

CYDA's response to the Australian Government's Early Years Strategy Discussion Paper

“Strategies come and go but my daughter only gets one childhood. Her needs, her strengths and her voice needs to be seen as an investment.”

- Mother of a child with disability



Content note: Discussion of ableism

Children and Young People with Disability Australia

April 2023

[REDACTED]

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A note on terminology:

Children and young people with disability

Using inclusive language and terminology has been recognised by the disability community for decades. Children and Young People with Disability Australia (CYDA) uses person-first language, e.g., person with disability. However, CYDA recognise many people with disability choose to use identity-first language, e.g., disabled person.

Families and caregivers

CYDA refers to children and young people with disability and their families and caregivers. We use the term 'families' as recognition of the different structures and arrangements and 'caregivers' to acknowledge not all children live in family environments. For the purposes of this submission, CYDA are detailing the experiences of children and young people with disability who are cared for by their families and caregivers.

Acknowledgements:

Children and Young People with Disability Australia would like to acknowledge the traditional custodians of the lands on which this report has been written, reviewed and produced, whose cultures and customs have nurtured and continue to nurture this land since the Dreamtime. We pay our respects to their Elders past, present and future. This is, was, and always will be Aboriginal land.



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Executive Summary and recommendations

As a representative organisation for children and young people with disability across Australia, CYDA supports the Early Years Strategy (The Strategy) as a critical component of delivering an enduring vision of what Australia wants to achieve for children and families in the early years. The envisioned Strategy also supports fulfilling our own purpose to ensure governments, communities and families are empowering children and young people with disability to fully exercise their rights and aspirations.

In the context of evidence demonstrating the additional ways that children and young people with disability are oppressed and marginalised due to their age and legal status, and drawing on data gathered from young people with disability, CYDA recommends the following:

Recommendations: General

Recommendation 1: Foreground the Strategy with anti-ableism framing

Before introducing The Strategy, we recommend that the Australian Government should:

- Undertake a co-designed, multi-stakeholder process to define a series of anti-ableist principles for use across the Strategy.
- uses an external organisation (or coalition of organisations) to undertake a review of each principle to ensure their adherence to anti-ableist principles.

Recommendation 2: Reform through co-design.

- Use genuine co-design approaches to develop and test all elements of The Strategy's design, including allowing input from young people with disability into the indicators and measurement tools, to highlight and prevent problematic framing and approaches.
- Establish a co-design working group to ensure the remainder of The Strategy implementation is carried out in partnership with young people with disability

Recommendation 3: Prioritising the needs of diverse groups through universal design/thinking

- We urge the Australian government to incorporate a universal design approach to the design, delivery, monitoring and evaluation of the strategy framework, to make The Strategy accessible for all, including children and young people with disability.

Recommendations specific to the discussion paper topics

Recommendation 4: Realise an aspirational vision of early childhood for children with disability

- Incorporate the five key elements of CYDA's vision of early childhood for children with disability; Activate child voice, support the workforce, calibrate funding, enhance and support adjustments, collaborate. (See Table 1)

Recommendation 5: Prioritise policies that give children with disability the best start in life

CYDA urges the Australian Government to align the policy priorities of The Strategy closely to the [Early Childhood Targeted Action Plan](#) as outlined in [Australia's Disability Strategy 2021-2031](#).

CYDA calls on the Australian Government to give children their best start in life. Specifically, CYDA joins calls by [The Parenthood](#), [Thrive by Five](#), [Every Child](#) and the [Centre for Policy Development](#) for the Australian Government and The Strategy to ensure: a) Universal access to education and care – affordable, high quality, inclusive, easy to access, b) simplification of the currently confusing, expensive array of services and schemes, and; c) data are collected and shared at all levels of government to improve evidence of the range and quality of early childhood services.

Recommendation 6: The Strategy should reflect human rights principles

- Ensure The Strategy reflects human rights principles by including the following five principles: Child-centred, Anti-Ableist, Co-designed, Universal design, Non-discrimination

Recommendation 7: The Strategy should address data and evidence gaps

- Collect evidence directly from children with disability to inform the development of The Strategy. Track the pathways and outcomes of children through different systems by ensuring better data linkage and the joining of data sets.

Introduction

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

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

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

CYDA welcomes the opportunity to respond to the Department of Social Services Early Years Strategy Discussion Paper.

This submission builds on our previous work and evidence to inform the Early Years Strategy by emphasising what children and families in Australia need in the early years. Our submission highlights CYDA's vision for children and young people with disability that they are given a lifetime of choices and opportunities and that they are included from the earliest age, particularly in early learning, education, and care.

This submission draws from data gathered by CYDA, including:

- CYDA's 2022 survey respondents (n=181) about experiences of early childhood education and care. The majority (97%) responses were from family members or care givers of a child or young person with disability and were published in a report¹
- Data gleaned from past sessions and events run by CYDA, including:
 - The National Youth Disability Summit 2020, two consultations which gathered feedback from young people with disability on the topic of the Australian Disability Strategy guide,
 - Consultations run in conjunction with the Centre for Inclusive Design (2022) about establishing good practice guidelines for engaging with people with disability (used with permission).
 - The LivedX consultations which captured the Lived-Experience and Lived-Expertise of young people with disability on topics and issues they value and deemed important. The series brought together young people from around Australia to share their insights, experiences and ideas for a future that embraces young people with disability and enables them to thrive.

There were seven sessions held over the course of seven months in 2021 covering:

¹ Dickinson, H., Smith, C., Yates, S., Faulkner, A. (2022) Taking the first step in an inclusive life – experiences of Australian early childhood education and care. Report prepared for Children and Young People with Disability Australia (CYDA), Melbourne. <https://cyda.org.au/search/details/352/report-taking-the-first-step-in-an-inclusive-life-experiences-of-australian-early-childhood-education-and-care>

- Inclusion
- Decision making
- Employment
- Tertiary education: university
- Tertiary education: TAFE and Vocational Education and Training
- LGBTQIA+ people with disability: community and;
- LGBTQIA+ people with disability: health

Quotes from these projects are anonymised and labelled as such in the text.

Additionally, this submission was shaped by CYDA staff, the majority of whom have personal and/or family experience of disability.

CYDA also supports the following positions in conjunction with this submission

[Position Paper](#) on Segregation

The Australian Coalition for Inclusive Education's ['Driving change: A roadmap for achieving inclusive education in Australia'](#) (How to make education better - [Easy English version](#))

Australian Research Alliance for Children and Youth (ARACY)'s [The Nest](#) child wellbeing framework

Early Childhood Australia's [Statement on the inclusion of every child in early childhood education and care](#) and draft [Statement on Play](#)

Early Childhood Australia and Early Childhood Intervention Australia's [Position statement on the inclusion of children with a disability in early childhood education and care](#)
Thrive by Five & The Minderoo Foundation's [Time to Act: Investing in our children and our future](#)

Play Group Australia's National Advisory Group's [Playgroup Statement 2022](#)

Context and evidence for CYDA's submission

From the earliest moments of life, children and young people with disability face intersecting discrimination from the medical and health service sector, educational systems, government support services, and the community. A meta-analysis of 328 studies in 2014 found that the impact of these cumulative instances of perceived discrimination, including ableism, is associated with a higher level of psychological distress and decreased wellbeing, especially in children.² More recently, research has revealed increased likelihood of trauma in people with disability³, something the Disability Royal Commission has also noted in its progress reports⁴.

The fact that these experiences coincide with a significant and once in a lifetime phase of brain development and physical growth, make children particularly vulnerable to experiencing lifelong negative impacts from discrimination and exclusion.

Australian children with disability should feel healthy, safe, connected, supported, challenged, and engaged. This is consistent with the United Nations Convention on the Rights of the Child⁵, and the Charter on the Rights of People with Disability (CRPD).

Systemic change is necessary to ensure children and young people are granted the same opportunities as their non-disabled peers, as they transition through critical developmental and life stages. Across many systems, we are failing to provide equitable and effective support.

The Australian Early Development Census (AEDC) covers children's development in five domains: physical health and wellbeing, social competence, emotional maturity, language and cognitive skills (school-based), communication skills and general knowledge.

AEDC publicly available data at a community level includes demographic data for all children included in the census but includes scores only from children who don't have any diagnosed "Special Needs" (disability). The Front Project noted this exclusion in its 2022 report 'Supporting all children to thrive: The importance of equity in early childhood education.'⁶

In 2022, the Australian Department of Education received a report on the development of potential indicators of development for children with disability using the Australian Early Development Census (AEDC).⁷ We have included initial data from this work.

² Schmitt, M.T. Et. Al. (2014). *The Consequences of Perceived Discrimination for Psychological Well-Being: A Meta-Analytic Review*. Psychological Bulletin, Vol 140(4), pp.921-948.

³ Ullmann, H. Et Al. (2022). *Stressful Life Events Among Children Aged 5-17 Years by Disability Status: United States 2019*. NCHS Data Brief No. 431. Available at: <https://www.cdc.gov/nchs/products/databriefs/db431.htm>

⁴ See 'Document Library' for progress reports <https://disability.royalcommission.gov.au/document-library>

⁵ Convention on the Rights of the Child, United Nations, 1989 entry into force 2 September 1990, in accordance with article 49, <https://www.unicef.org/child-rights-convention/convention-text>

⁶ The Front Project (2022) Supporting all children to thrive: The importance of equity in early childhood education. Available at: <https://www.thefrontproject.org.au/policy-and-research/research-reports/supporting-all-children-to-thrive>

⁷ Taylor Fry, (2022), 2021 AEDC indicators of development for children with disability, Australian Department of Education

Definitions of Additional Health and Development Needs (AHDN) within the AEDC dataset and reported prevalence⁸

Definition	Number of children in 2021 AEDC	Proportion of children in 2021 AEDC
1. Having special needs (based on a medical diagnosis or diagnoses)	15,797	5.2%
2. Having at least one developmental difficulty that affects their ability to do schoolwork in a regular classroom	54,684	18.0%
3. Having at least one developmental difficulty that does not affect their ability to do schoolwork in a regular classroom	43,120	14.2%
4. Requiring further assessment to determine if they have a developmental difficulty that affects their ability to do schoolwork in a regular classroom.	47,873	15.8%
In at least one of the AHDN groups	99,647	32.8%

Indicators of being AHDN developmentally on track by AHDN groups, 2021

Cohort	Physical health and wellbeing	Social competence	Emotional maturity	Language and cognitive skills (school-based)	Communication skills and general knowledge
Group 1	36%	27%	28%	44%	34%
Group 2	53%	45%	47%	56%	49%
Group 3	75%	71%	71%	83%	75%
Group 4	56%	44%	48%	56%	54%
All children, excluding those with known Special Needs	78%	76%	77%	83%	77%

⁸ Taylor Fry, (2022), 2021 AEDC indicators of development for children with disability, Australian Department of Education

CYDA's Early Childhood Education and Care (ECEC) Survey 2022

CYDA has been gathering feedback on educational experiences from its members via formal surveys since 2010. These surveys have consistently found that students with disability are excluded in their education. CYDA introduced an ECEC-specific survey (as part of a suite of education surveys undertaken in 2022) to understand whether the same kinds of issues are experienced in early childhood education and care settings.

The results of CYDA's ECEC Survey 2022 are shared in the [report](#): "*Taking the first step in an inclusive life - experiences of Australian early childhood education and care*".⁹ This survey (which included majority responses from family members of children and young people with disability) provides vital information on children and families experiences including;

- Early childhood education settings accessed,
- supports received by young children, and;
- outlines areas of concern.

Despite the majority of respondents (83%) indicating that their child was welcomed in ECEC settings, such positive experiences are overshadowed by concerning reports of bullying, exclusion and limitations to engagement activities as the following results indicate:

- Nearly 30% reported exclusion from excursions, events or activities and about the same number reported bullying from other children or staff
- One in five reported that their child had been refused enrolment
- Nearly a quarter said their child had been limited in the number of hours they were allowed to attend

CYDA's previous work

CYDA's work is rights-based and led by the direct experiences and diverse voices and visions of children and young people with disability across Australia. CYDA grounds its work in evidence and a human rights approach. Our previous work, including policy submissions, reports, collaborative work with other organisations, the development of fact sheets and early childhood resources are detailed in the Appendix 1.

⁹ Dickinson, H., Smith, C., Yates, S., Faulkner, A. (2022) Taking the first step in an inclusive life – experiences of Australian early childhood education and care. Report prepared for Children and Young People with Disability Australia (CYDA), Melbourne.

Challenges with delivering on the early years strategy and vision

The people, places and systems that relate to early childhood including— maternity hospitals, playgroups, early childhood education and care settings, child health, family support, the NDIS early childhood approach, housing, social services and child protection – are somewhat disconnected.

These systems span federal and state/territory governments, and separate ministries and departments within governments. This complexity is confusing for families and caregivers to navigate and children risk falling between the gaps of a fragmented system.

Challenges to be addressed:

- Lack of voice and agency for children and young people with disability
- Workforce burden; largely underpaid and under resourced
- Compounding and ongoing impact of systemic and structural inequity
- Inherent ableism and societal beliefs undermining human rights and legislation
- Policy settings and structures of Australia's federal, state, territory and local government
- Relatively new investment in the National Disability Data Asset and continuing data gaps and deficiencies

Areas for reform:

- Early childhood education and care (ECEC) sector including the Inclusion Support Program (ISP)
- Early childhood approach of the National Disability Insurance Scheme (NDIS); consider recommended changes that emerge from the outcome of the Independent Review of the NDIS (2022/2023)
- Other areas including but not limited to:
 - Effective design and use of community-based services and support models
 - Variations in experience and documentation for transitions to school
 - Maternal and childhood health services

Levers for change:

To achieve a meaningful Early Years Strategy the challenges listed above need to be addressed. A way of getting there is to be focused, persistent and make better use of the following key levers for change.

- [Australia's Disability Strategy 2021-2031](#)
- [Disability Standards for Education](#)
- [Review of the NDIS](#)
- [National School Reform Agreement](#)
- [Disability Royal Commission](#)
- [National Disability Data Asset](#)
- [National Disability Research Partnership](#)
- [The Australian Institute Disaster Resilience](#)

CYDA's general response to the Early Years Strategy

CYDA acknowledges the diversity of frameworks, principles and standards that have been considered to ensure a holistic Early Years Strategy. However, we are compelled, by our mandate to represent the needs and interests of children and young people with disability, to re-frame the discussion to drive more effective change. Therefore, before responding directly to the questions as presented in the discussion paper, we wish to discuss the conceptual framing of The Strategy as a whole. The following discussion is presented in three sections. First, we present an anti-ableist framing to foreground the proposed strategy, second, we suggest a co-design approach to the department's strategy work, and third, we request the implementation of a universal design approach.

1. Foreground the Strategy with anti-ableism framing

Recommendation 1

Before introducing The Strategy, we recommend that the Australian Government should:

- Undertake a co-designed, multi-stakeholder process to define a series of anti-ableist principles for use across The Strategy
- Use an external organisation (or coalition of organisations) to undertake a review of each principle to ensure their adherence to anti-ableist principles.

1.1 What is ableism?

Ableism has been described from a number of perspectives. A commonly cited definition from a disability studies perspective describes it as follows:

“A network of beliefs, processes and practices that produce a particular kind of self and body (the corporeal standard) that is projected as the perfect, species-typical and therefore essential and fully human. Disability, then, is cast as a diminished state of being human.”¹⁰

In practice, ableism is being perpetuated when, based on your understanding of someone's disability, you:

- incorrectly make assumptions about someone's abilities or desires
- treat someone in a patronising manner or infantilise them, assuming they are younger and/or less capable than they actually are
- make decisions on behalf of someone after assuming they can't
- assume something about one person based on what you experienced about someone else
- treat someone as 'inspirational'¹¹ for doing things they consider to be normal

¹⁰ Campbell, F. (2001) *Inciting legal fictions: 'disability's' date with ontology and the Ableist body of the law.* Griffith Law Review 2: 42–62. Available at: <https://research-repository.griffith.edu.au/handle/10072/3714>

¹¹ See Stella Young's TED talk for more detail. https://www.youtube.com/watch?v=SxrS7-l_sMQ

- tease or ridicule someone, even when you consider it to be ‘harmless fun’, or create a slur against someone that impacts their reputation with others
- overlook someone for an opportunity based on assumptions about their abilities
- ask intrusive questions about people’s lives or bodies
- refer to, or talk to the carer that is accompanying someone
- fail to include someone because you didn’t think of it, it felt too hard, or you were too awkward to ask them about their accommodations and access needs
- notice someone else doing or saying something ableist and decide not to say or do something about it.

CYDA’s numerous consultations with young people with disability demonstrate that ableism is at the core of many of the unsettling and detrimental experiences they describe. The following consultation participants describe this:

“In my experience, the Disability Employment Service operators are quite ableist. And just try and fill a box without seeing me as a person with interests, needs, and passions. One DES recommend[ed] that I work in a call centre, despite me being situational mute in social settings.”

– Participants in Lived X Financial Security and Employment consultation, 2022.

“I could lose my registration as a provisional psychologist specifically because I’m disabled, and a lot of programs where you have to be AHPRA registered, the Australian Health Practitioner Registration Authority”.

– Participant in Lived X Inclusion and Decision Making consultation, 2022

“A lot of people tend to think blind/ low vision [equates to] not being able to hear.”

– Participant in Disability Pride Youth Forum, 2022

Fundamentally, dominant socio-cultural understandings and attitudes – both historical and current – are the root of violence and abuse against children and young people with disability. The way we colloquially speak about disability, and how it is considered and represented in policy and law making, operates alongside the cultural norm of children and young people being expected to yield to powerful others. From this emerges a unique and dangerous dynamic that supports the cultural acceptance of the abuse, neglect and mistreatment of children and young people with disability. As such, approaches that disrupt the mechanisms of ableism, create long-term community attitude change, and promote understanding and respect for people with disability are critically important.

1.2 How ableism perpetuates harmful policies and practices

As an important decade-long strategy, investment by the Commonwealth in the Early Years Approach, along with developing and monitoring strategic reform in other areas such as Early Childhood Education and Care and Australia’s Disability Strategy, must model an anti-ableist approach in order to avoid inadvertently perpetuating harmful ideas of normative personhood, especially in the context of children.

Fiona Kumari Campbell, disability studies scholar, explains:

*“The norm produces violence by not allowing people to be what they desire to be at the most fundamental aspects of life; hence it is violence by restriction and negation”.*¹²

A culture of ableism, and other forms of discrimination, endure where individual and organisational discrimination goes unchallenged. For instance, segregated delivery of public services perpetuates the belief that people with disability are not worthy of being accommodated alongside everyone else in the community, creating an ‘othering’ effect. The Disability Royal Commission demonstrated that within these segregated environments, which children and young people are more commonly funnelled into, people with disability experience more exposure to violence, abuse, neglect and exploitation. This finding prompted CYDA to join with 41 other organisations to call for an end to segregated environments¹³.

Similar to the extensive research that was conducted to create a sociological framework to address family violence¹⁴, ableism requires a reckoning to expose the structures, norms and practices that maintain and perpetuate discrimination and abuse at every level in society. The work of the Disability Royal Commission initiated this process in an institutional setting, finding substantial evidence to demonstrate that inclusion benefits everyone¹⁵.

At the grassroots level, largely comprised of young people with disability, a disability pride movement is growing in response to the entrenched ableism that negatively impacts their daily life.

One young person on social media articulates this movement as follows:

“Disability Pride is the reckoning of The Ableist Society—of course it doesn’t want us to find our Disability Pride as Disability Pride threatens its very existence. When the systems of oppression rely on ignorance and exclusion, Disability Pride is a danger.

*When we are pridefully disabled, we live in direct rebellion of the status quo and challenge the systems that be through radical self acceptance. We are able to see through the world’s longest generational curse and fight back against the inhumane devaluation of Disability. The stigmas surrounding my disabled identity is not my burden to bear, but to break.”*¹⁶

Listening to the concerns and aspirations of young people, and recognising the powerful force of this movement, CYDA held a Disability Pride Youth Forum in September 2022. This formed the basis of one of our final submissions to the Disability Royal Commission. The following quotes from participants highlight the importance of this movement in combating ableism:

“ [For me this means] taking pride in my existence regardless of my disability.... Being the best version of myself [and] not yearning to be like another person.”

¹² Campbell, F. K. (2013). *Problematizing Vulnerability: Engaging Studies in Ableism and Disability Jurisprudence*, Keynote presentation. Available at:

<https://documents.uow.edu.au/content/groups/public/@web/@law/@lirc/documents/doc/uow166211.pdf>

¹³ <https://ourroyalcommission.com.au/endsegregation-joint-media-release/>

¹⁴ Our Watch, Australia’s National Research Organisation for Women’s Safety (ANROWS) and VicHealth. (2015). *Change the story: A shared framework for the primary prevention of violence against women and their children in Australia*. Our Watch, Melbourne, Australia.

¹⁵ Parliament of Victoria, Family and Community Development Committee, Inquiry into Social Inclusion and Victorians with Disability, Final Report (September 2014) p 20

¹⁶ Art Activism by Marie D.L. (2022). Available at: <https://fb.watch/iKwJc-Jst6/>

“[To help us share in pride] we need to check [look out] for each other, makes sure we are included in government activities and politics.”

1.3 Improving policies and practices through an anti-ableist approach

Truly innovative and effective early childhood approaches need to begin with anti-ableism¹⁷. Using this ideology to underpin the development of The Strategy will highlight the core beliefs, practices and processes that steer the department’s conceptual framework and all the activities that flow from it. This kind of review work can be as simple as analysing a piece of content to consider how problems are framed.

Barriers to inclusive education prevent children and young people who experience disability from learning and participating fully, with far-reaching and lifelong implications. Major barriers include negative attitudes and stigma around ‘difference’ and ‘disability’, inadequate education and professional development for teachers and specialist support staff, and systemic barriers, such as inadequate funding and support from education authorities. Underpinning these barriers is ongoing ableism.

There continues to be considerable discussion of the potential of education to bring about social change, with emphasis placed on the importance of working with children, from an early age onwards, to break the cycle of entrenched ableism. However, if adults have not examined their own attitudes and practices, they are likely to perpetuate that cycle and ultimately prevent inclusive education being realised.

Children and young people’s attitudes and choices are shaped significantly by the attitudes of their family and community. There is also a growing body of research demonstrating the importance of teacher attitudes. Research finds that positive teacher attitudes are a key to inclusive practice, creating the necessary conditions for engaging in inclusive education.

1.4 Applying an anti-ableist approach to The Early Years Strategy

This kind of review work can be as simple as analysing a piece of content to consider how problems are framed. The example below from The Early Years Strategy Discussion Paper (Section 2, p.10)¹⁸ uses an ableist lens to describe the problem of developmental vulnerability.

“Some groups are more likely to experience developmental vulnerability - First Nations children, children in regional and remote areas, children with language backgrounds other than English, and children with disability. Children frequently experience more than one kind of disadvantage. For example, children with disability are more likely to live in single income households (Sollis, 2019); and regional and remote areas are more likely to be socio-economically disadvantaged (ABS, 2016). These multiple types of vulnerability compound and make it harder for children and families to thrive without the right support.”

¹⁷ See Cheri Byrne-Haber’s (disability expert and activist) nine steps to being anti-ableist <https://sheribyrehaber.medium.com/are-you-ready-to-be-anti-ableist-in-2021-239103637949>

¹⁸ <https://engage.dss.gov.au/early-years-strategy/early-years-strategy-discussion-paper/>

Framing the subject as ‘some groups’ creates distance that serves to relegate people with disability to the category of ‘other’, making it easier to discriminate against them. The above paragraph in the Discussion Paper then assigns vulnerability, and in turn the source of the problem, to the states and traits of people with disability (single income households, education, where they live), casting them as outside the norm and problematising them. This form of ableism has been highlighted by researchers as obscuring the role of the social environment in disability, causing people to “falsely treat impairments as inherently and naturally horrible and blame the impairments themselves for the problems experienced by the people who have them”.¹⁹

The focus and emphasis of the paragraph should be on the actual problem – the ableist systems of beliefs, processes and practices that people with disability have no choice but to engage with, in order to live their lives. Drawing on the social model of disability as well as anti-ableist principles this paragraph can be more accurately written as:

A network of inherently ableist beliefs, processes and practices operating across the government services responsible for delivering education, healthcare, housing, transport, and welfare, can be identified as the key contributor for children with disability experiencing disproportionately higher rates of socio-economic disadvantage than their non-disabled peers.

Re-writing this phrase has the effect of re-framing the way the reader thinks about the topic and indeed what they consider the problem to be, in this case the structures, mechanisms and practices across the social services sector, rather than the users of those services.

If we consider the following statement (italicised below), taken from the same paragraph in the discussion paper, perhaps we can highlight the problem of assigning the success or failure of a system on its users, by using the same reframing approach.

“Some groups are more likely to experience developmental vulnerability . . . These multiple types of vulnerability compound and make it harder for children and families to thrive”.²⁰

Rather than trying to solve the ‘problem’ of developmental vulnerability of children with disability, this should focus on the root cause of the problem:

The overall aim . . . is to disrupt the network of inherently ableist beliefs, processes and practices within early childhood education and care, policy and practice that prevent early childhood settings from creating meaningful, sustainable, and inclusive opportunities for children with disability.

There is growing evidence to suggest that investment in early childhood education and care can be an important way to improve the cognitive and social development of children. The skills and competences that children acquire at this stage facilitate learning through the rest of a child’s life.²¹

Unless underlying ableist assumptions and biases are made explicit, The Strategy risks the same outcomes as many of the strategies that preceded it. As the discussion paper

¹⁹ Amundson, R & Taira, G. (2016). *Our Lives and Ideologies: The Effect of Life Experience on the Perceived Morality of the Policy of Physician-Assisted Suicide*, Journal of Disability Policy Studies, Vol16, p.54.

²⁰ The Early Years Strategy Discussion Paper (Section 2, p.10)

²¹ Delalibera, B. R., Ferreira PC. Early childhood education and economic growth. Journal of Economic Dynamics and Control. 2019;98:82–109

outlines, "Many of these Commonwealth early childhood policies and programs and their funding are delivered across different departments and agencies. This structure tends to create silos that discourage collaboration across organisations and may hamper the Commonwealth's efforts to deliver the best outcomes for children and families. While some inroads have been made into improving service delivery and coordination in the early years, there is still more to be done". (p.5)

We are heartened by the anti-ableist sentiment in some aspects of the discussion paper, which are respectful and inclusive of diversity: "The Strategy will be inclusive. Children with disability or with developmental concerns deserve the same positive experiences and opportunities to thrive as all children". (p.7), but we also highlight that a more holistic approach is required to eradicate the long-term detrimental effects of ableism for children and young people with disability.

The following section discusses co-design as one remedy for top-down policy approaches that fail to consider the problematic assumptions and biases that are built-in.

2. Reform through co-design

Recommendation 2

- CYDA recommends using genuine co-design approaches to develop and test all elements of The Strategy's design, including allowing input from young people with disability into the indicators and measurement tools, to highlight and prevent problematic framing and approaches.
- Establish a co-design working group to ensure the remainder of The Strategy implementation is carried out in partnership with young people with disability

Based on ongoing consultation with children and young people with disability and their families CYDA advocates for genuine co-design as best practice for inclusion in all disability related policy and program work. Therefore, we recommend co-design as an integral component to ensure that The Strategy achieves its purpose to be an effective road map for guiding early years' policies and programs across the Commonwealth.

2.1 What is co-design and why it is important

Co-design emerges from a tradition of participatory and collaborative design. Drawing on Blomkamp's²² widely accepted definition of co-design for policy making, developed in the Australian context for public policy co-design is as follows:

"Co-design is both cooperative and collaborative, using design-led processes that drive innovation, involving and framing those affected by policy issues as creative experts of their lived experience, and using practical and accessible tools to generate and test experience and ideas.

²² Blomkamp, E. (2018). *The Promise of Co-Design for Public Policy*, Australian Journal of Public Administration, vol. 77, no. 4, pp. 729–743. Available at: <https://doi-org.ezproxy.cqu.edu.au/10.1111/1467-8500.12310>

A Disability Royal Commission research report recommends co-design, stating that it validates “the collective voices and lived experience expertise of people with disability in the way the interventions are designed and conducted”²³.

2.2 What young people with disability say about co-design

Through CYDA’s consultations with young people about the development of other strategies such as The Guide to The Australian Disability Strategy (ADS) and Good Practice Guidelines for Engagement of People with Disability, co-design was considered crucial to the development of policy, strategy, and services that impact children and young people’s lives.

The design of the Early Years Strategy should be no different.

Building on this evidence from the CYDA community, we recommend early engagement with families, children and young people with disability to inform future drafts of The Strategy.

The co-design approach was reflected in our consultation with young people regarding the guide to the ADS. For instance, one young person shared a comment via written feedback that encapsulated the experience of ‘othering’ that people can feel when consulted in inauthentic ways:

“It’s important that you place [people with disability] in a position to run and be part of making/writing up the evaluation report and not just placing us to be the subjects of it”. —Young person with disability, Australia’s Disability Strategy consultation, 2022

Another young person participating in the same consultation shared their thoughts on the process of co-design:

“I guess what I was thinking was allowing disabled people to be consulted at multiple stages throughout the design process of the evaluation, initially before anything is designed, looking at what the goal is, what the information they’re trying to get out of the evaluation is and helping to suggest ideas of going about this, questions to ask, et cetera and then being able to come back and see the draft of what’s being created, give feedback on that.

And then even if it’s just sending through the final draft and giving an all-clear and just being able to provide feedback throughout it, provide your own opinions and it’s even better if they are able to have disabled people on board within the team themselves that are creating the evaluation but that’s of course up to the organisation, would be my thoughts”.

—Young person with disability, Australia’s Disability Strategy consultation, 2022

As this young person suggests, understanding what the goal is from the beginning of the process is an important part of co-design. CYDA recommends children and young people with disability be a part of defining what success looks like in the context of the vision for The Strategy. Views about success may differ between cohorts, so it is important to recognise this and seek to understand those perspectives.

²³ Fisher, K. Et. Al. (2022). *Research Report: Changing community attitudes to improve inclusion of people with disability*. Available at: <https://disability.royalcommission.gov.au/publications/changing-community-attitudes-improve-inclusion-people-disability>

2.2 Building the case for authentic co-design

Co-design is a process not a single event. It involves meaningful and genuine engagement from beginning to end, with all stakeholders actively involved to ensure success. The aspiration to contribute in meaningful ways to public policy and programs that impact them has emerged from many of CYDA's consultation with young people, on a range of topics.

Some of CYDA's previous work has found that people with lived experience of disability are often cynical of being consulted in disingenuous and non-impactful ways:

"If you're going to consult, you need to genuinely want to consult. Listen and be ready to make changes and take action on what people with disability are actually saying to you. Don't just do it to tick a box."

– Young person with disability, Good Practice Guidelines for Engagement of People with Disability consultation, 2022.

CYDA's recent consultation on evaluation tools for Australia's Disability Strategy, prompted one participant to coin the term "us based" to describe their desire to be involved in disability related policy issues:

*"I think just really getting us involved in anything really is just really the main way to go in order to have a proper – I want to say outcome but a proper actual voice or an understanding of us based issues. Because a lot of the time, even for **us based** issues they won't bring in disabled people".*

– Participant in CYDA Australia's Disability Strategy consultation, 2022

Another participant in the same consultation discussed their ideas for genuine and continuous involvement in program and policy design and implementation:

"Don't bring in people on not even a casual basis to give their thoughts and opinions on things like this. Actually, establish some sort of position or whatever that gives us the ability to, if you want our voices and our opinions fine, but we'd have the right to be – on the continuous basis, yeah fine. But we need everything else that comes with the continuous basis. So proper payments, super, all that kind of stuff".

Young people told us they wanted to be involved in organisational policy development and design:

"Instead of having ableds [non-disabled people] design what they think we need and what they think we want, actually having us do it ourselves because there are plenty of ways to facilitate that."

– participant in LivedX consultation, inclusion and decision making (2021)

Furthermore, *Nothing without us*, is a renowned catchcry in the disability community and one we hear commonly from the children and young people with disability we engage with, phrased succinctly by one young person:

"Involve people with a disability in decision making".

—Participant, Australia's Disability Strategy consultation, 2022

2.3 Maximising the application of co-design to The Strategy

In the context of the drafting of an Early Years Strategy, the first step for the government to building a co-design approach is to set up a co-design working group to ensure the remainder of The Strategy implementation is carried out in partnership with people with disability. Additionally, it is imperative that any proposal impacting young people with disability have representatives from this cohort in the working group. Ideally, people with disability would already be part of a reference group (or similar) for larger or more substantial ongoing projects.

3. Prioritising the needs of diverse groups through universal design/thinking

Recommendation 3

- We urge the Australian government to incorporate a universal design approach to the design, delivery, monitoring and evaluation of the strategy framework, to make The Strategy accessible for all, including children and young people with disability.

CYDA acknowledges the commitment of the Australian government to ensure that The Early Years Strategy will be built on the foundation that every child deserves the opportunity for the best start to life, a chance to achieve their goals and dreams while ensuring that no child or family is held back or left behind. To best accomplish this, CYDA recommends the government consider the diverse needs of children and young people with disability and their families in the design. By considering the various requirements and abilities of *all* throughout the design of The Strategy, a universal design approach must create policy, products and services that meet peoples' diverse needs. If The Strategy and underlying framework is universally designed at the outset to be accessible and usable, everyone benefits. Simply put, universal design is good design²⁴.

3.1 The case for universal design

Universal design refers to the “design of products and environments to be usable by all people to the greatest extent possible, without the need for future adaptation or specialised design”²⁵. In the context of an Early Years Strategy, this means designing, delivering, monitoring and evaluating The Strategy’s framework, action and policy priorities to be accessible, usable and meaningful to children and young people across the broadest diversity ranges. An inclusive strategy facilitates access, participation, and success across all domains of a child's early years. This approach acknowledges that The Strategy would meet the needs of all people who wish to use it. A universal design strategy is not a special requirement for the advancement of only a minority of the population. It is a fundamental condition of good design for the benefit of all.

Policy responses and strategies which assume the experience and impact of disability is the same can fail to take into account intersectional impacts disproportionately affecting groups

²⁴ <https://universaldesign.ie/what-is-universal-design/>

²⁵ Centre for Excellence in Universal Design. *What is Universal Design*. Available at <https://universaldesign.ie/what-is-universal-design/>

of people with disability.²⁶ Therefore, the Early Years Strategy should consider incorporating a targeted approach to engage with children, young people with disability and their families who face intersectional barriers, especially those from First Nations communities, Culturally and Linguistically Diverse communities, the LGBTQIA+ community, those living in rural/remote Australia, disadvantaged socio-economic areas etc., and include them at the heart of the design process.

Several national strategies and policies have adopted various mechanisms to include these priority groups in recent years. For example, the Australian Disability Strategy acknowledges the intersectionality and diversity of children and young people with disability, and the Early Childhood Targeted Action Plan sets out actions to ensure these children are supported to reach their full potential. Similarly, the NDIS is co-designing a specific First National Strategy²⁷ and a new CaLD strategy²⁸ to deliver better outcomes to participants from these backgrounds. However, whether these segmented approaches have a meaningful impact on children and young people from the priority groups remains to be seen.

A recent report²⁹ on child development – including developmental vulnerability³⁰ and the domains that make up child development based on the Australian Early Development Census (AEDC) found that:

- Aboriginal and Torres Strait Islander children have high levels of vulnerability: 42.3% are vulnerable in one or more domains, compared to 20.6% for non-Aboriginal or Torres Strait Islander children.
- Children in the most disadvantaged socio-economic areas are twice as likely to be developmentally vulnerable (33.2% compared to 14.9%) and three times more likely to be vulnerable in more than one domain (19.1% compared to 6.7%) than children in the most advantaged socio-economic areas.
- In very remote areas, nearly one in two children are vulnerable in one domain (46.2%) compared to one in five children (20.8%) in major cities.
- More than 90% of children who are not proficient in English are developmentally vulnerable, with 60.5% of these children vulnerable in more than one domain.

To address these gaps and increase accountability for the wellbeing, education, health (including mental health), safety and development of Australia's children and young people

²⁶ Australia's Disability Strategy 2021-2031. Available at

<https://www.disabilitygateway.gov.au/sites/default/files/documents/2021-11/1786-australias-disability.pdf>

²⁷ NDIS First Nations Strategy. Available at <https://www.ndis.gov.au/about-us/strategies/first-nations-strategy>

²⁸ NDIS Cultural and Linguistic Diversity Strategy. Available at <https://www.ndis.gov.au/about-us/strategies/cultural-and-linguistic-diversity-strategy>

²⁹ The Front Project. (2022). *SUPPORTING ALL CHILDREN TO THRIVE; The importance of equity in early childhood education*. Available at

<https://www.thefrontproject.org.au/media/attachments/2022/05/04/supporting-all-children-to-thrive-report.pdf>

³⁰ The AEDC classifies children as 'on track', 'at risk' or 'vulnerable' depending on how they score in each area of development, known as a domain. Children who are developmentally vulnerable demonstrate a much lower than average ability in at least one AEDC domain. The five domains measured are physical health and wellbeing, social competence, emotional maturity, language and cognitive skills (school-based), and communication skills and general knowledge. - Ibid

with disability, CYDA recommends that The Early Years Strategy ensure that it is universally designed.

3.2 What young people say about the benefits of universal design/thinking

Young people from the CYDA community also identified universal design as a significant recurring theme and design solution during the LivedX consultation series³¹. Although focusing on the tertiary education sector, the feedback from young people recommending the implementation of the universal design approach has applicability in the early years learning space as well.

The comments about universal design from young people who participated in the consultations spanned the physical campuses to course delivery:

“The architecture itself should be designed with disability in mind.”

“Don't make accommodations for students, assume that there are students [with disability] are going to almost definitely be in those classes. And make it just a [fundamental] part [of the design]. Just assume we're going to be there.”

“I think a lot of the supports and accommodations should benefit all [...] not just people with accessibility needs.”

– participants in LivedX consultation, tertiary education (2021)

³¹ LivedX series <https://cyda.org.au/search/details/353/livedx-2022-series-full-policy-paper-tertiary-education-and-learning>

CYDA's response to the discussion questions

In the following section, we draw even further on the data collected from families, children and young people with disability to respond to the questions outlined in the Discussion Paper. Focusing our expertise, on content rather than format, we respond to all questions, excluding the questions about structure.

1. Vision/Outcomes

Recommendation 5: Realise an aspirational vision of early childhood for children with disability

- Incorporate the five key elements of CYDA's vision of early childhood for children with disability; Activate child voice, support the workforce, calibrate funding, enhance and support adjustments, collaborate. (See Table 1- below)

1.1 CYDA's vision of early childhood for children with disability

The early years of a child's development can impact their entire lives. Accessible and inclusive early childhood experiences – play, learning, care, education, and development - are the surest and most sustainable pathways to an inclusive life and all the benefits that brings to the child, their family, peers, and their community.

"Inclusion means that every child has access to, participates meaningfully in, and experiences positive outcomes from early childhood education and care programs."³²

Table 1 The five elements of a vision of early childhood for children with disability

1. Activate our children's voices

- Activating and collecting input from young children on their experiences and goals
- Families, caregivers, communities and systems have high expectations and aspirations for children

2. Support the workforce

- All stakeholders drive inclusion from the earliest age, focusing on access, engagement and development

3. Calibrate the funding

- Investing in inclusive and accessible environments where children are welcomed and valued

³² Early Childhood Australia. (2016). *Statement on the inclusion of every child in early childhood education and care*. Available at: <https://www.earlychildhoodaustralia.org.au/our-work/inclusion-resources/>

4. Enhance support and adjustments

- Investing in support and adjustments for children and their families across local communities where they live, play and learn

5. Collaborate

- Collecting and sharing data to understand outcomes and drive investment and accountability

1.2 Expectations of children with disability

Young people with disability explain regularly to CYDA the impact of other people's expectations on their everyday lives. These might be low expectations, over-protectiveness, overly high expectations, or a lack of willingness to understand that a child's abilities and development can vary across time and environments.

Most commonly written about are low expectations and the tendency for diagnosis and disability to drive conversations and choices, not necessarily the natural rhythms and activities of childhood. There is also the influence and direction of the medical approach to disability tending to subvert a child's human rights and a family's (or caregiver's) natural authority.

Young people who experience chronic or episodic disabilities or conditions speak to the fluctuating nature of their health, functional capacity and emotional wellbeing and the discrimination they face in their everyday lives.

"I think it really is a big thing with the medical model of disability, and the way that we're seen as impaired, without looking at the way that society is built to render us, when they're inaccessible."

– young participant in LivedX consultation, Healthcare Settings for LGBTQIA+ Youth with Disability (2021)

1.3 Societal beliefs

The Early Years Catalyst initiative reported in August 2022 that young children and their families face embedded narratives and deep systemic forces³³. The deeply held societal beliefs identified included:

- We are a society that is prepared to live with poverty
- Families are a no-go zone
- Parenting comes naturally
- What's not normal is 'other' (the exception)

Looking specifically at 'What's not normal is 'other' (the exception)', The Early Years Catalyst reported what participants feel is holding the 'current state' in place, particularly in terms of undesirable outcomes. The feedback includes:

³³ Fiona McKenzie and Eve Millar, 2022. Mapping the systems that influence early childhood development outcomes. Prepared by Orange Compass for the Early Years Catalyst, August 2022. <https://www.earlyyearscatalyst.org.au/field-insights/>

- Societal fear, aversion to disability and poverty
- Disability, disadvantage is your problem not ours
- Govt policies / programs are designed for the majority not the exception
- Systems reward normal and punish those who don't fit the "norm"
- Something wrong with parents that produce a child with disability or 'special' needs
- Wider society/voters don't care if something is unfair if they are 'the other'
- We support inclusion until it challenges our views of ourselves
- They don't need same standard of support as a normal person- should be grateful for what they get
- Poor people, disabled people are not normal or mainstream or common

Children and young people with disability look to their families (and/or caregiver/s) first and foremost for protection from harm, and for guidance to navigate their lives safely and securely. Where families must deal with ableism, structural inequity, and deeply held societal beliefs about their own role as a family, children and young people with disability are immediately placed at a disadvantage. This disadvantage is not because of the nature of their disability, but society's inability to support and provide adjustments for their differences.

1.4 Early childhood intervention and inclusion

Early childhood intervention, or '*therapy*' as it is often referred to, is a key ingredient when combined with the basics of childhood – fun, family and play. CYDA believes one does not replace or subvert the other. Early intervention is effective when it can be leveraged into everyday places and activities. Whether it is role modelling language, using physical techniques at the park, or colouring in with a more stable grip, early intervention continues to be a great enabler for inclusion, and helps create new pathways to ordinary places and experiences.

At times, there is a risk that families divert most of their attention and effort to early childhood intervention. It is crucial that the places where it is delivered, as well as the people responsible for services and supports, feel welcoming, supportive and understanding. People and places in the child's (or their family's) own local community may feel less so. Families tell CYDA that they go where they and their child feel welcome and understood. Any exclusion or isolation does everyone harm; Young children, disabled or non-disabled, miss out on formative experiences together.

Many families of children and young people with disability share with CYDA their concerns about an over emphasis on the need for early intervention and therapy at the expense of childhood play and development experiences. This pressure or emphasis can come from families themselves, health professionals, and/or other members of their communities. It is therefore critical for the role of play and the importance of play to be recognised by all parties involved.

1.5 Disability pride and identity

During CYDA's 2020 National Youth Disability Summit, young participants expressed disability pride and a sense of community with other people with disability. Some young people also shared that being actively involved in the disability community can lead to feelings of disability pride. Many families find it difficult to talk to their child about their disability or their diagnosis. Young people share with CYDA the power of role models who have disability and the need for representation of people disability in everyday situations, media and popular culture. Young people value how role models present new options and

help pave the way for different life paths. One 2020 Summit participant shared that they wished they had role models earlier in life to show them “*that this life [that they are now living] is possible.*”

Many of the supportive and necessary conversations about disability and difference must start in early childhood both for children with and without disability. A range of adults in a child’s and family’s life can role model the language and approach to talking about a child’s disability in a way that supports their growth and development of their identity. There is no one way to approach this as the experience of disability varies – timing of diagnosis, nature of disability, need for functional support, nature of disability and the structural and environmental factors in a child’s life.

2. Policy priorities

Recommendation: Prioritise policies that give children with disability the best start in life

- CYDA urges the Australian Government to align the policy priorities of the early childhood strategy closely to the [Early Childhood Targeted Action Plan](#) as outlined in [Australia’s Disability Strategy 2021-2031](#). Especially to:
 - Enable early identification of disability or developmental concerns and develop clearer pathways and timely access to appropriate supports
 - Strengthen the capability and capacity of key services and systems to support parents and caregivers to make informed choices about their child
 - Encourage a stronger sense of inclusion and provide opportunities for parents, carers and children to build peer networks, including for Aboriginal and Torres Strait Islander and culturally and linguistically diverse parents and caregivers.
- CYDA calls on the Australian Government to give children their best start in life. Specifically, CYDA joins calls by [The Parenthood](#), [Thrive by Five](#), [Every Child](#) and the [Centre for Policy Development](#) for the Australian Government and the strategy to ensure:
 - Universal access to education and care – affordable, high quality, inclusive and easy to access
 - Simplification and coordination of the currently confusing and expensive array of services and schemes
 - Data are collected and shared at all levels of government to improve evidence of the range and quality of early childhood services.¹³

The early years of a child’s development can impact their entire lives. Accessible and inclusive early childhood experiences are one of the surest and most sustainable pathways to an inclusive life and all the benefits that brings to the whole family, including balancing work and care responsibilities.

Dependent on the support, engagement and experiences children and their families/caregivers and communities receive during early years, this life stage can bring both opportunity and risk.³⁴ Tragically, we know that many children are not able to access

³⁴ Thrive by Five & The Minderoo Foundation. (2017). *Time to Act: Investing in our children and our future*. Available at [TB5 Time2Act 20170119 FNL Digital-p.pdf \(minderoo.org\)](#)

equitable or adequate support. Specifically, not every currently has access to high quality, affordable and inclusive Early Childhood Education and Care and Outside School Hours Care. As result, more than one in five Australian children enter primary school 'developmentally vulnerable'.³⁵ This is in addition to the children who already have a diagnosed disability.

Therefore, the Australian Government must invest in:

Quality: The federal systems that influence and should support key aspects of early childhood development are underperforming and must improve. For instance, our early learning centres are of inconsistent quality.

Too many do not meet National Quality Standard (NQS). According to National Quality Framework Snapshot June 2020, 17.7 per cent of centres did not meet the NQS, rising to 18.4 per cent for long day care (excluding preschools).³⁶

Affordability: Australia's early learning centres are also some of the most expensive in the Organisation for Economic Co-operation and Development (OECD). According to the *Household, Income and Labour Dynamics in Australia (HILDA)* Survey, approximately 27 per cent of household income is absorbed by childcare.³⁷ These costs have more than doubled since 2002.³⁸

Inclusion: The COVID-19 pandemic has exposed the fragilities and inequalities in a range of service systems for children with disability and their families.³⁹ [Australia's Disability Strategy](#) recognises that high quality early childhood education sets children up with the foundations for success and that inclusion must begin from the earliest ages with a focus on access and participation of all children in early childhood education and care.⁴⁰

Connected services: The service systems that relate to early childhood development – including childcare, preschool, child health, family support, the NDIS early childhood approach and child protection – are disconnected. Policy, process and programs for these systems span federal and state/territory governments, and a mix of ministries and departments within governments. This complexity is confusing for families and caregivers to navigate and children risk falling between the gaps of a fragmented system.

³⁵ Australian Early Development Census. *Australian Early Development Census National Report 2018: A Snapshot of Early Childhood Development in Australia*. Department of Education and Training. Available at [AEDC 2018 National Report.pdf](#)

³⁶ Australian Children's Education and Care Quality Authority. (2020). *NQF Snapshot: Q2 2020*. Available at [NQF Snapshot Q2 2020.pdf \(acecqa.gov.au\)](#)

³⁷ Ruppanner, L. (2019). *HILDA findings on Australian families' experience of childcare should be a call-to-arms for government*. Available at [HILDA findings on Australian families' experience of childcare should be a call-to-arms for government \(unimelb.edu.au\)](#)

³⁸ *ibid.*

³⁹ Dickinson, H., Yates, S. (2020). *More than isolated: The experience of children and young people with disability and their families during the COVID-19 pandemic*. Report prepared for Children and Young People with Disability Australia (CYDA), Melbourne

⁴⁰ Commonwealth of Australia. (2021). [Australia's Disability Strategy 2021-2031](#)

3. Principles

Recommendation 6: The Strategy should reflect human rights principles

- Ensure The Strategy reflects human rights principles by including the following five principles: Child-centred, Anti-Ableism, Co-design, Universal design, Non-discrimination

To achieve the vision of the strategy, the Australian Government needs to commit to the development and implementation of policies, programs, services and systems which reflect human rights principles.

CYDA grounds our work in evidence and a human rights approach. There are a range of international instruments that establish normative standards and principles for the treatment of children and young people with disability, including:

- The United Nations Charter on the Rights of People with Disability (CRPD)
- Convention on the Rights of the Child (CRC)
- International Convention on the Elimination of All Forms of Racial Discrimination
- International Covenant on Civil and Political Rights
- International Covenant on Economic, Social and Cultural Rights
- Declaration on the Rights of Indigenous Peoples

We recommend the following Guiding Principles for the strategy based on the above instruments and core values and principles of CYDA.

Principle 1 - Child-centred

Through adopting a child-centred principle, The Strategy commits to have a consistent focus on children and young people's needs, including those with disability. The strategy would also ensure that children and young people have ongoing and accessible opportunities to express their views on the progress, evaluation, and the outcomes of the Strategy.

Principle 2 – Anti-Ableism

Inherent ableism and societal beliefs undermining human rights and legislation. To mitigate this risk, The Strategy needs to be built on an anti-ableist framework to create long-term community attitude change around ableism and promote understanding and respect for all people with disability, including children in early childhood education and care.

Principle 3 - Co-design

Develop and test indicators and measurement tools, such as surveys, with people with disability and representative organisations to highlight and prevent problematic framing and approaches

Principle 4 - Universal design

The strategy needs to incorporate universal design principles in designing, delivering, monitoring and evaluating its framework, action and policy priorities; so that it is fully inclusive and is accessible, usable and meaningful to children and young people and their families across the broadest diversity ranges.

Principle 5 – Non-discrimination

The strategy will ensure that no child or young person shall not be discriminated on the basis of age, gender, race, culture, disability, vulnerability or sexuality.

4. Evidence-based approach

Recommendation 7: The Strategy should address data and evidence gaps

- Collect evidence directly from families, children and young people with disability to inform the development of The Strategy.
- Track the pathways and outcomes of children through different systems by ensuring better data linkage and the joining of data sets

4.1 Gaps in evidence and research - Children Voices should be heard

Despite The Strategy Discussion Paper's reference to the prevalence of rich sources of data about children and families that can be used to guide the priorities and performance of the Strategy⁴¹, we draw attention to AIHW's report on Australia's children, that there are few examples where children's opinions or experiences are collected as evidence⁴². Whilst population-level monitoring occurs at a national level, this is administrative (information collected as part of service delivery) and from surveys administered to adults. Further, "there are currently no national indicators to measure how children transition through major development stages, or how children interact with services and move through different systems...[and] ... there is limited ability to track children through different data sources to assess their outcomes".⁴³

4.2 Gaps in existing frameworks: Inadequacy of resources to achieve child well-being

[The Nest](#) is Australian Research Alliance for Children and Youth's (ARACY) wellbeing framework for children and conceptualises wellbeing as six interconnected domains that support each other to help children reach their potential. To have optimal wellbeing, a child needs to be adequately resourced in all six domains.

Below we have included (available) key data across the six domains of the Nest, highlighting the evidence gap between outcomes for children with disability against each domain.

⁴¹ <https://engage.dss.gov.au/early-years-strategy/early-years-strategy-discussion-paper/> (p.7)

⁴² Australian Institute of Health and Welfare, Australia's children, web report, last updated 25 February 2022. <https://www.aihw.gov.au/reports/children-youth/australias-children/contents/data-gaps/overarching-data-gaps>

⁴³ Ibid

1. Valued, loved, and safe

Compared to their peers, children with disability are⁴⁴:

- at more than three times higher risk of physical violence
- at nearly three times higher risk for sexual violence
- over four times higher risk for emotional abuse and neglect.

2. Material basics

Poverty

- 16% of all children were living in poverty in 2019-20⁴⁵
- one-parent families with a child with disability are more likely (44%) to have a low weekly equivalised family income⁴⁶

Geography

- Children in inner regional areas were more likely to have a disability than children in major cities (10.4% or 80,400 compared with 7.0% or 239,700). 8.3% of children in outer regional and remote areas were reported as having a disability.

Housing

- The percentage of dependent children with disability aged 0-14 years by tenure type:⁴⁷
 - Owner 54.5%
 - Renter 42.3%
 - Rent-free 2%
 - Other tenure type 0.5%
- Of people with disability accessing specialist homelessness services:⁴⁸
 - 9% are under 9 years old
 - 2.6% 10-14 years
 - 3.2% 15-17 years
 - 10.1% 18-24 years
- 5% of people with disability aged 0-24 years live in a dwelling modified for their disability⁴⁹

⁴⁴ 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://aifs.gov.au/child-family-community-australia/understanding-safeguarding-practices-for-children-with-disability-when-engaging-with-organisations)

⁴⁵ Davidson, P; Bradbury, B; and Wong, M (2023), *Poverty in Australia 2023: Who is affected Poverty and Inequality Partnership Report no. 20*. Australian Council of Social Service and UNSW Sydney

⁴⁶ Australian Institute of Health and Welfare (2022) *People with disability in Australia*, AIHW, Australian Government

⁴⁷ Australian Institute of Health and Welfare (2018) Table LIVI6 2018, AIHW, Australian Government

⁴⁸ Australian Institute of Health and Welfare (2019) Table SHSC3 2019, AIHW, Australian Government

⁴⁹ Australian Institute of Health and Welfare (2019) Table NEED2 2018, AIHW, Australian Government

3. Healthy

Over 300,00 babies are born in Australia every year. In 2018, 357,500 or 7.7% of children under 15 were reported as having disability.⁵⁰

Need for assistance by age, 2016 and 2021⁵¹

Age grouping	2016 (%)	2021 (%)
0 - 4 years	1.1	1.4
5 - 14 years	3.3	4.4
15 - 24 years	2.2	3.0

4. Learning

In 2019, children with disability made up 6.8% of those enrolled in a preschool program in the year before full time schooling (children aged 4 and those aged 5 who were not repeating).⁵²

In 2021, the proportion of children enrolled in a preschool program in the year before school (YBFS) who had disability was 6.2%, compared with 7.6% representation of children with disability in the community in 2018.⁵³

5. Participating

- Exclusion: Suspensions, expulsions and cancellations of enrolments begin in the first year of school when children can be as young as four years old⁵⁴
- Social participation: In the previous 12 months, nine out of ten (89.8%) children (aged 5-14 years) with disability participated in social activities⁵⁵

6. Positive sense of identity and culture

- Sex: Boys were more likely than girls to have a disability (3.3% of boys aged 0-4 years, compared with 1.5% of girls and 7.5% of boys aged 5-14 years, compared with 3.7% of girls)
- First Nations children: Indigenous children were more likely to have a disability (20.9% or 58,000)⁵⁶

⁵⁰ ABS (2019) [Disability, Ageing and Carers, Australia: Summary of Findings](#), ABS website, accessed 11 February 2022.

⁵¹ ABS (2022) Profile of people with a core need for assistance in Australia, Information on need for assistance, Source: Disability and carers: Census 2021

⁵² Australian Institute of Health and Welfare (2022) People with disability in Australia, AIHW, Australian Government, accessed 03 November 2022.

⁵³ Australian Government, (2023) Australia's Disability Strategy Outcomes Framework, March 2023

⁵⁴ Graham, Killingly, Laurens, Sweller, (2021), Suspensions and expulsions could set our most vulnerable kids on a path to school drop-out, drug use and crime, The Conversation. Available at: <https://theconversation.com/suspensions-and-expulsions-could-set-our-most-vulnerable-kids-on-a-path-to-school-drop-out-drug-use-and-crime-166827>

⁵⁵ ABS (2019) [Disability, Ageing and Carers, Australia: Summary of Findings](#), ABS website

⁵⁶ ABS 2019. [National Aboriginal and Torres Strait Islander Health Survey, 2018–19](#). Cat. no. 4715.0. Canberra: ABS.

- Culturally and linguistically diverse (CALD) background children: Despite the prevalence of disability for CALD children being the same as non-CALD children, a smaller proportion of NDIS participants aged 0-14 are from a CALD background⁵⁷ 4 (31% for CALD compared to 38% for non-CALD)⁵⁸

4.3 Data gathering and sharing

The direct experience of children and young people with disability and the policy experience of CYDA demonstrates that there is a significant need to improve the collection and use of data at a range of levels within the ECEC and education systems, at the individual, system, and jurisdictional levels. Additionally, there is a need to examine how data is used to inform policy and practice in the ECEC and education systems. CYDA continues to advocate for the improvement and refinement of data collection from early childhood and school education to strengthen the evidence base and improve educational outcomes.

“...society cannot be equitable unless all children are included, and children with disabilities cannot be included unless sound data collection and analysis render them visible.”⁵⁹

Without high-quality data, there are limited opportunities to develop evidence-based approaches to protect children and young people and monitor existing and new interventions.⁶⁰

4.4 Track the pathways of children through different systems by linking data sets

We support the recommendation of AIHW in its 2022 report, to link data from two or more sources⁶¹, to improve understanding of:

- How children transition between key developmental stages and their outcomes at different stages of their life
- The pathways children take through different services and the points where intervention would be most effective
- The relationships between risk factors, protective factors and outcomes, which interventions are most likely to provide positive outcomes, and which indicators can be used as predictive tools for monitoring
- How children’s wellbeing or service use differs among different population and geographic groups, where data on a specific population group may only be available in 1 data set

⁵⁷ SSI. (2018). Still outside the tent, Cultural diversity and disability in a time of reform – a rapid review of evidence, Available at:

https://www.ssi.org.au/images/stories/documents/publications/Still_Outside_the_Tent_Final.pdf

⁵⁸ NDIS. (2019) *Culturally and Linguistically Diverse participants report*. Available at:

<https://data.ndis.gov.au/reports-and-analyses/participant-groups/culturally-and-linguistically-diverse-report>

⁵⁹ United Nations Children’s Fund 2013, *State of the World’s Children 2013: Children with Disabilities*, United Nations, New York, p. 63.

⁶⁰ 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](https://www.aifs.gov.au/child-family-community-australia/understanding-safeguarding-practices-for-children-with-disability-when-engaging-with-organisations) (aifs.gov.au)

⁶¹ Australian Institute of Health and Welfare (2022) Children with disability in Australia. Available at: <https://www.aihw.gov.au/reports/children-youth/australias-children/contents/data-gaps/improve-evidence>

Appendices

Appendix 1– Examples of gathering children and young people’s voices

Example 1



[What do you think?](#), an accessible online tool was developed and launched by The Association for Children with a Disability in October 2022.

Its purpose is to gather input to help develop more inclusive playgrounds. It was designed to be a fun, easy to use and accessible online platform where children with disability and developmental delay can have their say about what’s important to them. Children are being asked to share their ideas and thoughts on playgrounds. [More information can be found here.](#)

“Being able to watch the questions in Auslan and answer by taking a photo was something I’d never seen before. It’s great that my child, who’s non-verbal, can have a voice.” – Parent

Example 2

[Australia’s National Children’s Commissioner](#) ran a survey in 2022⁶² on mental health and the COVID-19 pandemic. The survey received over 4,500 responses from children aged 9-17 and produced a ‘child-friendly’ version of the report. Most children responding to the survey were in the youngest and second youngest age groups (66% aged 9–11 and 18% aged 12–13). 7% of children who responded identified as having a disability. This matches the national average for children - 7% of children in Australia have some level of disability, as of 2020.⁶³ The full survey report collated responses to key questions and displayed responses by demographic group, for example:

⁶² Australian Human Rights Commission. (2022). ‘Mental health shapes my life’: COVID-19 & kids’ wellbeing Available at: <https://humanrights.gov.au/our-work/childrens-rights/publications/mental-health-shapes-my-life-covid-19-kids-wellbeing-2022>

⁶³ AIHW, Australia’s children (Online Report, 2020) 93 Available at: <https://www.aihw.gov.au/reports/children-youth/australias-children/contents/about>

Top three things that help children stay happy and hopeful across different groups:

Aboriginal and/or Torres Strait Islander children (n=179):

1. Support of my parents and family
2. Spending time with pets
3. Listening to or playing music

Children with a disability (n=256):

1. Support of my parents and family
2. Using technology for things like games and social media
3. Listening to or playing music

Example 3

CYDA's 2020 National Youth Disability Summit Position Papers

- [National Youth Disability Summit - What young people with disability said - Education Position Paper](#)
- [National Youth Disability Summit - What young people with disability said - Employment Position Paper](#)
- [National Youth Disability Summit - What young people with disability said - Mental Health and Wellbeing Position Paper](#)
- [National Youth Disability Summit - What young people with disability said - NDIS Position Paper](#)
- [National Youth Disability Summit - What young people with disability said - Awareness, Access and Inclusion Position Paper](#)

Example 4

LivedX 2022 series

Young people with disability are not accessing education, including university and Vocational Education and Training (VET), on an equal basis to their peers without disability.⁶⁴ To understand the experiences and perspectives of young people with disability in tertiary education, CYDA hosted two consultations and a one-on-one interview, with a total of 17 participants in September and October 2021. These consultations were co-designed by a working group of young disabled people.

- [LivedX 1: Tertiary education and learning](#)
- [LivedX 2: Financial security and employment](#)
- [LivedX 3: Healthcare settings for LGBTQIA+ youth with disability](#)
- [LivedX 4: Community spaces for LGBTQIA+ youth with disability](#)
- [LivedX 5: Inclusion and decision making](#)

⁶⁴ AIHW. (2022). People with disability in Australia. Available at: Engagement in Education (aihw.gov.au)

Appendix 2 - CYDA's work on early childhood

1. [Report](#): Taking the first step in an inclusive life Experiences of Australian early childhood education and care
2. National Framework for Protecting Australia's Children 2009-2020, [CYDA Submission](#)
3. National Strategy to Prevent Child Sexual Abuse Final Development Consultation Paper [Response](#)
4. NDS & NDIS Outcomes Framework Introductory Paper, [CYDA Submission](#)
5. [Pre-Budget submission](#): Drive inclusion and equity for children and young people with disability 2021-22
6. [Pre-Budget submission](#): Invest in children and young people with disability: their voices and their future 2023-24
7. Review of the Disability Standards for Education 2005, [CYDA Submission 2020](#)
8. Senate Inquiry into on the national trend of school refusal, CYDA [submission](#)
9. Senate Select Committee on Autism inquiry, [CYDA Submission](#)
10. Tasmania's Child and Youth Wellbeing Strategy, [CYDA Submission](#)
11. [Submission](#) to the National Disability Strategy beyond 2020
12. [Response](#) to the DRC's Rights and Attitudes issues paper
13. [What young people with disability said: Awareness, Access + Inclusion](#)
14. [Briefing Paper](#) for the Families Australia and Children and Young People with Disability Australia (CYDA) Forum
15. [Submission](#) to the Supporting young children and their families early, to reach their full potential consultation paper

CYDA fact sheets

- [Understanding ECI language](#)
- [Supporting the development of children and young people with disability](#)
- [Services and supports in the early years](#)
- [About family-centred practice](#)
- [Building strong families](#)
- [Tips for early intervention from CYDA Webinar on Early Childhood](#)
- [What is inclusive education?](#)
- [Addressing ableism in education](#)