

CYDA's submission to the National Disability Advocacy Framework 2022-2025 consultation

**Children and Young People with Disability Australia
July 2022**

Authorised by:

Mary Sayers, Chief Executive Officer

Contact details:

Children and Young People with Disability Australia

E. marysayers@cyda.org.au

P. 03 9417 1025

W. www.cyda.org.au

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.

Contents

Recommendations.....	3
Introduction.....	5
Children and young people’s needs and rights must be reflected in the framework	7
Embed the rights of children and young people in the framework’s principles	7
Stronger commitments and actions around child and youth specific individual advocacy services	8
Equip young people with the tools needed to navigate complex systems.....	9
Safeguard the sustainability of the sector.....	10
Guaranteeing Disability Representative Organisations and other disability advocacy organisations are sufficiently funded to fulfil their remit.....	10
Ensuring people with disability can access timely support.....	12
Clearer language for defined outcomes	13
Clearer language and division of tangible, measurable outcomes to prevent jurisdictions avoiding responsibility	13

Recommendations

Recommendations for the framework to better include the rights and needs of children and young people

- The framework should include the Convention of the Rights of Children with Disability as an underpinning principle to ensure the rights of children and responsibilities of government and disability advocacy services to uphold these rights is reflected.
- The Participation and Inclusion principle should be amended to read '*Disability advocacy is an essential tool for fostering the full and effective participation and inclusion of people with disability in society, **including through providing age appropriate assistance and platforms***' to safeguard the important role the disability advocacy sector plays in upholding the rights of children and young people to express their views.
- The framework should include clear outcomes and actions to ensure people with disability across Australia have consistent access to specialised individual advocacy that have capabilities to offer culturally and life stage appropriate support. More specifically, CYDA urges the Department to include clear objectives and outcomes for each state and territory to have a child and youth orientated, cross-disability individual advocacy service.
- The framework should outline specific key outcomes and objectives ensuring that people with disability across Australia have culturally and life stage appropriate access to self-advocacy resources and supports. Specifically, CYDA calls for clear outcomes around committing to self-advocacy, capacity building and leadership programs for children and young people with disability.

Recommendations to safeguard the sustainability of the disability advocacy sector

- Under the proposed framework's 'Responsibilities, Reform and Policy Directions' section, the dot point '*Ensuring the funding of disability advocacy is transparent, equitable and accountable, and geographical coverage and services gaps are identified and addressed*' should be amended to instead read '*Ensuring the funding of disability advocacy is transparent, **sufficient**, equitable and accountable, and geographical coverage and services gaps are identified and addressed*' to safeguard a commitment from governments to adequately fund the sector
- The proposed framework's '*Regardless of where they live, people with disability can access quality and independent advocacy support*' outcome should be changed to '*Regardless of where they live, people with disability can access quality, **well-resourced and timely** independent advocacy support*' to ensure governments sufficiently resource individual advocacy services to meet community demand.
- Under the '*Roles, Responsibilities and Policy Directions*' section, there should be a clear expectation set for the gathering of consistent data across states and territories, including collecting data about individuals who are turned away from services and for what reason. This will help ensure that the information about 'service gaps' include the experiences of those who could not successfully attain individual advocacy supports.

Recommendation for clearer and more tangible language in the framework’s objectives and outcomes

- The framework should include clearer divisions of responsibility between the types of disability advocacy services and more tangible, measurable outcomes to ensure that there is a consistent commitment and service offerings across all states and territories.

Introduction

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

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

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

CYDA welcomes the opportunity to provide a response to the *National Disability Advocacy Framework 2022-2025* (framework) consultation.

Disability advocacy – in all forms – is critical in ensuring the rights of people with disability are protected and upheld. While disability advocacy should never replace government responsibility, in a world where we know our imperfect systems are currently letting people with disability down, it holds a crucial role in protecting people’s rights, holding government to account and demanding change. Over the next three years where the new, ambitious Australia’s Disability Strategy is currently being implemented, disability advocacy will be integral in supporting its realisation and identifying where gaps exist.

Systemic change – and as such, systemic advocacy – 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. At a glance we know:

- Nearly half of all young people with disability are unemployed or underemployed¹
- Students with disability leave school before the age of 16 at a rate nearly three times higher than that of their counterparts² and are less likely to complete year 12 or attain a tertiary education, such as a gaining a bachelor’s degree or higher³

¹ 47.8 percent; AIHW. (2020). *People with disability*. Available at <https://www.aihw.gov.au/reports/disability/people-with-disability-in-australia/contents/employment/unemployment>

² 10.9 per cent of young people aged 15 to 24 have left school before the age of 16 compared to 3.6 per cent of young people without disability; AIHW. (2020). *People with disability in Australia*. Available at <https://www.aihw.gov.au/reports/disability/people-with-disability-in-australia/contents/education-and-skills/educational-attainment>

³ AIHW. (2020). *People with disability in Australia*. Available at <https://www.aihw.gov.au/reports/disability/people-with-disability-in-australia/contents/education-and-skills/educational-attainment>

- More than double the proportion of the young respondents with disability in a national youth survey felt negative or very negative about the future compared to their non-disabled peers⁴
- Nearly half of young people with disability aged 15 to 24 years (49 per cent) rely on income support payments as their main source of income compared to 14 per cent of those without disability⁵
- Compared to their peers, children with disability are⁶:
 - 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.

CYDA acknowledges the deep importance the framework plays in supporting the capabilities, reach and impact of the sector – and as such, people with disability’s lives. We also agree the previous framework is outdated and does not reflect the contemporary needs of the disability community or the nature of disability supports and services. For instance, there are next-to-no inclusions of children and young people’s needs⁷ in the previous framework, yet we know in the current environment that nearly fifteen per cent of all Australians with disability are aged 24 years and younger⁸ and more than half of all NDIS participants are children and young people⁹.

In understanding that this framework will set the tone for future funding and agreements between governments, CYDA is concerned that some of the proposed framework’s ambiguity and very high-level language leaves room for governments to avoid full commitment to resourcing what is needed to support a sustainable, effective and efficient disability advocacy service network.

In this submission we’ve detailed the inclusions that are needed in the framework to meet the needs of children and young people. This includes stronger incorporation of the rights of children and young people, and clearer commitments and objectives in providing consistent, specialised supports to children and young people through individual and self-advocacy supports. In this submission CYDA also calls for the inclusion of clearer wording and commitments from government to ensure that the sector is funded adequately and that there is more clarity in the roles and expectations from government, as established tangibly in the framework.

In addition to this submission, CYDA also formally endorses Disability Advocacy Network Australia’s (DANA) Submission on the National Disability Advocacy Framework and its recommendations.

⁴ Mission Australia. (2019). *Young, willing and able: Youth Survey Disability Report 2019*. Available at <https://www.missionaustralia.com.au/publications/youth-survey/1610-young-willing-and-able-youth-survey-disability-report-2019/file>

⁵ AIHW. (2019). *People with disability in Australia: In brief*. Available at [People with disability in Australia 2019: in brief \(Full publication;21Aug2019Edition\)\(AIHW\)](#)

⁶ 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 \(aifs.gov.au\)](#)

⁷ There were two mentions of age as a potential factor of discrimination in the previous National Disability Advocacy Framework

⁸ AIHW. (2020). *Table PREV1: Prevalence of disability, by age group, disability status and sex, 2018*. Available at <https://www.aihw.gov.au/getmedia/9e8d4142-6bda-4b09-a0d9-63852729f386/aihw-dis-72-prevalence-of-disability.xlsx.aspx>

⁹ 58 per cent, as at 31 March 2022; NDIA. (2022). *Explore data*. Available at [Explore data | NDIS](#)

Children and young people’s needs and rights must be reflected in the framework

Embed the rights of children and young people in the framework’s principles

Recommendation

- The framework should include the Convention of the Rights of Children with Disability as an underpinning principle to ensure the rights of children and responsibilities of government and disability advocacy services to uphold these rights is reflected.
- The Participation and Inclusion principle should be amended to read ‘*Disability advocacy is an essential tool for fostering the full and effective participation and inclusion of people with disability in society, **including through providing age appropriate assistance and platforms**’ to safeguard the important role the disability advocacy sector plays in upholding the rights of children and young people to express their views.*

For the framework to reflect the contemporary service environment and the diversity of the disability community, there must clear inclusion and consideration of the rights of children. As such, we urge the Department to include the Convention of the Rights of Children with Disability (CRPD) as one of the underpinning principles. This convention clearly stipulates the non-negotiable standards and rights of children which must be upheld by our governments, and subsequently, our service systems. This is particularly fundamental because in national and state and territory disability frameworks and policies, the inclusion of children’s needs are generally framed through a lens of vulnerability – with a focus on the compliance of people working with children, rather than promoting cultural conditions that recognise the importance of children’s rights and relationships.¹⁰

While we are encouraged to see the United Nations Convention on the Rights of Persons with Disabilities (CRPD) as informing and supporting the framework in the draft proposal for consultation, we do wish to highlight the Article 7(3) of the CRPD express their views and have these views listened to.

Article 7(3) of the CRPD states:

“Children with disabilities have the right to express their views freely on all matters affecting them, their views being given due weight in accordance with their age and maturity, on an equal basis with other children, and to be provided with disability and age appropriate assistance to realize that right”.

Other than through their representative organisations, including CYDA, there are very few mechanisms in place to uphold children and young people’s right to have a voice and be heard. As such, we recommend that the framework has stronger language to ensure agreeing governments are committing to supporting – and funding – the disability advocacy sector’s important role in realising the government’s obligations as signatories of the CRPD.

¹⁰ 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>

Stronger commitments and actions around child and youth specific individual advocacy services

Recommendation

- The framework should include clear outcomes and actions to ensure people with disability across Australia have consistent access to specialised individual advocacy that have capabilities to offer culturally and life stage appropriate support. More specifically, CYDA urges the Department to include clear objectives and outcomes for each state and territory to have a child and youth orientated, cross-disability individual advocacy service.

While it's welcomed that there is reference to intersectionality, CYDA believes that 'respecting for intersectionality and diversity' as a principle alone is not clear or strong enough to result in tangible outcomes or service offerings for different communities, including children and young people.

Intersectionality, including age, is fundamental to disability advocacy (or any human service) because it both impacts individuals' experiences in systems and society, as well as their interactions with support services and personal. As such, there must be advocacy support available for diverse communities that a) have an in depth understanding of the specific systemic challenges that intersectional groups experience, and b) capabilities to offer a culturally and life stage appropriate support.

Children and young people with disability face intersecting discrimination and exclusion from the earliest ages. This spans the medical and health service sector, educational systems and the community. They are also going through a significant and once in a lifetime developmental phase. This discrimination and exclusion can have lifelong impacts if not addressed early.

Despite the disadvantage in education, there is a significant lack of education advocacy to buffer from this discrimination and exclusion. Recent hearings of the Disability Royal Commission have highlighted the nature and extent of this problem.

For the framework to meet its intended objective of '*People with disability access effective disability advocacy that promotes, protects and ensures their full and equal enjoyment of all human rights, enabling full community participation and inclusion*', ensuring access to specialised services for children and young people that cater to and understand identity, intersectionality and how they interact with service systems is vital.

There exists a glaring gap of inconsistent individual advocacy supports specifically for children and young people across the country. Each year, CYDA receives hundreds of calls from families needing individual advocacy assistance and reporting that they cannot access the support they need. This is largely because in many states and territories there are no specialised supports and services for children and young people.

Additionally, our annual education surveys¹¹ tell us of the extent of and impact educational exclusion that impacts on children and young people with disability from the early years right through to post-secondary education. This was exacerbated throughout the pandemic.

In our experience, where there are specific state-based organisations for children and young people with disability¹², it is easier for young people with disability and their families to have their issues resolved. Localised services can build relationships with their respective government to resolve issues quickly and have targeting understanding of local service systems, school structures and barriers. Further, they are also best positioned to advocate for local systemic change.

Equip young people with the tools needed to navigate complex systems

Recommendation

- The framework should include clear outcomes and actions to ensure people with disability across Australia have consistent access to specialised individual advocacy that have capabilities to offer culturally and life stage appropriate support. Specifically, CYDA calls for clear outcomes around committing to self-advocacy, capacity building and leadership programs for children and young people with disability.

Since the last iteration of the National Disability Advocacy Framework, the Australia's disability service system looks entirely different with a move away from state-based services and the transformation to national individualised supports under the NDIS. As at March 2022, more than half a million people – the majority of who are children and young people ages 24 years and younger – are active NDIS participants.¹³ While not all children and young people with disability are NDIS participants, for many it is a critical and their only avenue to accessing the supports they need.

While the NDIS can bring about lifechanging opportunities for people with disability, in its current form the relatively new system is producing inequitable outcomes for different groups. Access to and use of the NDIS is complex and an administrative heavy system. It is those who are equipped with the personal resources to navigate the system and self-advocate for their needs who are more likely to have successful outcomes.

While ultimately the NDIS – and other complex and administrative heavy systems, such as the Disability Support Pension – should be reformed to prevent inequities, it's also fundamental that people have timely access to capacity building and self-advocacy resources to help protect them from our imperfect systems. This is especially important for children and young people who are interacting with various systems at critical life and developmental stages.

There already exists positive examples of self-advocacy, capacity building and leadership programs targeting young people delivered by including the Youth Disability Advocacy Network (WA), Enabled Youth Disability Network (SA), Youth Disability Advocacy Service (Vic), Women with Disability

¹¹ Children and Young People with Disability Australia. (2019). *Time for change: The state of play for inclusion of students with disability.*; Dickinson, H., Smith, C., Yates, S., Bertuol, M. (2020) *Not even remotely fair: Experiences of students with disability during COVID-19.* Report prepared for Children and Young People with Disability Australia (CYDA), Melbourne.

¹² Family Advocacy (NSW), the Association for Children with Disability (Vic), the Association for Children with Disability (Tas) and the Youth Disability Advocacy Service (Vic)

¹³ NDIS. (2022). *Explore data.* Available at <https://data.ndis.gov.au/explore-data>

Australia and CYDA, however it is difficult for organisations to sustain and build upon these programs when the funding is short term and intermittent. As such, in this framework it's important to establish a clear precedent for governments to commit to resources self-advocacy programs and resources for different groups, including specifically for children and young people, across the country.

Safeguard the sustainability of the sector

Guaranteeing Disability Representative Organisations and other disability advocacy organisations are sufficiently funded to fulfil their remit

Recommendation

- Under the proposed framework's 'Responsibilities, Reform and Policy Directions' section, the dot point '*Ensuring the funding of disability advocacy is transparent, equitable and accountable, and geographical coverage and services gaps are identified and addressed*' should be amended to instead read '*Ensuring the funding of disability advocacy is transparent, **sufficient**, equitable and accountable, and geographical coverage and services gaps are identified and addressed*' to safeguard a commitment from governments to adequately fund the sector.

Nearly one fifth – or 4.4 million – of Australians have disability.¹⁴ Further, nearly one in ten of all children and young people have disability.¹⁵ Naturally, among Australians with disability, there are many diverse groups, with various intersectional identities who experience society and service systems in vastly different ways. While the proposed framework sets a strong tone of the importance of disability advocacy, it does not clearly stipulate the responsibilities of government to ensure the sector is adequately resourced to fulfil its remit: to provide “access to effective disability advocacy that promotes, protects and ensures people with disability the full and equal enjoyment of all human rights enabling community participation”¹⁶.

The systemic issues affecting the rights of children and young people with disability are extremely broad, spanning a large range of government portfolios and topic areas including child protection, health, education, employment, the NDIS, quality and safeguarding. This means that children and young people's voices need to be heard through participatory processes across a wide range of policy areas, facilitated by their national representative organisation.

CYDA receives core funding of \$383,294 per annum for systemic advocacy from the Department of Social Services. We welcome the promise by the incoming Albanese Government to double disability advocacy funding, however the mechanism for delivery of these funds is still unclear.

¹⁴ Australian Institute of Health and Wellbeing. (2020). *Prevalence of disability*. Available at <https://www.aihw.gov.au/reports/disability/people-with-disability-in-australia/contents/people-with-disability/prevalence-of-disability>

¹⁵ Ibid.

¹⁶ <https://www.dss.gov.au/our-responsibilities/disability-and-carers/program-services/for-people-with-disability/national-disability-advocacy-program-ndap>

Our responsibility in our current funding agreement with the Commonwealth is extensive and is as follows.

<p>The aims of the Activity are to:</p> <p>2.1 support national Disability Representative Organisations (DROs) for people with disability, and/or represent disability service providers who support people with disability;</p> <p>2.2 ensure that disability issues and a diversity of voices are represented in Australian Government decision making and policy outcomes; and</p> <p>2.3 support people with disability and/or lived experience of disability, and/or service providers supporting people with disability. These people and service providers are the focus of the systemic advocacy services funded under the DRO Grant Opportunity.</p> <p>3. Activity obligations</p> <p>You must achieve the aims of the Activity through systemic advocacy which leads to improvements in the lives of people with disability, by influencing:</p> <p>3.1 people with disability and/or lived experience of disability;</p> <p>3.2 policy makers (governments)</p> <p>3.3 researchers;</p> <p>3.4 national organisations (disability and allied sectors);</p> <p>3.5 service providers supporting people with disability; and</p> <p>3.6 business and community organisations.</p>
--

The core funding allocated to advocacy organisation such as CYDA is relatively small, given the well-known and extensive discrimination, abuse and neglect faced by children and young people with disability. We cannot meet all the requests we receive for systemic advocacy across government which spans education, NDIS, quality and safeguarding, social services, prevention of abuse and neglect, etc. This means CYDA must undertake prioritisation and 'triaging' of our systemic advocacy work and our staff are often stretched very thin. However, despite this our impact is significant. This has been boosted by funding from the Information Linkages and Capacity Building grants.

Despite our small staffing, in the 2020-21 year alone CYDA:

- Received 385 phone calls requesting information services
- Provided 26 submissions to government consultations and inquiries
- Provided seven submissions to the Disability Royal Commission
- Published four research reports in partnership with University of New South Wales and the University of Melbourne
- Gave evidence at three Parliamentary and three Disability Royal Commission hearings
- Developed and sent 16 e-newsletters to our memberships with sector updates and opportunities
- Engaged and supported more than 400 young people in programs, consultations, hearings and capacity building opportunities
- Chaired the National Youth Disability Network, Australia Coalition for Inclusive Education (ACIE) and the Disability Representative Organisations Disability Royal Commission Working Group
- Produced 12 media releases and had 22 media appearances
- Sat on 25+ research, advocacy and government advisory groups

While CYDA supplements the resourcing of our systemic advocacy work through grants and other funding streams, such as the Information Linkages and Capacity Building grant program and philanthropic organisations, the reality is the funding provided by the Department of Social Services to deliver our core advocacy work is insufficient. Reliance on ad-hoc funding creates program, and therefore employment, insecurity and risks our organisation, and other Disability Representative Organisations, to lose quality staff to more stable sectors.

To realise the objectives of the new disability advocacy framework, governments must commit to the sustainability of the disability advocacy sector and adequately fund them to deliver their program objectives.

Ensuring people with disability can access timely support

Recommendations

- The proposed framework's '*Regardless of where they live, people with disability can access quality and independent advocacy support*' outcome should be changed to '*Regardless of where they live, people with disability can access quality, **well-resourced** and **timely** independent advocacy support*' to ensure governments sufficiently resource individual advocacy services to meet community demand.
- Under the '*Roles, Responsibilities and Policy Directions*' section, there should be a clear expectation set for the gathering of consistent data across states and territories, including collecting data about individuals who are turned away from services and for what reason. This will help ensure that the information about 'service gaps' include the experiences of those who could not successfully attain individual advocacy supports.

The framework does not reflect the challenges that families of children with disability and young people with disability experience in accessing individual advocacy support or the inadequate resourcing of services to meet community demand. We often hear from members of our community the immense and critical value of individual support and services when trying to navigate complex service systems and defend their rights. However, we also hear that many young people and families are turned away from services or put on long wait lists because of capacity and resourcing issues.

The framework must include a clearer outcome statement about access to timely support to ensure governments are adequately resourcing individual advocacy organisations to meet the needs of the disability community when they most need it.

Clearer language for defined outcomes

Recommendation

- The framework should include clearer divisions of responsibility between the types of disability advocacy services and more tangible, measurable outcomes to ensure that there is a consistent commitment and service offerings across all states and territories.

Clearer language and division of tangible, measurable outcomes to prevent jurisdictions avoiding responsibility

Acknowledging the importance of the precedent this framework sets in future funding and cross-government agreements, CYDA is concerned that some of the language and statements are too high-level and may result in being misconstrued in practice. For example, while the framework acknowledges the different definitions of disability advocacy, these differences are not referred to in the framework's objectives or policy directions. This ambiguity may prevent equal commitments from governments to ensure equitable access to a diverse variety of advocacy services across states and territories, and in turn, undermine efforts of this framework to establish consistent offerings across the country.

The outcomes outlined in the current framework, whilst well intended, are too high level to effectively measure impacts in their current format. We recommend that the framework identify outcomes that are specific and time-bound. We also propose that DSS identify **how** the outcomes will be measured. We outline below suggested approaches to consider:

- Assess the impact of advocacy outcomes by conducting longitudinal research and evidence-based data collection. Conduct a desktop audit to identify existing approaches for evaluating advocacy impact. For e.g., Deloitte Access economics outlined a mixed-method research approach to assess the impact of advocacy for the aged-care sector¹⁷. Such a model could be adapted and targeted toward people with disability.
- Monitor and evaluate the effectiveness of the advocacy framework through ongoing engagement with people with disability, especially children and young people, through co-designed, targeted surveys and research.
- Standardise the way outcomes are measured, to compare the impact of different types of advocacy such as self and systemic advocacy.
- Improve information sharing between advocacy services and use individual advocacy reporting to inform the work of the disability sector and government.
- Collect consistent and relevant data across all nationally funded and state and territory individual disability advocacy organisations through agreement with states and territories for a national minimum dataset for disability advocacy.

¹⁷<http://www.daru.org.au/wp/wp-content/uploads/2015/08/Advocacy-Outcomes-FINAL-Deloitte-report.pdf>

- Compile a national annual or biennial report, like the “Disability Advocacy by the Numbers Report”¹⁸ developed by the Disability Advocacy Resource Unit in Victoria to identify systemic issues across Australia, and for particular cohorts that need to be addressed by Australian and State and Territory Governments.

¹⁸ https://www.daru.org.au/wp/wp-content/uploads/2017/08/BTN-July2017_main-report_P2.pdf
