#footnote-47) showing that the rate of young NDIS 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.

One of the more common employment supports received by young NDIS participants is School Leaver Employment Supports (SLES). 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, there is no clear evaluation data to determine if the support is effective and achieving real employment outcomes.

Acknowledging the lack of appropriateness of the current NDIS model and its failing to factor in or cater to the distinct needs of children and young people, CYDA urges the Australian Government to develop an NDIS practice framework for working with participants aged 0-25 to ensure service improvement and consistency across the country. This framework should be accompanied by workforce training and clear accountabilities to ensure continuity of support across systems such as education, health and child protection. The framework should be informed by evidence-based practice and developed with Disability Representative Organisations to ensure its suitability.

## Recommendation 7: Fund outcomes monitoring for children and young people with disability

The current development of the National Disability Data Asset (NDDA) is a welcomed initiative. Data collection on Australians with disability – particularly children and young people – has historically been lacking. As such, it is difficult to ascertain the extent to which people with disability are disadvantaged or thriving in different systems and areas of community life. An example of this is data collected on children and young people in the youth justice system. While the limited data that is available indicates a significant majority of detainees have one or more disability, there is not clear or consistent information on the number of children and young people with disability within youth justice systems, the support they receive, and the outcomes they experience.

While the NDDA is a good start in ensuring that children and young people are adequately supported and do not ‘fall in the cracks in and between systems’, the current investment is only for an 18-month pilot – a relatively short timeframe, particularly considering how many life transitions (which hold potential risks or opportunities) children and young people experience in the first 25 years of their life. With the pilot being so short, the NDDA cannot capture longitudinal data or medium to longer term outcomes. This risks government, advocates and services not fully understanding or misinterpreting what is working, what is not, and where future interventions or change is needed. Ultimately, the effectiveness of the NDAA will be undermined if it is not fully funded.

CYDA recommends the NDDA is fully funded, and that its development and implementation genuinely engage advocates and experts around specific cohorts to ensure the right data is collected to monitor outcomes over time.

## Recommendation 8: Ensure the Royal Commission into the Violence, Abuse, Neglect and Exploitation of People with Disability can meet its terms of reference

People with disability have historically been – and continue to be – subject to widespread and high rates of violence, abuse and neglect. The ongoing Royal Commission into the Violence, Abuse, Neglect and Exploitation of People with Disability (Disability Royal Commission) is a significant piece of work that has helped provide a more comprehensive understanding of this mistreatment, including the settings where it occurs, why it occurs, and the impact it has on individuals and the wider community. Importantly, the Disability Royal Commission has identified system failures and a lack of safeguards which, if improved, could prevent future incidents of violence and mistreatment.

The work of the Disability Royal Commission is an enormous undertaking. Unlike other Royal Commissions and inquiries which tend to have a targeted focus on particular settings or systems, the scope of the Disability Royal Commission is vast and complex. It was initially expected that a final report, including recommendations, would be released by 22 April 2022. However, due to the broad terms of reference and the areas of concern that have arisen through the hearings as well as interruptions caused by COVID-19, the Commissioners have called for the Commission to be extended until September 2023.

CYDA echoes this call and recommends the allocation of funds for the extension of Disability Royal Commission should be reflected in the upcoming Budget. This includes funding support services for individuals as well funding advocacy and representative organisations to help ensure that different groups within the disability community are included on an equal basis for the life of the Royal Commission.

## Recommendation 9: Adequately resource the new National Disability Strategy’s actions and strategies

While the initial *National Disability Strategy 2010-2020* vision and scope was ambitious and welcomed by the disability community, 10 years on it is widely acknowledged the Strategy fell flat in delivering many of its intended outcomes. A review into the implementation of the Strategy commissioned by the DSS[[47]](#footnote-48) and a Senate Inquiry into the delivery of outcomes[[48]](#footnote-49) under the Strategy both identified that there was a lack of a coordinated approach across policy areas and jurisdictions to implement the Strategy and produce tangible outcomes.

A new Strategy is currently being created and is expected to be finalised in 2021. The new National Disability Strategy (NDS) requires a specific focus on children and young people with disability, which will have lifelong benefits. CYDA urges the government to allocate sufficient funding to implement the governance and delivery of the National Disability Strategy, and to ensure children and young people with disability and their representative organisations are meaningfully included in guiding and monitoring the progress of the Strategy’s actions and strategies.

## Recommendation 10: Boost funding for systemic and individual advocacy for children and young people with disability for better outcomes

Systemic advocacy conducted by human-rights based Disability Representative Organisations, like CYDA, work towards reform and change of social systems and structures that discriminate against, or contribute to, the abuse and neglect of 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, to name a few. 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 assist the Australian Government by providing systemic advocacy to ensure inclusive and evidence based public policy. For example, the way CYDA conducts systematic advocacy for children and young people with disability includes; conducting research and conducting consultations and focus groups with our members; responding to government inquiries and reviews to ensure the needs of children and young people with disability are met; being a member of government advisory groups to provide advice; and facilitating collaboration with and across a range of sectors on the rights of children and young people with disability.

“Individual advocacy is when a professional advocate supports a person with a particular problem. An individual advocate either supports a person one-to-one or supports them to advocate for themselves. The advocate will support someone with an issue they have not been able to solve on their own. An individual advocate must be independent, only be on the side of the person with disability, and only represent their interests.”[[49]](#footnote-50)

The main source of funding for individual disability advocacy is through the National Disability Advocacy Program (NDAP) funded by the Australian Department of Social Services, and in some states and territories individual advocacy services receive additional funding from these governments.

While there is a shortage of all individual advocacy services 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 as there are very few specific advocacy services for this cohort, and limited capacity to meet their needs within mainstream disability advocacy services.

CYDA receives hundreds of calls every year from families needing individual advocacy assistance. In our experience, where there are specific state-based organisations for children and young people with disability[[50]](#footnote-51), it is easier for young people with disability and their families/caregivers to have their issues resolved. In many states and territories there are no specialised services, and we hear numerous reports of the difficulty young people and families have in accessing the support they need.

For the rights of children and young people with disability in Australia to be upheld in line with the CRPD, we believe there should be a boost in funding for both systemic and individual advocacy. Research shows this will bring a return on investment to governments (by diverting issues away from other government services and systems) of $3.50 for every $1 invested.[[51]](#footnote-52) While this cost-benefit analysis examined individual advocacy for people with disability across the life course, it is reasonable to assume the return would be greater when investing in advocacy services for children and young people with disability given the evidence around early intervention and the importance of development opportunities in the 0-25 year period for later life outcomes.

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11. 16.1 per cent compared with 6.9 per cent of participants without disability; Mission Australia. (2019). *Young, willing and able*: *Youth Survey Disability Report 2019*. Available at https://www.missionaustralia.com.au/publications/youth-survey/1610-young-willing-and-able-youth-survey-disability-report-2019/file [↑](#footnote-ref-12)
12. 10.9 per cent of young people aged 15 to 24 have left school before the age of 16 compared to 3.6 per cent of young people without disability; AIHW. (2020). *People with disability in Australia.* Available at [https://www.aihw.gov.au/reports/disability/people-with-disability-in-australia/contents/education-and-skills/educational-attainment](https://www.aihw.gov.au/reports/disability/people-with-disability-in-australia/contents/education-and-skills/educational-attainment%20) [↑](#footnote-ref-13)
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15. ibid. [↑](#footnote-ref-16)
16. Cologon, K. (2013) *Inclusion in Education: Towards Equality for Students with Disability,* Children with Disability Australia, Melbourne, p.3. [↑](#footnote-ref-17)
17. Concluding Observations: UN Report on Australia’s Review of the Convention on the Rights of Persons with Disability (CRPD), 24 September 2019 [↑](#footnote-ref-18)
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Professor Anne Daly Discipline of Economics University of Canberra Greg Barrett Canberra Rhiân Williams Canberra https://www.dana.org.au/wp-content/uploads/documents/Disability-advocacy-CBA-2.pdf [↑](#footnote-ref-52)