

“All decisions are important, and they all affect our human rights”.

CYDA’s response to the Disability Royal Commission’s background paper: Supported decision-making and guardianship: proposals for reform.

**Children and Young People with Disability Australia
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Key messages and recommendations

Children and young people have the right to say what they think should happen when adults are making decisions that involve them and to have their point of view considered.

Children and young people with disability have complex and nuanced lives and identities that need to be considered when working on policies and practices that impact them.

The resources, training and education proposed by the Disability Royal Commission (DRC) to embed supported decision making into the practices of the disability support sector should contain content specific to the experiences and needs of children and young people. As such CYDA makes the following recommendations.

Recommendation 1: Review the Principles of Supported Decision-Making to explicitly include the needs and experiences of children and young people.

- Remove references to 'adults' from the first three proposed principles and replace it with 'people'. Based on the marginalisation experienced by children and young people, consider specifying that references to 'people' and 'persons' include children and young people.
- Consider adding a principle or caveat to recognise that due to some people being multiply marginalised by their intersecting identities (such as youth, race, gender, sexual orientation and nationality) they are at increased risk of being excluded from co-design processes and access to supports.

Recommendation 2: Use a more inclusive framework to inform the supported decision-making model.

- Draw on existing models¹ for supported decision-making which doesn't explicitly exclude children and young people
- Ensure the supported decision-making model accounts for the transition from best interest's decision-making framework for under 18 year olds (UN Convention on the Rights of the Child) to one of will, preference and rights for over 18 year olds (UN Convention on the Rights of Persons with Disabilities).
- Ensure the supported decision-making framework is dynamic enough to support the evolving and fluctuating capacities of young people with disability across various settings – including family, out of home care, and institutional settings.

Recommendation 3: Prioritise training and resources to support children and young people as a distinct cohort

- Provide governance training to allow children and young people to participate in the implementation and governance of the national supported decision-making framework (as per reform proposal 13).

¹ <https://www.supportfordecisionmakingresource.com.au/module-1.html>

- Include training for supporters and community members to develop expertise and understanding in the rights, needs and experiences of children and young people with disability

Introduction

Children and Young People with Disability Australia (CYDA) is the national representative organisation for children and young people with disability aged 0 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 Disability Royal Commission's Supported decision-making and guardianship: proposals for reform roundtable².

This response builds on our previous submissions and evidence provided to the Disability Royal Commission (DRC) which highlights the systemic violence, abuse, neglect and exploitation of children and young people with disability.

Our submission draws on insights and quotes from young participants who attended our **LivedX Consultation Series**, a component of CYDA's Our Voices Our Visions: Youth Advocacy project, that took place between June and December 2021. Various quotes from participants of this project are used in this submission. Nine focus groups were co-designed and delivered with the assistance of young people with disability for the purpose of seeking the insights and experiences of children and young people on a range of topics and issues that impact them. Consultations engaged young people in discussions around decision making, autonomy and confidence.

This submission is also shaped by early findings from the Growing Up Making Decisions Project, a joint project between CYDA, University of New South Wales and Inclusion Australia. The study aimed to create an understanding of how young people with cognitive impairment grow up making decisions by identifying the policy, organisational arrangements and practices that respect and support the evolving capacity of young people with cognitive impairment to make their own decisions. Although, due to the stage of the project, we have been unable to provide direct quotes

² <https://disability.royalcommission.gov.au/publications/supported-decision-making-and-guardianship-proposals-reform-roundtable>

from participants, our response is informed by interviews with 17 young people, 13 parents/carers, and 22 stakeholders from across 16 organisations.

CYDA is committed to ensuring that children and young people with disability are afforded equitable opportunities to succeed and we advocate that this cannot be achieved until they feel fully included across all systems and community life, including in supported decision-making.

Being able to participate in making decisions is a fundamental human right.

Meaningful participation in decision making empowers individuals to exercise control over their own lives, improving their autonomy, wellbeing and personhood.³ Children and young people with disability, particularly those with cognitive impairment, are likely to need support to make some decisions about their lives.

Access to quality supported decision making—where individual participation is recognised as a right—is therefore paramount, as has been highlighted by the:

- Australian Disability Strategy⁴; Principle One, Respect for inherent dignity, individual autonomy including the freedom to make one’s own choices, and independence of persons.
- Australian Law Reform Commission’s proposal that “the will, preferences and rights of persons who may require decision making support must direct decisions that affect their lives”⁵
- National Disability Insurance Scheme’s (NDIS) emphasis on choice and control.
- United Nations Convention on the Rights of the Child; Article 12 that “States Parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child.”⁶
- National Principles for Child Safe Organisations⁷, principle 2 states, “Children and young people are informed about their rights, participate in decisions affecting them and are taken seriously”. These principles are based on the findings in the report from the Royal Commission into the Institutional Response to Child Sexual Abuse.

³ <https://www.supportforddecisionmakingresource.com.au/>

⁴ <https://www.disabilitygateway.gov.au/sites/default/files/documents/2021-11/1786-australias-disability.pdf>

⁵ ALRC, 2014, para 3

⁶ <https://www.ohchr.org/en/instruments-mechanisms/instruments/convention-rights-child>

⁷ <https://childdsafe.humanrights.gov.au/national-principles/about-national-principles>

Recommendation 1

Recommendation 1: Review the Principles of Supported Decision-Making to explicitly include the needs and experiences of children and young people.

- Remove references to ‘adults’ from the first three proposed principles and replace it with ‘people’. Based on the marginalisation experienced by children and young people, consider specifying that references to ‘people’ and ‘persons’ include children and young people.
- Consider adding a principle or caveat to recognise that due to some people being multiply marginalised by their intersecting identities (such as youth, race, gender, sexual orientation and nationality) they are at increased risk of being excluded from co-design processes and access to supports.

“Maybe I want to have a choice, but everything just gets planned for me, which isn’t really fun”.

There is an urgent need for policy settings that respond to the needs of children and young people with disability. Given that the principles being proposed in the Roundtable Paper will underpin and inform the guidelines and supported decision-making model, CYDA considers it critical that these explicitly include children and young people with disability. The UN Convention on the Rights of the Child explicitly states that children and young people should have a say in decisions that impact their lives. It is the position of CYDA that including young people in age-appropriate decision-making protects them from violence, abuse, neglect and exploitation, which is why children’s decision making is also included in the Child Safe Standards being used across Australia. Developing the skills and confidence to make decisions from a young age ensures that when children and young people with disability turn 18 and are then covered by the UN Convention on the Rights of Persons with Disability.

Young people with disability often remarked how their ability to make decisions is undermined, and in some cases, they are infantilised by professionals.

“All sorts of different decisions are important, but also being able to have the choice about whether or not you want to make the decision as well, and being included.”

*“I usually have a chance to [make decisions] until they find out that I am disabled and then they [professionals] immediately start talking to my mum who is with me or someone else. I find just having my choice **not** taken away as soon as they find out that I am disabled is more important to me than the actual decision, because I might want my mum to decide, but I want to be the one to decide that.”*

Examples such as these demonstrate the ways in which the will, preferences and rights of children and young people are often dismissed by the individuals and institutions that are designed to serve them. In order to uphold the UN Convention on the Rights of Child, all interfacing individuals and institutions must instead understand and respect the will, preferences and rights of children and young people with disability. CYDA notes the tension between these rights and the legality of

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decisions made by children under the age of 18 and addresses this in the next two recommendations.

Young people too, are aware of the drawbacks of not being legal decision makers because they are under 18 years old, in particular when there is a stark imbalance of power. *“I think yeah, a lot of the decisions that we should be able to make, we legally can’t if you were under the age of 18. And we don’t necessarily have control of that. No matter how good your decision supporter is, you often will need to get a parent or carer to sign off on different things”.*

“Clearly there’s a very clear division on what young people’s power of decision-making is when you’re under the age of 18. And that makes it particularly difficult in situations where malpractice is happening by adults that ultimately have the final say over you”.

Young people pointed out their competence as decision makers, pointing to opportunities for a framework that supports those younger than 18 to have access to supported decision making that will guide and empower them in preparation for turning 18. *“Also they think some things you just know. It doesn’t matter how young you are, sometimes you just know. But when it comes to say, surgeries or something, you might know. I know myself; I’ve done research on this. I’ve looked it up. I know this is what I want. And a doctor will be, “No, you’re only young. You don’t know what you want. You’re only this young. Of course you don’t have the right to be choosing what happens with your own body”.*

“We’re still learning how to [be] adult, so we need clear, engaging information and resources on how to navigate making decisions as living with disability. And role models are really important”.

The Roundtable Paper acknowledged that some people with disability face additional barriers to exercising their autonomy. However, CYDA believes the DRC could be more explicit in recommending actions for government to address the impact of being multiply marginalised, especially as these groups and individuals are more likely to be excluded from processes such as the design and implementation of these principles, guidelines, and models for decision-making.

Young people are aware that their intersecting identities can make things more complex and that this can impact their relationships with those supporting them. *“I find that [medical professionals] don’t believe me because they think I’m young and also that I’m confused by my disability. So I find that a lot of people think a lot of things can’t overlap, like say ADHD and autism. Or being trans and something else. I just find that a lot of people think things can’t overlap, what all can very likely, very easily overlap”.*

Many young people have told us they want to be supported by people who acknowledge and celebrate their intersecting identities.

“A major thing is celebrating it. I think particularly people ... from different backgrounds go through so much already that making sure everything is as a supportive and safe space as possible is the best way to be an ally.”

Recommendation 2

Recommendation 2: Use a more inclusive framework to inform the supported decision-making model.

- Draw on other models for supported decision-making which do not explicitly exclude children and young people
- Ensure the supported decision-making model accounts for the transition from best interest's decision-making framework for under 18 year olds (UN Convention on the Rights of the Child) to one of will, preference and rights for over 18 year olds (UN Convention on the Rights of Persons with Disabilities).
- Ensure the supported decision-making framework is dynamic enough to support the evolving and fluctuating capacities of young people with disability across various settings – including family, out of home care, and institutional settings.

CYDA is in favour of a supported decision-making model that can be embedded into the relevant laws and legal frameworks to enable all people with disability to exercise their human right to make decisions. However, we are concerned that neither the guidelines, nor the model presented in the Roundtable Paper are inclusive of children and young people with disability and does not account for the complexities (legal and otherwise) of the transitional period of childhood to adulthood or the dynamic nature of support needs across the lifespan.

In keeping with the authors of the La Trobe Support for Decision Making Practice Framework, who state on their training website, “We no longer talk about whether a person has the capacity to make a decision, but what support do they need to make it?”⁸ CYDA believes a person-centred approach that includes children and young people will be most successful.

The various research and activities undertaken by CYDA show overwhelmingly that children and young people with disability want to be treated as though they are competent. For instance, when we asked young people what helped them feel in control of their decision making, one person responded, “*Just being treated well, being treated nicely, like you're actually competent*”.

They provided examples of when their competence was questioned and explained how this impacted their feeling of dignity. “*Something to consider is making sure that when decision supporters are working with us, that they're not using patronising language, and that they're being really aware that a lot of the time having disabilities makes us grow up pretty quickly. We know what we need. We know our own bodies*”.

⁸ <https://www.supportfordecisionmakingresource.com.au/module-1.html>

Drawing from early findings in the Growing Up Making Decisions project ⁹, young people showed an awareness of their understanding of the risk inherent in some decisions but clearly communicated that they still want to be afforded the dignity of being able to make mistakes.

Using a framework that includes safeguards, an understanding of will, preferences and rights, a definition of presumption of decision-making capacity specific to children and young people with disability will protect them from risk of violence, abuse, neglect and exploitation. The various child safe standards operating across Australia rely on children developing self-advocacy and decision-making skills which won't be effective if they haven't been included in supported decision-making legislation until they are 18.

CYDA argues that having supporters who can connect with and understand young people with disability will ensure that in the case of supported decision-making across multiple contexts, their will, preferences and rights are more likely to be upheld. Young people also expressed a desire for someone who can connect with them and show an interest in their lives. *"Then just also knowing you as a person. They can say, if you're starting to go out of yourself, they can ask about, "Hey, what's the latest thing happening in your favourite show?" So they take a special interest also in you. Say, "How's your dog going?" I find that is also really nice that someone has actually taken an interest and I don't feel like I'm just a number on their sheet to check in on".*

Including children and young people in the decision-making model will ensure that information is presented in a way that is accessible to them. Participants from the Growing Up Making Decisions project shared their challenges in dealing with the various bureaucracies they were required to engaged with. For instance, many people lamented the inaccessibility of the NDIS and other forms they are often presented with and explained that they generally require help from family or support workers to fill them out.

LivedX participants identified some desirable traits among professionals and other decision supporters including *"patient"*, *"no agenda"*, *"non-judgmental"*, *"share lived experience"*, *"reliable"*, *"flexible"*, *"good listener"*, and people who hold themselves accountable and who are genuine.

⁹ <https://www.unsw.edu.au/arts-design-architecture/our-research/research-centres-institutes/social-policy-research-centre/our-projects/growing-up-making-decisions>

Recommendation 3

Recommendation 3: Prioritise training and resources to support children and young people as a distinct cohort

- Provide governance training to allow children and young people to participate in the implementation and governance of the national supported decision-making framework (as per reform proposal 13).
- Include training for supporters and community members to develop expertise and understanding in the rights, needs and experiences of children and young people with disability

The participation by children and young people in multiple projects and activities at CYDA has been a powerful demonstration of the will and competence in governance and decision making that exists in this cohort.

For instance, each year CYDA auspices a Co-design Committee which provides paid opportunities for young people to actively participate as decision makers in project delivery work for young people with disability—culminating in the co-design and facilitation of the annual National Disability Youth Summit¹⁰. CYDA's Youth Council provide similar opportunities for young people to gain valuable governance experience, with the most recent cohort of nine young people designing and implementing a series of consultations on issues that impact the lives of young people with disability and producing five topic papers on the outcomes. Additionally, young people have input into, and assisted with content delivery for our Inclusion in Early Childhood webinar series. These, and many other examples of collaboration have demonstrated that young people with disability overwhelmingly want their voices, ideas and opinions included in these forums and when provided with these opportunities they demonstrate their potential as future leaders and change-makers.

CYDA has innumerable examples of children and young people with disability being overlooked, dismissed, condescended to and underestimated because of their intersecting age and disability. For instance, *“I know that I go into chemists or the doctors or something, and I’ll be with my carer. They’ll straight away see me in the wheelchair and straight away start talking to anyone else but me. And straightaway they think that I can’t make my own decisions”*.

Another young person shared an experience they had in hospital with a medical professional, *“They proceeded to misgender me, and also demean me, and say ... ‘You’re just a little girl. You don’t know what you’re doing’. So, taking away both, my ability to make a decision ... but also when there was an opportunity for me to make my own decisions and have control, that medical professional actively undermined [me]”*.

Training and resources should extend to individuals and institutions that engage with children and young people with disability. This young person's experience exemplifies the importance of training

¹⁰ <https://www.cyda-nyds.com/>

and awareness raising across the community, and especially in institutions that provide services to young people. It also demonstrates the potential outcomes of not treating young people as competent decision-makers.

“I was on a certain medication that it didn’t seem to be working very well for me. I talked to them about leaving and they just kept pushing it harder. That nearly made some irreversible things happen. And put me in hospital a few times because they wouldn’t listen to what I was saying, and kept just putting more drugs in me”.

Demonstrating a need to address power and hierarchy and a decision-making model, this young person highlighted the power dynamic of decision making between young people and their supporters. *“I think with my friends there, I can tell them, not that they’re wrong, but I can tell them that it’s not right for me. Like we can share stuff and know that there’s no judgement, there’s no expectations. We’re just like supporting each other. Whereas like family, parents, healthcare professionals, it’s different because there’s like a power imbalance there. And I don’t feel like I can just assert myself the same way”.*

Young people have awareness about what they need to make good decisions. For instance, one young person told us, *“Having the information we need to make the right decisions presented in an accessible way to us. In a way that we can understand is really important”.*

Another added, *“Information you can take away and read in your own time or come back to, is really important. Not being rushed to make decisions”.*

Another young person demonstrated the impressive self-advocacy skills shown by many as they explained how they would like to be engaged with as they make decisions. *“I find that also what helps me make decisions is not just having only multiple choice, but having multiple ways of explaining it, because I usually don’t understand a lot of things the first time. If you just explain it the same way again, I’m still not going to understand it”.*

CYDA strongly urges the DRC to include awareness and understanding of cognitive impairment in children and young people in the training resources for the decision-making model.