

Submission regarding the successor plan to the National Framework for Protecting Australia's Children 2009-2020

Children and Young People with Disability Australia

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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 around 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 submission to inform the development of a successor plan to the National Framework for Protecting Australia's Children 2009-2020. Our submission focuses on a number of areas from the discussion paper, which align strongly with CYDA's advocacy over time.

It is critical that young people with disability are included, meaningfully and authentically, in every step of these processes. CYDA has supported Children's Commissioner Anne Hollands and the Australian Human Rights Commission to conduct focus groups with young people with disability, and parents and caregivers. Young people must continue to be involved in every stage of plan finalisation, implementation, and evaluation, to ensure that the plan remains responsive to their needs. This should be done through a formal engagement process with appropriate funding and remuneration.

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, and that much work is needed to ensure all our service systems are accessible and inclusive for all our children.

Our submission also outlines our recommendations for improving accountability around implementation of the successor plan, across departments and jurisdictions. This includes the development of an outcomes framework and the development of an independent oversight function to monitor and report on progress against the plan, as recommended by PwC's evaluation report. CYDA also recommends improved data collection processes as key mechanisms to ensure accountability, and investment in human rights-based disability representative organisations to provide systemic advocacy.

We were very pleased to see that children and young people with disability are recognised as a priority cohort for the successor plan. We note that the priority groups identified in the discussion

paper are not discrete groups – that there may be, and often are, intersections between them which lead to additional and compounding discrimination and disadvantage for some children and young people. For example, children with disability are over-represented in the child protection and out-of-home care systems, as are First Nations young people. It is critical that the successor plan and its implementation thoughtfully and genuinely responds to intersectional discrimination and disadvantage.

Fundamentally, ableism – the discriminatory and damaging attitudes, both historical and current, held by society are the root of violence and abuse against people with disability. From the way we colloquially speak about disability to the way disability is considered and represented in policy and law-making, pervasive ableist norms create a cultural acceptance of the abuse, neglect, and mistreatment of people with disability. As such, primary prevention mechanisms that create long-term community attitude change around ableism and promote understanding and respect for all people with disability, including children and young people, are crucial. Addressing the drivers of child abuse and neglect by taking a primary prevention approach, will be critical for the successor plan, as recommended by PwC's evaluation report.

Involving children and young people in every step

CYDA is pleased to see that one of the proposed guiding principles for the successor plan is to “listen and respond to the voice of children and young people and the voice of those who care for them” and to ensure their participation in decision-making. Children and young people being front and centre in the decisions that affect them is a key priority for CYDA, and is built into our strategic plan. Our ideal future is one in which children and young people are recognised as the agents and experts in their life, making informed decisions as they grow; are included in ways that are meaningful to them; and have their human rights upheld.

A report we commissioned in 2014 showed that:

“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.¹”

Participation can occur at different levels, including at a:

- Local/individual level: such as decision making and influencing change for daily living.
- Structural level: influencing change in systems, such as within education and community.
- Systemic level: influencing change at a society/policy level.²

The 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.³”

The ongoing impact of these barriers was highlighted by young people who attended CYDA’s 2020 National Youth Disability Summit (NYDS). The Summit was established with the vision to create an inclusive environment where young people with disability from across Australia could come together

¹ 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

² 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.

³ Simmons, C., Robinson, S. (2014), p. 33

as a community and use their voices to shape the future. The Summit was designed by and for young people with lived experience of disability.

A major theme that emerged across entire Summit was the opportunity to better listen to young people with disability. Creating space for young people with disability was highlighted as a pathway toward a more inclusive society. Participants at the Summit emphasise that no one knows what young people need better than they do, so they must be supported to be at the centre of solutions for change to be effective.

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

“Our needs get met the best when we’re the ones that get to define what they are.” - Young participant at the 2020 NYDS

Young people with disability rarely have opportunities to meaningfully engage with government policy development processes or consultation; and there is a long way to go to ensure these processes are genuinely inclusive and built on co-design principles.⁴ At the national level, policy impacting children and young people with disability sits across multiple policy portfolios, including:

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

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

Additionally, children and young people with disability often face barriers to participating in consultative process because of inaccessible processes (including inadequate information delivery, meeting structures, interpreters, assistive technology), and we have seen little evidence that government consultative processes are responding to these needs adequately. This notion was echoed in the Social Deck’s recent consultation report to help shape the next National Disability Strategy, which confirmed young people ‘do not find current mechanisms used by governments to engage on these issues appealing, suitable or easy to access’.⁵

⁴ “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>

⁵ Social Deck. (2019). *Right to opportunity Consultation report to help shape the next national disability strategy*. Available at https://www.dss.gov.au/sites/default/files/documents/12_2019/nds_beyond2020_fullreport-161219_0.pdf, p. 64

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

The NSW Office of the Children's Guardian has recently released '*Empowerment and Participation: a guide for organisations working with children and young people*'.⁶ The guide uses Laura Lundy's model for the participation of children which has four elements: Space, Voice, Influence and Audience. The Lundy model also informs the Irish Government's National Framework for Children and Young People's Participation in Decision-Making.⁷

At a recent Policy Forum co-hosted by Families Australia and CYDA two young people spoke of how young people need to be placed at the centre of all decision making about them. In their words:

“It is time to include us and recognise us and put us at the forefront. We are not a monolith for you to talk over and you will never be able to protect and serve us until we are there with you. Nothing about us without us”

“As a young person, if you don't have a family that is supportive of disability and supportive overall, you can be overlooked and there's really little you can do. We're left to fend for ourselves with no supports, no financial means and no policy to consider us”

For children and young people with disability to engage with government safely, confidently, and meaningfully, extensive pre-briefing, tailored accessibility support and post-briefing support is needed. This support is best provided by disability advocacy organisations like CYDA, and state/territory-based organisations for work in those jurisdictions. Our organisations have the skills and expertise to ensure safe, meaningful and supported engagement activities. Peer support and peer work approaches have also been shown to be effective in consumer participation and engagement.⁸ It is also critical that intersectionality amongst the diverse groups of people identified is recognised and appropriately supported in engagement and collaboration.

Effective engagement through the development, implementation and monitoring of the successor plan should involve the establishment of a formal advisory process for children and young people with disability which includes young people themselves, families and caregivers, and representative organisations. This should be appropriately funded and supported to recognise the value of people's time and the importance of providing accessible engagement options.

⁶ Office of the Children's Guardian NSW, *Empowerment and Participation: a guide for organisations working with children and young people*, viewed 22 April 2021, <https://www.kidsguardian.nsw.gov.au/ArticleDocuments/838/Empowerment-and-ParticipationChildSafeStandards.pdf.aspx?Embed=Y>

⁷ Available here: [Participation Framework - HUB na nÓg \(hubnagog.ie\)](https://www.hubnagog.ie/participation-framework)

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>

Ensuring truly universal access to services and supports

“As a nation, we do not currently have a systemic and coordinated approach to child and youth well-being:

- We do not have a coherent, holistic or concerted national strategy, framework or plan for child and family wellbeing
- Our current child-related national strategies – in areas such as health, education, child protection, ECEC, disability and mental health – do not yet link well enough or sufficiently drive joined up responses
- We are lagging comparable OECD countries.
- Our systems are failing far too many First Nations children and families.
- Our capability and governance for systems approaches is immature.”⁹

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.

What inclusion means to young people¹⁰

Inclusion for young people in our network means that disability is seen as “*normal*” and “*not something less than*”. Further, that people without disability would not use harmful labels and biases and are willing to educate themselves about others’ experiences. One young participant added that inclusion requires that people with disability are always included from the beginning and not as an “*afterthought*”.

Many young people also understand the concept as going together with “*respect*”, “*dignity*” and “*acceptance*”.

“To me inclusion means respect as well. It means consideration of people with all kinds of disabilities, not picking and choosing which ones you want to accommodate. And it means if you’re going to provide representation of people with disabilities, you do it accurately, you’re not engaging in harmful stereotypes.”

“I guess inclusion to me has always been about feeling represented. So seeing people with all different abilities, different ages, disabilities both visible and invisible, all represented as one, not in an example of difference.”

⁹ Hogan, M., Hatfield-Dodds, L., Barnes, L and Struthers, K (2021). *Systems Leadership for Child and Youth Wellbeing: Stage 1 Synthesis Report*. Every Child and Australia and New Zealand School of Government (ANZSOG), Australia. www.everychild.co

¹⁰ From CYDA’s 2021 submission to the Disability Royal Commission in response to its *Promoting Inclusion* issues paper, <https://www.cyda.org.au/resources/details/288/response-to-the-disability-royal-commission-s-promoting-inclusion-issues-paper>.

“It [disability] would be a more open everyday part of life that we’re just like any other person. We’re human. We have the same needs and wants just ours need to be adapted in a different way.”

The early years

Early experiences are critical. Young people with disability speak of their early childhood experiences and the memories of fun had with their friends and family – mud, music, parties, playing at the park etc. The wellbeing of Australia’s children is based on all children having their needs met. Needs that span services and support for their health, learning, housing, feeling loved and safe, and feeling good about who they are.

There is evidence that for young children with disability there is an over-reliance on early intervention, segregated settings and special programs, leading children and families away from the natural childhood environments and children their own age.

Barriers include:

- Culture and ableism - Difference or delays in development (diagnosed or not) often divert children and families from the natural paths of childhood
- Lack of voice - Children and young people with disability are not front and centre and their voice is not heard or sought
- Resources - Information (and influences) is widely available and voluminous with a strong emphasis on the child meeting development milestones. Resources where available tend to be siloed and directed to ‘special’ programs and segregated settings.
- Capacity and capability of informal supports – There is pressure on accessing ‘early intervention’ and parallel need to build an inclusive community around child and family. This is coupled with an over reliance on the resilience and capacity of parent/carer/family to always advocate for their child in every area of the child’s lives, with little or no funding or development of independent and individual advocacy support.
- Capacity and capability of formal supports - Lack of investment for professionals across all systems as to children and young people’s human rights, the law, the evidence base and the benefits for everyone.
- Intersectionality - Formal and informal social supports struggle to deal with intersectionality between disability and other areas of difference.

Out-of-home care and justice systems

Despite poor data collection across jurisdictions, CYDA can ascertain that children and young people with disability are overrepresented in out-of-home care and justice settings where they are more likely to be institutionally vulnerable.

For example, in a sample of detainees in a youth training centre, nine of 10 young people had disability-related needs. This is the clearest data we have on disability prevalence as the relevant government department “has advised [the Training Centre Visitor] that it is unable to collect data

about disability.”¹¹ Similarly, 89 per cent of young people detained in Western Australia’s youth detention facility were found to have at least one “severe neurodevelopmental impairment.”¹²

Mendes and Snow found that while there was very little reliable information about the number of children and young people with disability in the out-of-home-care system across Australia, or the types of disability they have, studies have indicated that the group is overrepresented in entering the system.¹³ Once in the system, children and young people with disability are also more likely to experience extended stays in-care and placement disruptions and are less likely to be reunified with birth parents than their peers without disability.¹⁴

Dedicated resources are required to explore the true extent of this overrepresentation, what supports children and young people with disability receive in these settings, and to understand and address the root causes of the overrepresentation. This is an area CYDA urges the Royal Commission to investigate in more detail, and we are pleased to see there will be an upcoming public hearing examining the experiences of First Nations young people with disability in out-of-home care systems.

Safeguarding arrangements

A recent review¹⁵ mapped out and examined the various national, state and territory policies, agreements and frameworks that relate to child safety across Australia. Altogether 56 policies were included in the analysis, including disability specific-policies such as the *Disability Standards for Education 2005* and the *National Disability Insurance Scheme Quality and Safeguarding Framework*. The review found that the documents generally constructed children and safety in two ways: a focus on children needing protection from harm or as a recognition of children’s rights, agency and capabilities. The latter, which is becoming increasingly evident in child safe policies, represents the child as having autonomy and having opportunities to influence decisions that affect their lives.

The review then explicitly analysed how children with disability and children in the out-of-home care system were framed in child safe policies. It found their inclusion in general was minimal, and in the few instances where the cohorts are included, they are only represented in terms of their perceived vulnerability.

The authors also highlighted that the documents that related to the disability sector predominantly called for compliance of adults in the child’s life and lacked any real promotion of cultural conditions that recognise the importance of children’s rights and relationships. This discourse then shapes how organisations view children and young people in their work, how they work with them, and what ‘safety’ mechanism/s they do or don’t offer. The review concluded that policy plays an important role in shaping organisational practices, and national bodies and organisations should explore and

¹¹ 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, p.99.

¹² Sample of 99 children. Bower, C., Watkins, R.E., Mutch R.C., et al. (2018) Fetal alcohol spectrum disorder and youth justice: a prevalence study among young people sentenced to detention in Western Australia, *BMJ Open*,8:e019605. doi: 10.1136/bmjopen-2017-019605

¹³ Mendes, P., & Snow, P. (2014). The needs and experiences of young people with a disability transitioning from out-of-home care: The views of practitioners in Victoria, Australia. *Children and Youth Services Review*, 36, 115-123. <https://doi.org/10.1016/j.chilyouth.2013.11.019>

¹⁴ MacDonald, S., Ellem, K., & Wilson, J. (2016). Supporting Young People with an Intellectual Disability Transitioning from Out-of-Home Care to Adult Life in Queensland, Australia. In P. Mendes & P. Snow (eds), *Young People Transitioning from Out-of-Home Care*. DOI 10.1057/978-1-137-55639-4

¹⁵ Powell, M. A., Graham, A., Canosa, A., Anderson, D., Taylor, N., Robinson, S., Moore, T., & Thomas, N. P. (2020). Children and safety in Australian policy: Implications for organisations and practitioners. *Australian Journal of Social Issues*. <https://doi.org/10.1002/ajs4.134>

amend their policies so they are constructed in a way that improve child safety and wellbeing in meaningful and functional ways.

In line with children and young people with disability's rights, these child safe policies should be designed to promote their agency and autonomy. As recent research¹⁶ working with children and young people with disability has identified, the cohort has nuanced circumstances and understandings of safety, and what helps and hinder safety. This work should be built upon by national bodies, the Disability Royal Commission, and the successor plan to ensure that child safe frameworks and child safe organisational practices and principles meaningfully include the voice of children and young people.

Appropriate service responses to harm

To prevent further trauma or harm, it is essential that services and supports can be accessed safely and appropriately by children and young people with disability who have or experiencing abuse and mistreatment. A research report commissioned by the Royal Commission into Institutional Responses to Child Sexual Abuse found that people with disability who have experienced child sexual abuse rarely have access to therapy and supports that is adapted for their needs.¹⁷ Disability related service providers generally had little understanding of therapeutic responses, and many counsellors and therapists have insufficient knowledge in working with people with disability, particularly intellectual disability.^{18,19}

Subsequently, in the Royal Commission's final report there was a recommendation that "the Australian Government and state and territory governments should fund support services for people with disability who have experienced sexual abuse in childhood as an ongoing, integral part of advocacy and support and therapeutic treatment service system responses for victims and survivors of child sexual abuse".²⁰ Additionally, there was a recommendation that sexual assault services should work collaboratively with key services, such as disability-specific services, youth justice, and child and youth services to better meet the needs of victims and survivors.²¹

Women with disability experience additional and specific issues accessing safe services when they have experienced violence or abuse. The domestic and family violence service system can be inaccessible, and there is a lack of awareness of family violence and gender-based violence in the disability service sector.²² As a result, and because of limitations of other tertiary responses, such as emergency services, Australia's National Research Organisation for Women's Safety (ANROWS) researched and developed a set of guidelines for tertiary response services to respond effectively to the needs of women with disability.²³

¹⁶ Robinson, S., Graham, A., Fisher, K., Meltzer, A., Blaxland, M., & Johnson, K. (2017). *Preventing abuse and promoting personal safety in young people with disability: Final report*. Available at [Preventing Abuse and Promoting Personal Safety in Young People with Disability \(rcydpd.edu.au\)](https://rcydpd.edu.au); Robinson, S., & Graham, A. (2020). Feeling safe, avoiding harm: Safety priorities of children and young people with disability and high support needs, *Journal of Intellectual Disabilities*, 1-20. DOI: 10.1177/1744629520917496

¹⁷ Breckenridge, J., & Flax, G. (2016) *Service and support needs of specific population groups that have experienced child sexual abuse*, Royal Commission into Institutional Responses to Child Sexual Abuse, Sydney.

¹⁸ *ibid.*

¹⁹ Royal Commission into Institutional Responses to Child Sexual Abuse. (2017) *Final Report: Volume 9 Advocacy, support and therapeutic treatment services*. Available at [Final Report - Volume 9, Advocacy, support and therapeutic treatment services \(childabuseroyalcommission.gov.au\)](https://childabuseroyalcommission.gov.au)

²⁰ *ibid.*, Recommendation 9.3, p. 174

²¹ *ibid.*, Recommendation 9.7

²² Dyson, S., Frawley, P., & Robinson, S. (2017). *Whatever it takes? Access for women with disabilities to domestic and family violence services: Final report*. Australia's National Research Organisation for Women's Safety Limited.

²³ *ibid.*

These guidelines are:

- Promoting access and accessibility
 - This includes removing physical barriers and barriers to communication and understanding
 - It also includes ensuring the service feels safe and approachable, and is affordable and available
- Building cross-sector collaboration
 - This broadly entails increased collaboration between domestic and family violence, disability-specific services and other tertiary services to learn from each other and develop ways of working together
- Involving women with disability
 - This entails women with disability informing service development and cross-sector collaboration work.
 - It also includes using women's' expertise to provide practical support within the services, such as establishing peer support groups
- High quality data collection
 - Services should collect quantitative and qualitative data on the disability experiences of service to inform service improvement

CYDA welcomes the additional funding that was allocated to domestic and family services, and the targeted services for women with disability, in the Federal 2021-22 Budget. We urge the Government when contracting these services to appropriately fund them to incorporate ANROW's guidelines to ensure that they can effectively respond to the needs of children and young people with disability, including young women and gender-diverse young people, and their families.

Improving data collection and information sharing

Efficient and effective data collection is a key policy priority for CYDA, and it is essential for improving outcomes for Australia's children and young people with disability. As a representative organisation, we use multiple avenues to understand the experiences of children and young people so we can best provide an informed voice on the social issues important to them. One of these avenues is the use of data. However, often CYDA is unable to ascertain information specific to children and young people with disability, with available data being aggregated at higher population levels. That, or the data just does not exist.

Without comprehensive data, there is little opportunity or incentive to develop evidence-based approaches that could protect children or young people, nor can existing or new interventions be properly monitored.²⁴

While we can determine that children and young people with disability experience maltreatment at higher rates than their counterparts without disability, there is no national or consistent data collection across states on the following:^{25,26,27}

- Risk or prevalence of sexual abuse of children and young people with disability and the related impacts on them and their family
- Risks or allegations of maltreatment of children and young people with disability
- Data from care and protection proceedings involving children and young people with disability
- Accurate rates of children and young people in out-of-home care and juvenile justice settings
- Rates of bullying and harassment
- Rates of use of restrictive practices across different settings, including the education, disability services, out-of-home care, and justice systems
- NDIS Quality and Safeguarding Commission reporting on children and young people with disability.

In addition to these data gaps, CYDA has found that data collection in general for children and young people with disability across the systems they interact with is also inadequate or not collected entirely. Examples of current data gaps to monitor risk and full participation and rights of children are set out in Table 1 below.

It is often difficult for representative and advocacy organisations, researchers, services and the public alike to fully understand the success (or pitfalls) of programs and policies affecting people

²⁴ Wayland, S & Hindmarsh, G. (2017). Understanding safeguarding practices for children with disability when engaging with organisations. Available at [Understanding safeguarding practices for children with disability when engaging with organisations | Child Family Community Australia \(aifs.gov.au\)](https://www.aifs.gov.au/family-community-australia/understanding-safeguarding-practices-for-children-with-disability-when-engaging-with-organisations)

²⁵ *ibid.*

²⁶ Llewellyn, G. (2021). "Sexuality and the disregard of lived reality: The sexual abuse of children and young people with disabilities." In R. Shuttleworth & L. Mona, *The Routledge Handbook of Disability and Sexuality*. Routledge: New York.

²⁷ Fortune, N., Badland, H., Clifton, S., Emerson, E., Rachele, J., Stancliffe, R. J., Zhou, Q., & Llewellyn, G. (2020). The Disability and Wellbeing Monitoring Framework: data, data gaps, and policy implications. *Australian and New Zealand Journal of Public Health*, 44(3), 227-232. <https://doi.org/10.1111/1753-6405.12983>

with disability because there is a lack of sufficient data. Publicly available disaggregated data is particularly lacking.

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

While disaggregated data by disability and by age is difficult to obtain in itself, it is almost impossible to get data for children and young people with disability with other intersectional characteristics such as gender diversity, those from First Nations or culturally and linguistically diverse communities, socio-economic status or location (e.g., rural/remote). To ensure the successor plan is genuinely reflective of the experiences of different groups, and that its progress can be monitored, CYDA recommends intersectional and disaggregated data is collected and monitored for all cohorts and demographics (e.g., age, regionality/rurality, socio-economic status, ethnicity, gender diversity, etc.).

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:</p> <ul style="list-style-type: none"> • Subject to an investigation of a notification • 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
Education	Enrolment and settings

	<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) • 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)

<p>NDIS – data gaps</p>	<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
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Additionally, existing data collection methods fail to capture the experiences of all people with disability. For instance, the ABS Survey of Disability, Ageing and Carers, one of the richest sources of data on Australians with disability, does not include the same level of detailed information on the social and economic aspects of life for this of people living in cared accommodation as for those who live in private dwellings.²⁸

The Personal Safety Survey – a survey conducted by ABS to focus on experiences of violence and personal safety of people with disability – historically has also failed to capture experiences of all the wide demographics of the disability community. In addition to only collecting data from people in households (and not from those living in institutional settings), the most recent survey did not collect sensitive data, including experiences of violence from those who selected to answer by proxy for individuals who could not answer for themselves because of illness/injury or language difficulties.²⁹ As result, the survey findings underrepresented the experiences of people with a profound or severe communication disability.³⁰

By leaving out specific cohorts – arguably those who are subjected to more risk of experiencing abuse – in national data collection, future policy development will fail to rectify the reality of the pervasiveness of the maltreatment of people with disability. We are hopeful the National Disability Data Asset (NDDA), currently being piloted, will go some way to addressing gaps in data collection and useability, however it is only currently funded for 18 months. We urge the Australian Government to fully fund the NDDA, and ensure its development and implementation genuinely engages people with disability, advocates, and experts around specific cohorts to ensure the right data is collected to monitor outcomes over time.

²⁸ Fortune, N. (2020). *Collecting data on people with disability – who is being left out of the picture?* Available at http://www.powertopersuade.org.au/blog/collecting-data-on-people-with-disability-who-is-being-left-out-of-the-picture/22/9/2020#disqus_thread

²⁹ Simon-Davies, J. (2018). *Personal Safety of People with Disability*. Available at [Personal Safety of People with Disability – Parliament of Australia \(aph.gov.au\)](#)

³⁰ *ibid.*

Measuring and achieving outcomes for Australia's children and young people

PwC's 2020 evaluation of the National Framework recommended the adoption of an outcomes framework to guide and measure efforts and the commissioning a national prevalence study on child abuse and neglect, as well as independent monitoring and reporting mechanisms to ensure accountability. CYDA strongly supports these findings. We have provided similar feedback to the Australian Government in its development of the new National Disability Strategy as well.

As identified by PwC, a whole-of-government approach is required to improve outcomes for children over time, and to strengthen the implementation of the successor plan. Accountability and connection within and between the multiple relevant government plans and strategies (Appendix A in the consultation discussion paper), and their implementation, is also critical for improving outcomes. It is encouraging to hear acknowledgement in the discussion paper that efforts will be made "to ensure that efforts are not duplicated across the plans, and that we work together to address the drivers of child abuse and neglect."

Too often in the past we have seen hopeful and strong visions in plans like the National Framework and the National Disability Strategy, but we have then fallen short in terms of investment and implementation. Beyond the shortcomings on paper, this lack of progress and accountability has life-changing consequences for children and young people with disability. Too often, CYDA hears stories of children and young people with disability 'falling through the gaps' due of the lack of clarity of responsibilities between national and state and territory systems. This has never been more evident than now, with the ongoing Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability highlighting the neglect children and young people with disability experience across systems and their intersections including, but not limited to, the NDIS, education, health, justice, out-of-home care, and housing.

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

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

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

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

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

To monitor the progress of governments in achieving agreed outcomes, there should be an independent oversight agency responsible for producing annual, publicly available reports. This could be similar to the approach recently introduced around the Closing the Gap Information Repository through the Productivity Commission.³¹ Further work must be undertaken in consultation with people with disability and Disability Representative Organisations to determine where this function will best sit. Regardless of where this function sits, it must be fully resourced to ensure it is able to maintain consistent, timely and rigorous reporting. Similar to that of the Closing the Gap agreement, this reporting should be tabled in parliament annually to ensure the Australian Government responds publicly to the plan's implementation and progress.

Fundamentally, there needs to be genuine commitment from governments across the country. The National Framework was in place for more than 10 years, but the PwC evaluation report found it had "not resulted in the achievement of its high-level outcome of a substantial and sustained reduction in child abuse and neglect."³²

Financial investment was identified by stakeholders consulted for PwC's evaluation as a key inhibitor to the achievement of outcomes, and there was no dedicated investment plan attached to the Framework. Financial investment in implementation will be a critical element of ensuring the successor plan is effective in achieving its objectives and supporting the development of a safer and more inclusive society.

CYDA recommends that the framework includes clear accountability measures for all parties involved. We hear from our membership that they often have difficulties accessing supports, with different departments and systems passing the buck to other departments and systems who they believe are 'more responsible' for providing support.

While responsibility for achieving desired life outcomes may be shared across systems or jurisdictions, this does not mean the child or young person is not eligible or in need of multiple streams of support. For instance, a student with disability should be able to easily and fairly receive educational and learning supports through their state-system, whether or not they are receiving individualised funds through the NDIS. The conceptualisation – and implementation – of shared outcomes in the final framework should reflect the fact that these systems need to complement, not replace, each other.

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

³¹ <https://www.pc.gov.au/closing-the-gap-data>

³² PwC (2020), *Evaluation of the National Framework for Protecting Australia's Children 2009-2020*, for the Australian Department of Social Services, p.56.