



Children and Young People
with Disability Australia

**Submission to the Disability Royal Commission in
response to the Rights and Attitudes Issues Paper**

October 2020

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Executive summary

Children and young people with disability need a childhood, adolescence, and early adulthood just like everyone else. They need to have loving home environments, where their families have high expectations and hopes for their future, they need to be involved in high quality early childhood education and care, have a good transition to school, and be educated alongside their peers with high quality curriculum. They need opportunities to experience extracurricular activities, build friendships and peer networks, take risks, and go through rites of passage with, and like, everyone else. Sadly, we know that for many young people with disability, these inclusive opportunities – to learn, develop, and grow alongside diverse and non-disabled young people – are the exception rather than the rule.

In order to meet its Terms of Reference, the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (DRC) must examine the experiences of children and young people in depth, so future generations do not face the same discrimination, neglect, violence, and abuse that children and young people face today. What happens between birth and 25 years of age is critical for the child and young person and their development at the time, and also has substantial impacts on their later lives – support and interventions here are important to prevent violence, abuse, neglect and exploitation of people with disability in adulthood.

In this submission we cover the rights for children and young people with disability, and the challenges they face in having their rights upheld. We also discuss the importance of representative organisations for children and young people with disability and the crucial role of independent, systemic, individual, and self-advocacy to assist in upholding their rights. Supportive community attitudes to disability must begin in childhood and the early years of life and be a key priority for all governments and other stakeholders across Australia.

Recommendations

Ensure the rights of children and young people with disability

- The new 10-year National Disability Strategy has a strong commitment and focus on ensuring the rights of children and young people with disability, as outlined in the UN CRPD, can be fully realised in the next 10 years
- The DRC conducts full inquiry into the rights of children and young people with disability across all domains and with a focus on the prevention of violence, abuse, neglect, and exploitation in the future
- There be stronger legislation, monitoring and accountability of the rights of children and young people with disability

Provide advocacy services for children and young people with disability

- 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
- In every state and territory in Australia there is funded cross-disability human-rights based individual advocacy with speciality in promoting the rights of children and young people with disability

- The NDIS Information, Linkages and Capacity Building Program has a focus on building the capacity of children and young people with disability to become self-advocates

Change community attitudes about children and young people with disability

- The next 10-year National Disability Strategy has a major focus on changing community attitudes to disability
- The NDIS has a clear focus and accountability for promoting full inclusion, and strong developmental pathways and transitions for children and 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 0-25 years. CYDA has an extensive national membership of over 5,000 young people with disability, families and caregivers of children with disability, with the majority of our members being families.

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

- Listen and respond to the voices and experiences of children and young people with disability.
- Advocate for children and young people with disability for equal opportunities, participation and inclusion in the Australian community.
- Educate national public policy-makers and the broader community about the experiences of children and young people with disability.
- Inform children and young people with disability, their families and care givers about their citizenship rights and entitlements.
- Celebrate the successes and achievements of children and young people with disability.

CYDA is pleased to provide this response to the Disability Royal Commission's rights and attitudes issues paper.

Ensure the rights of children and young people with disability

Recommendations:

- The new 10-year National Disability Strategy has a strong commitment and focus on ensuring the rights of children and young people with disability, as outlined in the UN CRPD, can be fully realised in the next 10 years
- The DRC conducts full inquiry into the rights of children and young people with disability across all domains and with a focus on the prevention of violence, abuse, neglect and exploitation in the future
- There be stronger legislation, monitoring and accountability of the rights of children and young people with disability

Children and young people with disability need a childhood, adolescence and early adulthood just like everyone else. They need to have loving home environments, where their families have high expectations and hopes for their future, they need to be involved in high quality early childhood education and care, have a good transition to school, and be educated alongside their peers with high quality curriculum. They need opportunities to experience extracurricular activities, build friendships and peer networks, take risks, and go through rites of passage with, and like, everyone else. Sadly we know that for many young people with disability, these inclusive opportunities – to learn, develop, and grow alongside diverse and non-disabled young people – are the exception rather than the rule.

Australia is a signatory to both the United Nations Convention on the Rights of Persons with Disabilities (CRPD) and the Convention on the Rights of Child (CRC). These human rights instruments must both be considered in order to uphold the human rights of children and young people with disability. While the CRPD covers the full spectrum of disability, some rights are more relevant to children and young people with disability and these are explored in our submission.

In order to meet its Terms of Reference, the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (DRC) must examine the experiences of children and young people in depth, so future generations do not face the same discrimination, neglect, violence, and abuse that children and young people face today. What happens between birth and 25 years of age is critical for the child and young person and their development at the time, and also has substantial impacts on their later lives – support and interventions here are important to prevent violence, abuse, neglect and exploitation of people with disability in adulthood.

CYDA's submission on the "Draft Accessibility Strategy of the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability"¹ noted that children and young people with disability were largely absent from the strategy draft, and we have not yet seen an updated version. It is crucial the DRC explores the specific risks to children and young people with disability and the violence, abuse and neglect they face. The direct participation of children and young people with disability and their families must be prioritised, including accessible and safe ways to capture their voice in submissions and formal and informal processes.

¹ Children and Young People with Disability Australia (2019) [Draft Accessibility Strategy of the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability](#)

Having a voice and being heard

The rights of children and young people with disability to express their views, and have these views listened to, are articulated in the CRPD and the 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.

CYDA is the national representative organisation for children and young people with disability. The CRPD explicitly recognises the role of representative organisations for children and young people’s participation (outlined in this submission under the section “importance of representative organisations”). However, other than through their representative organisations, there are very few ways for children and young people with disability to have a voice and be heard.

For example, 57% of current National Disability Insurance Scheme (NDIS) participants are aged under 25,² however there are no formal consultative forums that involve young people with disability, or families of young children. Additionally, despite one in five Australian students requiring adjustments in their education as a result of disability³, there are few mechanisms for them to be given voice at the school level or the regional and systems levels (state/territory/Australian jurisdictions).

In a report commissioned by CYDA in 2014, “Strengthening Participation of Children and Young People with Disability in Advocacy”, 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.⁴”

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.

² NDIA. (2020). *Simple participant data tool*. Available at https://data.ndis.gov.au/explore-data/simple-participant-data-tool?filter_one=age#search-participants-data-form

³ Steering Committee for the Review of Government Service Provision, Report on Government Services 2020: School education Data tables, February 2020, Table 4A.7 and Table 4A.3d

⁴ Simmons, C., Robinson, S. (2014) Strengthening Participation of Children and Young People with Disability in Advocacy. Report prepared for Children and Young People with Disability Australia.

<https://www.cyda.org.au/resources/details/86/strengthening-participation-of-children-and-young-people-with-disability-in-advocacy> p. 5

- Systemic level: influencing change at a society/policy level.⁵

The 2014 CYDA 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.⁶”

In 2020 CYDA received funding for two three-year NDIS Information Linkages and Capacity Building (ILC) projects to develop the leadership capacity of young people with disability. This includes the “National Youth Disability Leadership Program”, and in consortium with the Youth Affairs Council of Victoria (YACVic) and the Youth Disability Advocacy Service (YDAS) the “Victorian Emerging Leaders Program”. Both these projects aim to support young people with disability to build peer networks and develop their leadership and self-advocacy skills. As a result of this funding, our recent five day [National Youth Disability Summit](#) attracted over 250 registrations from young people with disability, which is as far as we know the largest event of its type for young people with disability in Australia.

While these and other community-led projects are hugely valuable, they are insufficient to ensure the inclusion of, and response to, children and young people’s voices and experiences at the system level. This requires active investment and commitment from governments at all levels. Government agencies and authorities must seek out and resource the safe and meaningful participation of children and young people with disability, supported by disability advocacy organisations like CYDA.

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.⁷ 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.

⁵ Lord, J. E., Guernsey, K. N., Balfe, J. M., Karr, V. L., & deFranco, A. S. (2012). Human Rights. Yes! Action and Advocacy on the Rights of Persons with Disabilities. In N. Flowers (Ed.), Human Rights Education Series, Topic Book 6, 2nd Edition (2nd ed.). Minnesota: University of Minnesota Human Rights Center, BlueLaw International, LLP on behalf of One Billion Strong.

⁶ Simmons, C., Robinson, S. (2014), p. 33

⁷ “Co-design is a process used to create products, services and programs. It brings people in as ‘design partners’, giving a voice to those who are often excluded from the design process. Decision-making, design, information sharing and project planning are among the equal roles between trained designers and design partners.” See, Future Social Service Institute (2018), RMIT University, What is Co-design? <https://www.futuresocial.org/wp-content/uploads/2018/08/FSSI-CoDesign-one-pager.pdf>

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 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/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. For children 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.⁸

Inclusive education

Article 24 of the CRPD and General Comment 4 (2016) are clear on the obligations of state parties to provide inclusive education for students with disability. CYDA has engaged extensively with the Disability Royal Commission on the topic of inclusive education for all students with disability. This includes:

- [Education of children and young people with disability Submission](#), October 2019
- [The review of senior secondary pathways into work, further education and training, Submission](#), December 2019
- [Driving change: a roadmap for achieving inclusive education in Australia](#), joint submission from the Australian Coalition for Inclusive Education, CYDA is chair, June 2020
- [Principles and recommendations for providing inclusive education for children and young people with disability in a 'time of crisis'](#) joint submission from the Australian Coalition for Inclusive Education, CYDA is chair, July 2020
- Witness Statement, COVID-19 Hearing, August 2020
- Overview of Responses to the First Education and Learning Issues Paper: Response by Australian Coalition for Inclusive Education, August 2020
- Witness Statement, Education and Learning Hearing, September 2020

Additionally, over the last 10 years CYDA has provided more than 40 submissions to Australian and state and territory governments to ensure the right to inclusive education is upheld, yet little has changed over this time.

Students with disability routinely face exclusion, segregation, discrimination, gatekeeping, and abuse and neglect in their education, with few consequences if schools or jurisdictions do not comply with Article 24 of the CRPD – or with the *Disability Standards for Education*, which sit under the *Disability Discrimination Act 1992*. The *Disability Discrimination Act 1992* (DDA) is the primary domestic means promoting the rights and entitlements of people with disability and eliminating

⁸ Greer, A. M., Amlani, A., Burmeister, C., Scott, A., Newman, C., Lampkin, H., ... & Buxton, J. A. (2019). Peer engagement barriers and enablers: insights from people who use drugs in British Columbia, Canada. *Canadian Journal of Public Health: A Publication of The Canadian Public Health Association*, 110(2), 227. <https://doi.org/10.17269/s41997-018-0167-x>

discrimination. Although the DDA makes it unlawful to contravene the Standards, the lack of accountability for non-compliance remains concerning. Given the limited accountability and compliance mechanisms at the state/territory and national levels, there is an important role for the Royal Commission in making decisive and strong recommendations to ensure students' right to inclusive education is upheld.

Article 8 (2, b) of the CRPD confirms state parties have an obligation to promote understanding and respect for the rights of persons with disability, through *“fostering at all levels of the education system, including in all children from an early age an attitude of respect for the rights of persons with disabilities”*.

Delivering genuinely inclusive education in every school is crucial to ensure children and young people with disability are visible, included, embraced and valued in all parts of our community from a young age. Significant evidence shows there are benefits for all students, not just those with disability, and for the broader school community, from inclusive education.⁹ Additionally, research around community attitudes and social change indicates that childhood is the key period for promoting and developing inclusive and equitable attitudes at the population level.¹⁰ Additional measures to ensure disability and its diversity is valued as a part of life would be including disability studies and disability rights in the Australian curriculum (including in civil rights content) and fostering disability pride and intersectionality approaches in schools.

Providing pathways securing employment

Article 27 of the CRPD articulates the rights of *“persons with disabilities to work, on an equal basis with others; this includes the right to the opportunity to gain a living by work freely chosen or accepted in a labour market and work environment that is open, inclusive and accessible to persons with disabilities”*.

Improving post-school outcomes for young people with disability, and supporting wellbeing throughout their lives, begins with positive and inclusive experiences in schools. People with disability in Australia are less likely to finish school and more likely to leave before the age of 16, and less than a third of people with disability aged 20 or over have completed Year 12-level schooling – compared with 62 per cent of people without a disability¹¹. High rates of school disengagement, lack of tailored support, and continuing segregating in schools contribute to poorer post-school opportunities and outcomes for young people with disability.

Our submission to the DRC on post-school pathways¹² highlighted the systemic issues faced by students with disability securing effective post-school transition support. CYDA's forthcoming response to the Disability Royal Commission's Employment Issues Paper similarly identifies the ways that systemic neglect impacts the employment opportunities of young people with disability; and makes a number of recommendations, including the need for:

- Investment in tailored supports for young people with disability to engage in work experiences

⁹ See Kathy Cologon, Towards inclusive education: a necessary process of transformation, Commissioned report prepared for CYDA, 2019

¹⁰ Cara Gleeson, C., Kearney, S., Leung, L. & Brislane, J. (2015). *Respectful Relationships Education in Schools: Evidence Paper*. Available at https://d2bb010tdzqag7.cloudfront.net/wp-content/uploads/sites/2/2019/06/24035720/Evidence-paper-respectful-relationships-education-AA-updated_1.pdf

¹¹ Australia Institute of Health and Welfare (2019). <https://www.aihw.gov.au/reports/disability/people-with-disability-in-australia/educationand-skills>

¹² CYDA (2019) [The review of senior secondary pathways into work, further education and training, Submission](#)

- Improved monitoring and public release of caseload and outcome data of young people with disability in employment programs
- Inclusive, accessible, and age-appropriate employment programs that are designed to address barriers to employment.

Independent living in the community

Article 19 (a) of the UN CRPD states *“persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangements”*.

The transition for young people with disability into independent living of their choice, away from their families, is a key need and part of their growth and development, as for other young people. However, young people with disability consistently tell us that access to accessible, affordable housing of their choice is a significant worry for them. Those involved in co-designing CYDA’s recent [National Youth Disability Summit](#) selected the NDIS and Housing as one of five priority topics to cover. These concerns are borne out by data which shows 5,000 younger people (under the age of 65) currently live in residential aged care facilities or at risk of placement there.¹³

More information from what young people want in the transition to independent living will be provided in future submissions by CYDA to the DRC.

Sexual and reproductive rights

UN CRPD Article 23 (a, b, c) recognises the rights of persons with disabilities *“to marry and to found a family on the basis of free and full consent”, “to decide freely and responsibly on the number and spacing of their children and to have access to age-appropriate information, reproductive and family education .. to enable them to exercise these rights”* and states that *“persons with disabilities, including children, retains their fertility on an equal basis with others”*.

In the Civil Society Shadow Report to the UN Committee on the Rights of Persons with Disabilities CRPD Review 2019, of which CYDA was a co-author, we noted:

- A parent with disability in Australia is up to ten times more likely than other parents to have a child removed from their care, often based on parental disability rather than evidence of neglect or abuse
- More than 15% of people with disability report difficulty accessing services to assist with being a parent
- People with disability in Australia experience gross violations of their sexual and reproductive rights
- Women with disability and LGBTIQ+ people with disability experience significant discrimination in accessing assisted reproductive technologies.¹⁴

There were a number of recommendations made in this report including “enacting national uniform and enforceable legislation prohibiting sterilisation and medically unnecessary interventions of

¹³ Australian Healthcare and Hospitals Association and Young People in Nursing Homes National Alliance (2020), *Improved support for younger people in residential aged care a welcome development*, Media release, 30 September.

¹⁴ Disability Rights Now (2019) *Australian Civil Society Shadow Report to the United Nations Committee on the Rights of Persons with Disabilities: UN CRPD Review 2019*, p. 34

people with disability and people with intersex variations in the absence of their prior, fully informed and free consent”¹⁵.

Women with Disability Australia (WWDA) has led long, sustained advocacy around the violation of people with disability’s sexual and reproductive rights, including forced sterilisation or other forms of medical interventions which seek to suppress normal bodily functions like menstruation. Current legislative frameworks around Australia mean that “girls with disability can continue to be sterilised for non-therapeutic reasons as long as guardians and health practitioners are able to demonstrate it is in her ‘best interests’”¹⁶.

School-based sexuality education is important for “assisting young people to find reliable information, supporting their decision-making, reducing risky sexual behaviour and consequently preventing the increase in sexual infections. In fact, young Australians themselves nominate school programs as one of the sources they use most for information on sexual health.”¹⁷ Unfortunately, for young people with disability this issue is often shrouded in secrecy and there are few accessible and inclusive sexuality education programs, which can leave them at greater risk of experiencing abuse.¹⁸

Two sessions were held on [sexual health](#) at CYDA’s recent National Youth Disability Summit, one for young people aged 15-17 years and one for those over 18 years. The lack of specific resources around sex and sexuality for young people with disability, and the need for greater support and accessibility of options for those in potentially abusive relationships were key themes raised by the 18+ group. Many young people in our under 18 group noted this was the first time they had access to sexuality education that was inclusive of intersectionality such as disability, gender and sexuality; and some noted this was the first time they had access to any sexuality education at all. Many commented they wish they had been able to access this sort of information sooner, and one young person shared their experience of being actively excluded from sex education classes at their school, and while other students in their class participated, they were required to do other work.

Much more needs to be done to empower young people with disability for their sexual, gender and relationship development and rights. CYDA supports WWDA’s recommendations to end the violation of people with disability’s sexual and reproductive rights in Australia.¹⁹

Violence, abuse and safeguarding

The Preamble of the CRPD (q) states “*women and girls with disabilities are often at greater risk both within and outside the home, of violence, injury or abuse, neglect or negligent treatment, maltreatment or exploitation*”. Article 16 (5) outlines the obligations of state parties to “*put in place effective legislation and policies, including women and child -focused legislation and policies, to ensure that instances of exploitation, violence and abuse against persons with disabilities are identified, investigated and, where appropriate, prosecuted*”

¹⁵ Ibid. p.10

¹⁶ Dunn, C (2018), *The Sterilisation of Girls with Disability: The State Responsibility to Protect Human Rights*, published by Women with Disabilities Australia <https://wwda.org.au/publication/the-sterilisation-of-girls-with-disability/>

¹⁷ Carman, M., Mitchell, A., Schlichthorst, M., & Smith, A. (2011). Teacher training in sexuality education in Australia: how well are teachers prepared for the job?. *Sexual Health*, 8(3), 269-271.

¹⁸ McDaniels, B. W., & Fleming, A. R. (2018). Sexual Health Education: A Missing Piece in Transition Services for Youth with Intellectual and Developmental Disabilities? *Journal of Rehabilitation*, 84(3), 28–38.

¹⁹ WWDA (2016) ‘*WWDA Position Statement 4: Sexual and Reproductive Rights*’. September 2016, Hobart, Tasmania.

The abuse and neglect of children and young people with disability is a longstanding and pervasive social problem. Children and young people with disability experience violence and abuse at approximately three times the rate of children without disability²⁰.

Australia does not have 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. This leads to a current lack of clarity and other issues around intersections between the NDIA, the NDIS Quality and Safeguards Commission, and state-based systems affecting children and young people with disability, including education, health, justice, and child protection.

Continuing interface issues for children and young people and their families/caregivers navigating these systems lead to poorer outcomes and can contribute to tragic outcomes for children who fall through the cracks between systems, as we saw in Queensland recently with the terrible treatment and death of Willow Dunn²¹ and the shocking abuse experienced by two autistic brothers²².

Children and young people with disability are over-represented in child protection services, out-of-home care and youth justice – but there is insufficient monitoring or accountability for reporting to identify the systemic abuse and neglect that has either led them to these systems or is an outcome of their involvement in the systems. A recent report from South Australia found that 9 in 10 of the detainees in an Adelaide youth justice facility had disability related needs.²³ CYDA's response to the DRC's criminal justice system issues paper provides a number of recommendations to improve systems for these young people.

There is considerable risk that further harm will occur to children and young people with disability without change to the ways that safeguarding mechanisms are currently implemented and overseen. CYDA is currently preparing a submission to the DRC on child protection and out of home care. We encourage the DRC to take a deep look into this issue. We are aware to date there has not been an issues paper or hearing held on this important issue, noting the upcoming First Nations hearing will investigate child protection issues.

Accountability, oversight and monitoring

Article 31 (1) of the UN CRPD calls on state parties to *“collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the present Convention”* and 31 (2) says the information *“shall be disaggregated, as appropriate, and used to help assess the implementation ... and to identify and address the barriers faced by persons with disabilities in exercising their rights.”*

Article 33 covers national implementation and monitoring, including placing a framework for implementation in a central place in government and 33 (3) *“Civil society, in particular persons with disabilities and their representative organizations, shall be involved and participate fully in the monitoring process”*.

²⁰ See, Robinson 2012, *Enabling and Protecting: Proactive approaches to addressing the abuse and neglect of children and young people with disability*, p. 12; Children and Young People with Disability Australia, Melbourne. See also: Robinson, S. & McGovern, D. (2014) *Safe at School? Exploring safety and harm of students with cognitive disability in and around school*. Lismore, Centre for Children and Young People. Report completed for the NSW Law and Justice Foundation.

²¹ Brisbane Times, May 2020, [Willow Dunn suffered 'sustained mistreatment', police allege](#)

²² The Guardian Australia, May 2020 [Queensland launches investigation into treatment of malnourished teens in Brisbane](#)

²³ SA Training Centre Visitor (2020) *Great responsibility: Report on the 2019 Pilot Inspection of the Adelaide Youth Training Centre (Kurlana Tapa Youth Justice Centre)*, Government of South Australia.

Currently across Australia there are few mechanisms that holistically plan for and monitor the rights of children and young people with disability. While both the National Disability Strategy 2010-20 (NDS) and the National Framework for Protecting Australia's Children 2009-20 offered an opportunity to ensure the rights of children and young people with disability are upheld and they are free from violence, abuse, neglect and exploitation, in reality little has changed since their introduction.

The 2019 review of the implementation of the National Disability Strategy found “people with disability from culturally and linguistically diverse and Indigenous backgrounds, women with disability, children with disability, LGBTI people with disability and other intersectional groups are not currently identified as groups with distinct or additional needs in the text of the Strategy.”²⁴ The report noted these groups experience specific barriers and need to be included in the next NDS. The review also identified the unproductive governance arrangements for the Strategy as the key roadblock to its effective implementation.

It is extremely difficult to monitor the violence and abuse of children and young people with disability and the National Framework for Protecting Australia's Children has weak mechanisms and data for oversight of children and young people. While both the NDS and the National Framework for Protecting Australia's Children are national strategies, state and territory governments are responsible for delivering major services that impact on children such as child protection, early childhood education and schooling and post-school transition, youth justice etc.

In order to be effective, measures to improve the safety and wellbeing of children and young people with disability must consider the challenges of our federated system and respond appropriately. One overarching strategy with few accountability measures, like the NDS, is likely to be insufficient in the future to realise the change needed. The DRC provides a unique opportunity to consider ways to cut across federal, state and territory responsibilities and recommend changes that will genuinely improve outcomes for, and protect the safety of, children and young people with disability.

The UN Committee on the Rights of Persons with Disabilities released its Concluding Observations following its review of Australia's compliance with the CRPD in September 2019. Notably, the Committee expressed serious concerns about a range of issues and strongly criticised, among other things, current legal and policy frameworks, and the general failure of Australia to harmonise domestic legislation with the CRPD.

On the whole, it can be concluded that successive Australian governments have failed to take effective steps to ensure appropriate national or state/territory legislative protections, accessible processes for making complaints and monitoring bodies and mechanisms to conduct systemic inquiries and report on how or whether these rights are being upheld. This includes the failure to establish effective processes involving people with disability through their representative organisations in monitoring the implementation of the CRPD.²⁵

²⁴ Davy, L., Fisher, K.R., Wehbe, A., Purcal, C., Robinson, S., Kayess, R., Santos, D. (2019). Review of implementation of the National Disability Strategy 2010-2020: Final report. (SPRC Report [4/19]). Sydney: Social Policy Research Centre, UNSW Sydney. <http://doi.org/10.26190/5c7494b61edc4>, p. 23

²⁵ Children and Young People with Disability Australia and All Means All – The Australian Alliance for Inclusive Education (2019), Joint submission to Inquiry into free and equal: an Australian conversation on human rights, Australian Human Rights Commission <https://www.cyda.org.au/resources/details/65/inquiry-into-free-and-equal-an-australian-conversation-on-human-rights>

Data gaps

There are also major data gaps for children and young people with disability across their life course (illustrated in Figures 1 and 2 below).

Figure 1: Services and supports available for children and young people with disability to promote full inclusion and rights



Figure 2: Key risks across the life course



While disaggregated data by disability and by age is extremely difficult to obtain (and in many cases is not collected), it is almost impossible to get data for children and young people with disability with other intersectional characteristics such as gender, those from First Nations or culturally and linguistically diverse communities, socio-economic status or location (e.g. rural/remote). Examples of current data gaps to monitor risk and full participation and rights of children are set out in the following table.

Some of the data is available through Freedom of Information requests, which CYDA has undertaken on many occasions, however the DRC could compel a range of jurisdictions to provide data about children and young people to inform its investigation and recommendations.

Table 1. Data gaps for children and young people with disability

| Area | Data Gap |
|---------------------------------------|--|
| Child protection and out-of-home care | <p>No national consistency of data for children and young people with disability: subject to an investigation of a notification</p> <ul style="list-style-type: none"> • on a care and protection order • in out of home care and the type of care arrangements e.g. residential, foster, kinship, or any other type of out of home care • who received child protection services • the subject of substantiations • the subject of non-substantiated cases • in voluntary out of home care and the type of out of home care e.g. residential, foster, kinship, or any other type of out of home care • on care and protection orders or out of home care and their enrolment in education including early childhood and school education (specifying if it is a special school or a general education school) and post-secondary education, • on care and protection orders or out of home care who are NDIS participants |
| Safeguarding– data gaps | <ul style="list-style-type: none"> • NDIS Quality and Safeguarding Commission reporting on children and young people with disability • Child safety bodies –state/territory commissioners, different legislation/roles • Children in out-of-home care/ youth justice – data on appropriate health checks/assessments/ underdiagnosed disability • Restrictive practices prevention fragmented across all settings - education, disability services, out of home care, justice |
| Education | <p>Enrolment and settings</p> <ul style="list-style-type: none"> • Enrolment of children with disability in Early Childhood Education and Care as a % of total population at same age • Number of students experiencing segregated education settings (e.g. ‘special school’ ‘specialist’ school or unit or classroom, ‘schools for specific purposes’, ‘special developmental’ schools, ‘education support’ units, ‘flexible learning’ centres, ‘learning studios’, ‘learning support’ centres, ‘multi categorical’ classes, diverse learning programs, learning enrichment centre, resource centres, disability units, and even ‘inclusive learning’ units and others) • Number of students home-schooling and why (e.g. experienced gatekeeping, educational neglect and discrimination) |

| Area | Data Gap |
|------------------------|---|
| | <ul style="list-style-type: none"> • Progress and accountability in phasing out segregated education as per CRPD <p>Educational inclusion</p> <ul style="list-style-type: none"> • Student voice and satisfaction • Attendance including full-time/part-time • Learning and engagement • Educational achievement • NCCD supports and adjustments provided • NCCD funding provided and spent <p>Educational exclusion and abuse</p> <ul style="list-style-type: none"> • Gatekeeping • Suspensions/expulsions • Restrictive practices • Bullying • Other forms of abuse and discrimination |
| Post school transition | <ul style="list-style-type: none"> • Transition supports provided in school and pathways • Type of school setting and educational outcomes • Lack of public data of young people aged 15-24 years and: <ul style="list-style-type: none"> ○ Vocational and higher education ○ Employment in ADEs ○ Employment in open employment ○ Income support and type (e.g. Job seeker, youth allowance, partial capacity to work DSP) |
| NDIS – data gaps | <p>Impact of NDIS for 0-25 years (56% of all participants) in:</p> <ul style="list-style-type: none"> • supporting educational inclusion in mainstream settings • supporting community inclusion • supporting development of peer networks • impact of support coordination on accessing high quality services • impact of School Leaver Employment Supports (SLES) on employment outcomes • transition to independent living |

The examples above are only some of the data gaps that currently exist around children and young people with disability in Australia. Alongside a new National Disability Strategy that adequately promotes the rights of children and young people, we need a comprehensive data strategy that monitors progress and outcomes over time.

Provide advocacy services for children and young people with disability

Recommendations:

- Ensure there is always a funded national children and youth representative organisation (CYDA) under Australia's obligations under the CRPD
- Boost funding to human-rights based Disability Representative Organisations providing strategic and systemic policy advice to government to ensure the rights of people with disability are upheld
- In every state and territory in Australia there is funded cross-disability human-rights based individual advocacy with speciality in promoting the rights of children and young people with disability
- The NDIS Information, Linkages and Capacity Building Program has a focus on building the capacity of children and young people with disability to become self-advocates

Importance of representative organisations

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 (3 directors) and family members of children with disability (4 directors), and our work is guided by and commits to the principles and rights recognised in the CRPD. The majority of CYDA's 12 staff are either people with a lived experience of disability (5 staff members), or family members of a person with disability (4 staff members).

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).

The CRPD expressly recognises the obligations of State parties to "*closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations*" (Article 4.4) and to involve "*in particular persons with disabilities and their representative organizations*" in monitoring the implementation of the CRPD (Article 33.3).

Subheading A in Part II of General Comment No.7 is titled "*Definition of 'representative organizations'*" and gives a comprehensive definition and explanation of "representative organizations" which begins by stating that "*the involvement and participation of persons with disabilities through 'representative organizations', or organizations of persons with disabilities, is inherent in both articles 4 (3) and 33 (3)*".

Paragraph 11 goes on to describe the general characteristics of "*organizations of persons with disabilities*" and then paragraph 12 specifically outlines "*different types of organizations of persons with disabilities that the Committee has identified*", including:

“Organizations including family members and/or relatives of persons with disabilities, which are pivotal in facilitating, promoting and securing the interests and supporting the autonomy and active participation of their relatives with intellectual disabilities, dementia and/or children with disabilities, when these groups of persons with disabilities want to be supported by their families as united networks or organizations. In such cases, these organizations should be included in consultation, decision-making and monitoring processes. The role of parents, relatives and caregivers in such organizations should be to assist and empower persons with disabilities to have a voice and take full control of their own lives. Such organizations should actively work to promote and use supported decision-making processes to ensure and respect the right of persons with disabilities to be consulted and to express their own views.”

This acknowledges that some types of organisations of persons with disabilities, namely organisations representing people with intellectual disabilities, dementia and/or children with disabilities, can include family members in recognition of the fact that to deny the status of these types of organisations would result in further marginalisation of these groups.

We note the particular efforts by the CRPD Committee to highlight children with disability in this context, given the additional barriers they face in relation to representation. Indeed, Article 4.4 of the CRPD and the title of General Comment No.7, expressly mention *"children with disabilities"*.

Paragraph 42 of General Comment No.7 then notes the duty of State parties under the CRPD to *"closely and timely consult with, and actively involve, persons with disabilities, through their representative organizations, including those representing women and children with disabilities, in the development and implementation of legislation and policies to implement the Convention and in other decision-making processes"* and paragraph 74 further urges State parties to *"take steps to ensure the participation and the active involvement of children with disabilities, through their representative organizations"*.

For a range of reasons including legal requirements, representative organisations of children with disabilities are generally governed by boards which include family members. That is true of CYDA as well where we have both young people with disability and family members on our board. It is important the DRC and other stakeholders are aware that there is a movement to define Disabled Persons Organisations as distinct from Disability Representative Organisations, noting the CRPD does not use the terminology of Disabled Persons Organisations.

This can mean organisations representing the rights of children and young people with disability are discounted by stakeholders as not being a disabled persons representative organisation. This can work against children and young people with disabilities' voices being heard.

“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 marginalized”²⁶

A recent example of this was during the COVID-19 situation. In the evidence we provided to the Disability Royal Commission COVID-19 hearing, we noted that children and young people with disability were missed in the planning for the pandemic and that there was inadequate attention to their needs.

²⁶ Gerison Lansdown, 'Children with Disabilities: Chapter 6' In Human Rights and Disability Advocacy, Maya Sabatello and Marianne Schulze (eds), (University of Pennsylvania Press, 2013).

The Management and Operational Plan for People with Disability,²⁷ the key government document setting out the pandemic response for people with disability in Australia, was developed by the Department of Health with the support of the Advisory Committee for the COVID-19 Response for People with Disability,²⁸ however CYDA was not invited to sit on this committee. We provided evidence to the DRC that the plan does not adequately cover the risks to children and young people with disability during the pandemic, and that there were no other formal mechanisms established to holistically consider the needs of children and young people with disability.

Systemic advocacy

Systemic advocacy conducted by human-rights based Disability Representative Organisations like CYDA lobby for reform and change of social systems and structures that discriminate against, or contribute to, the abuse and neglect of people with disabilities.

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.

CYDA receives core funding of \$300,000 per annum for systemic advocacy from the Department of Social Services. Our responsibility in our funding agreement with the Commonwealth is extensive and is as follows.

| |
|---|
| <p>The aims of the Activity are to:</p> <ol style="list-style-type: none">2.1 support national Disability Representative Organisations (DROs) for people with disability, and/or represent disability service providers who support people with disability;2.2 ensure that disability issues and a diversity of voices are represented in Australian Government decision making and policy outcomes; and2.3 support people with disability and/or lived experience of disability, and/or service providers supporting people with disability. These people and service providers are the focus of the systemic advocacy services funded under the DRO Grant Opportunity. <p>3. Activity obligations</p> <p>You must achieve the aims of the Activity through systemic advocacy which leads to improvements in the lives of people with disability, by influencing:</p> <ol style="list-style-type: none">3.1 people with disability and/or lived experience of disability;3.2 policy makers (governments)3.3 researchers;3.4 national organisations (disability and allied sectors);3.5 service providers supporting people with disability; and3.6 business and community organisations. |
|---|

The balance of CYDA's funding is tied to delivery of key projects including to support the National Redress Scheme, the Disability Royal Commission, and National Disability Insurance Scheme (NDIS) Information Linkages and Capacity Building Grants. Therefore, these projects

²⁷ Department of Health (2020) Management and Operational Plan for People with Disability

²⁸ Organisations and individuals represented on the Advisory Committee for the COVID-19 Response for People with Disability: Allied Health Professions Australia, Australian Association of Developmental Disability Medicine, Australian Government Department of Social Services, Australian Human Rights Commission, Council for Intellectual Disability, Department of Developmental Disability Psychiatry, University of New South Wales, First Peoples Disability Network, Get Skilled Access, Inclusion Australia, Melbourne Disability Institute, University of Melbourne, National Disability Insurance Agency, NDIS Quality and Safeguards Commission, Northcott, Office for Disability ACT, People with Disability Australia, people with lived experiences of being a carer and Summer Foundation

are not designed to deliver systemic advocacy, however they provide important themes and inputs for our systemic advocacy.

This is a small amount of funding given the well-known and extensive discrimination, abuse and neglect faced by children and young people with disability. This means CYDA must undertake prioritisation and 'triaging' of our work and our staff are often stretched very thin.

The ways we conduct systematic advocacy for children and young people with disability include:

1. Conducting research and conducting consultations and focus groups with our members.
For example:

Member surveys:

- 2019 National Education Survey (n=505 responses)
- 2019 Pathways for young people with disability after school Survey (n= 86 responses)
- 2019 We would like to hear your NDIS story survey (n=189 responses)
- 2020 COVID-19 (Coronavirus) and children and young people with disability survey (n=697 responses)
- 2020 National Education Survey (n=719 responses)

Member consultations and focus groups (recent examples):

- National Disability Strategy (2020)
- Disability Standards for Education Review (2020)
- NDIS COVID-19 webinars (2020)

Commissioned and CYDA produced research

- [More than isolated: The experience of children and young people with disability and their families during the COVID-19 pandemic](#), 2020
- [Not even remotely fair: Experiences of students with disability during COVID-19](#), 2020
- [Towards inclusive education: A necessary process of transformation](#), 2019
- [Time for change: The state of play for inclusion of students with disability](#), 2019
- [Post school transition: The experiences of students with disability](#), 2015
- [Strengthening participation of children and young people with disability in advocacy](#), 2014
- [Enabling and protecting: Proactive approaches to addressing the abuse and neglect of children and young people with disability](#), 2014
- [Belonging and connection of school students with disability](#), 2014.

2. Responding to government inquiries and reviews to ensure the needs of children and young people with disability

- Over our 10 years of operation we have provided hundreds of submissions to government inquiries and processes
- We provide evidence to parliamentary processes including Senate and parliamentary inquiries
- We provide formal and informal advice to government

3. Being a member of government advisory groups to provide advice. For example, CYDA is currently members of the following groups:
 - the National Disability Insurance Scheme (NDIS) Commission Disability Sector Consultative Committee
 - the NDIS CEO Forum
 - the NSW Department of Education Disability Strategy Advisory Group
 - the VIC Department of Education and Training COVID Advisory Group:
 - the Australian Curriculum Assessment and Reporting Authority (ACARA) Students with Disability Advisory Group
 - the Department of Social Services Disability Support Services Committee (DSSC)
 - the Department of Social Services Early Childhood Intervention Group
 - the Department of Social Services National Disability Strategy Reform Steering Group
 - the Department of Social Services Disability Gateway Reference Group.
4. Facilitating collaboration with and across a range of sectors on the rights of children and young people with disability. For example:
 - CYDA hosts a quarterly meeting for organisations with an interest in supporting children and young people with disability.
 - CYDA formed a national coalition on inclusive education (Australian Coalition for Inclusive Education)
 - During the COVID period, disability organisations have worked together to set their priorities. CYDA began holding weekly meetings with a range of stakeholders, including advocacy organisations and researchers, when the pandemic first broke out in Australia, to identify and provide advice on potential issues for children and young people.
 - Sector engagement and representation – for example, sitting on the Playgroup Australia Disability Advisory Board and the Victorian Council of Social Services Empowered Lives advisory group.

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 and abuse and neglect 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 (for example, the establishment of the DRC itself).

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 (as noted in the previous section) 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 and play a critical role in shaping community attitudes to children and young people with disability.

Individual advocacy

“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’ve 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”²⁹.

The main source of funding for 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 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 disability³⁰, it is easier for young people with disability and their families to have their issues resolved. In many states and territories there are no specialised services, and we hear many reports of the difficulty young people and families have in accessing the support they need.

The benefit of these organisations is they have strong relationships with state and territory governments so they can resolve issues quickly and they are state-based, so they understand the local service systems, school structures and barriers. They can also contribute strongly to systemic change through their advocacy locally. Being cross-disability advocacy organisations is also crucial as they can advocate for issues that impact many children and young people with disability despite their diagnosis/condition.

As well as facing disability-based discrimination, many children and young people also face other forms of discrimination and barriers. These forms of discrimination intersect and lead to compounding disadvantage and inequities. Those facing intersectional discrimination include First Nations children and young people, those from culturally and linguistically diverse communities or non-English speaking backgrounds, children and young people in LGBTIQ+ communities, children and young people in out-of-home care or youth justice systems, and those living in regional, rural and remote areas. Systemic and individual advocates with experience in all these areas are important as well as cross-disability organisations.

For the rights of children and young people with disability to be upheld in line with the CRPD we believe there should be a boost in funding for individual advocacy in states and territories. 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.³¹ While this cost-benefit analysis examined individual advocacy for people with disability across the life course, it is reasonable to

²⁹ Disability Advocacy Network Australia, Individual advocacy <https://www.dana.org.au/how-to-advocate/>

³⁰ Family Advocacy (NSW), the Association for Children with Disability (Vic), the Association for Children with Disability (Tas) and the Youth Disability Advocacy Service (Vic)

³¹ A Cost Benefit Analysis of Australian independent disability advocacy agencies

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>

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.

Individual advocacy organisations should also be funded to do systemic advocacy in their states and territories, so the issues they identify in their individual advocacy work, can lead to change in the systems and structures in states and territories.

Self-advocacy

Self-advocacy occurs by individuals speaking up for themselves and their rights, or in groups. There is a strong self-advocacy movement in Australia, stemming from the deinstitutionalisation movement and the work of disability activists through the 1980s and later. *“Self-advocacy groups are run by people with disabilities who have joined together to support each other and to have our voices heard. We work together to make sure we have the same rights, choices, and opportunities as anyone else in the community.”³²*

An important part of the growth and development process for young people is individuation – becoming one’s own person as distinct from one’s family. For young people with disability, the self-advocacy approach offers a strong and supportive way to do this. Several organisations across Australia work in this area, helping young people with disability to grow their self-advocacy skills, including the Youth Disability Advocacy Network (WA), Enabled Youth Disability Network (SA), Youth Disability Advocacy Service (Vic), Women with Disability Australia and CYDA. As noted earlier, we recently held the inaugural five-day [National Youth Disability Summit](#), which received over 250 registrations.

Building the capacity of young people with disability to self-advocate will bring lifelong benefits and will contribute to the broader suite of work in violence and abuse prevention. An opportunity to support self-advocacy activities more systematically could be for the NDIS ILC program to develop a specific grants round focusing on capacity-building and self-advocacy for children and young people with disability.

³² <https://www.voicestogether.com.au/self-advocates/what-is-self-advocacy/>

Change community attitudes about children and young people with disability

Recommendations:

- The next 10-year National Disability Strategy has a major focus on changing community attitudes to disability
- The NDIS has a clear focus and accountability for promoting full inclusion, and strong developmental pathways and transitions for children and young people with disability

People with disability have faced a long history of low expectations, and this pervasive attitude remains today. This attitude manifests in every area of life and interaction with community for people with disability, who face exclusion from mainstream settings from the earliest stages, such as micro-exclusions from community groups such as new mothers groups, playgroups, early childhood education and care. This is alongside the well-documented issues in other services and systems, as documented in our previous submissions to the DRC.

A 2018 survey of community attitudes towards people with disability shows approximately 17 per cent of survey respondents agree or strongly agree that children with disability should only be educated at special schools,³³ rather than being included in education settings with their non-disabled peers. A survey of 1,000 Australians also revealed harmful attitudes to inclusion of students with disability in education. Almost one in respondents were uncomfortable with their children sharing a classroom with people who have a significant intellectual disability. Fifty-five per cent of respondents said segregated education in special schools was better for students with intellectual disability³⁴. As noted in the Pro Bono News report, advocates such as CYDA were public in our concern about the media strategy for this research conducted by the Endeavor Foundation, which fed into already existing negative stereotypes held in the community.

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 disability³⁵, almost two thirds of employers are largely uncommitted to employing jobseeker with disability³⁶. Despite research finding that people with disability take fewer days off and less sick leave, and have a higher retention rate³⁷, a recent

³³ Bollier A,M,, Krnjacki, L., Kavanagh, A., Kasidis, V., Katsikis, G., & Ozge, J. (2018). Survey of Community Attitudes toward People with Disability: A report for the Victorian Department of Health and Human Services. Melbourne, VIC: Disability & Health Unit, Centre for Health Equity, University of Melbourne.

³⁴ Endeavour Foundation, Feb 2020 [Talking about taboos is the first step to change](#) and Pro Bono News, Feb 2020, [Aussies 'uncomfortable' with students with intellectual disability in their child's school](#)

³⁵ Commonwealth of Australia (2009) SHUT OUT: The Experience of People with Disabilities and their Families in Australia National Disability Strategy Consultation Report prepared by the National People with Disabilities and Carer Council

³⁶ Kellock, P. (2020). The Employer Experience: Hiring young people with intellectual disability. Ticket to Work. Available <https://tickettowork.org.au/research/article/the-employer-experience-hiring-young-people-with-i/>

³⁷ Australian Safety and Compensation Council. (2007) Are People with Disability at Risk at Work? A Review of the Evidence. Commonwealth of Australia.

community survey³⁸ 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?

Changing community attitudes to disability, including children and young people with disability is a necessary part of realising their rights, and preventing violence, abuse, neglect and exploitation. Research has shown this change needs to be at multiple levels, the personal level, the organisation level and the government level³⁹.

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

Organizational-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.”⁴⁰

Each of these intervention levels reinforces the others, and may be applied at the same time⁴¹. Long-term community attitude change must start with children, as we know many attitudes and biases are developed when children are very young.⁴² Children and young people with disability must be included in all aspects of community life, moving away from the traditional medicalised approaches with pathologise disability and tend to neglect the other aspects of the child’s life, wellbeing and rights. The same general features of development and learning apply to children with disability to those without disability, and this must be acknowledged and addressed within our service systems and communities.

We have written extensively in our submissions to the DRC about the benefits of inclusive education, for students with and without disability, for other members of school communities, and for changing community attitudes. We have raised our concerns about the ‘medicalisation’ of government programs like the NDIS, where medical therapies in a clinical setting are prioritised over

³⁸ Bollier A.M., Krnjacki, L., Kavanagh, A., Kasidis, V., Katsikis, G., & Ozge, J. (2018)

³⁹ Fisher, K. R., & Purcal, C. (2017). Policies to change attitudes to people with disabilities. *Scandinavian Journal of Disability Research*, 19(2), 161–174. DOI: <http://doi.org/10.1080/15017419.2016.1222303>

⁴⁰ Ibid, p. 163

⁴¹ Ibid.

⁴² Our Watch (2018). *Challenging gender stereotypes in the early years: the power of parents*. Melbourne, Australia: Our Watch.

home-based and community supports to help children and young people be fully included and supported in their development.

Our submission to the NDIS *Establishing a Participant Service Guarantee and removing legislative red tape* review⁴³ noted the importance of early childhood, adolescence and early adulthood for lifelong inclusion and demonstrated that the NDIS was essentially initiated in an adult paradigm, and has since been inadequately adapted to support children and young people with disability. With so much media focus and public attention on the NDIS, given the size of the Scheme, it provides a valuable opportunity to shape media narratives and community attitudes around inclusion and rights of people with disability. Additionally, without an overarching framework for children and young people with disability, the Scheme is unlikely to be able to appropriately meet their needs and support inclusion in the community, which will have lifelong impacts.

Finally, the Australian Government is currently undertaking consultation around the development of the next National Disability Strategy, which guides federal and state/territory governments in their policy directions and programming for people with disability. The NDS provides a crucial mechanism to changing community attitudes for children and young people with disability, and actions to bring about full inclusion and reduce the systemic barriers and abuse and neglect experienced by children and young people with disability.

Young people with disability, like all young people, are inherently invested in the future of our community and society, and they want to be the leaders to drive change. At our recent National Youth Disability Summit, the co-design committee made up of young people were clear in wanting to create a space for young people themselves to gather, identify the changes needed, and build networks. They want to be out in front, leading the way for change. This must be built into the design and delivery of all actions to improve community attitudes to disability.

⁴³ Children and Young People with Disability Australia (2019) Improving the NDIS for children and young people, Submission to the Review of the NDIS Act 2013, Establishing a Participant Service Guarantee and removing legislative red tape with disability and their families <https://www.cyda.org.au/resources/details/66/improving-the-ndis-for-children-and-young-people-with-disability-and-their-families>