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Please accept this letter and response to the NDIS Safeguarding draft proposals (refer Appendix A) as Children and Young People with Disability Australia's (CYDA) submission to the NDIS Review's consultation into *NDIS Participant Safeguarding*.

Children and young people with disability are a particularly vulnerable group where abuse and neglect is concerned. CYDA frequently hears of experiences of abuse in a range of settings. These include children being subjected to violence, seclusion and chemical, mechanical and physical restraint without accompanying positive behaviour support strategies in place.

The typical experience of abuse reported by CYDA members is reflected in available research, which states children with disability are three times more likely to be abused than other children. Children with communication difficulties and high behaviour support needs are believed to have a significantly higher risk of experiencing abuse.

As a result of system failures and pervasive negative discourses and attitudes about people with disability, children and young people are at heightened risk of experiencing abuse and maltreatment. While the prevalence of abuse is difficult to fully ascertain because of gaps in data collection and reporting, researchers[1,2,3] have established that:

- Children and young people with disability experience higher rates of violence and abuse than other children, and often experience multiple and ongoing episodes of violence.
- Compared to their non-disabled peers, children with disability are:
    - 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.

It is imperative that the proposal to provide safe-guarding in the NDIS is strong, effective, promotes high quality and provides robust safeguards. Our response focuses on issues of relevance to children and young people with disability.

Without targeted and adequate research, data, policy responses, action and intervention, children and young people will continue to feel the safety, social and economic impacts for a lifetime.

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[1] Centre of Research Excellence in Disability and Health. (2020). Violence against young people with disability in Australia. Available at
https://objects.storage.unimelb.edu.au/2016UOM009:figshare/24753587/YoungPplViolenceDisabilityFactSheet.pdf

[2] 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)

[3] Disability Person's Organastions Australia. (2019). *Violence, abuse, exploitation and neglect against people with disability in Australia. Available data as at March 2019*. Available at
https://dpoa.org.au/violence-abuse-exploitation-neglect-people-disability-australia-available-data-march-2019/violence-against-people-with-disability_dpoa_march-2019/

Please refer to the attached Appendix A for CYDA's responses to select draft proposals as outlined in the consultation paper. If you would like to know more about our submission or CYDA's work, please feel free to contact CYDA's Policy and Research Manager, Dr Liz Hudson on (03) 9417 1025 or lizhudson@cyda.org.au.

Kind regards,

Skye Kakoschke-Moore
Chief Executive Officer

![CYDA logo - Children and Young People with Disability Australia]

Appendix A CYDA's response to the Draft Proposals

The following response (See Table 1) is informed by CYDA's consultations with children, young people with disability and their families as detailed in the following source documents. In addition to considering CYDA's responses to draft proposals 1, 2 and 3, we recommend that the NDIS Review consider the overall content of each of the following reports, as they provide important insights about safeguarding for children and young people with disability.

Source Documents:

1. **CYDA's Submission to the Disability Royal Commission: Targeted Engagement with young people with disability**

   In enacting its strategic goal of supporting young people to take control and call out discrimination, abuse and neglect, CYDA collaborated with the Disability Royal Commission to undertake the targeted engagement, capturing the lived experience of several young people living with disability who have been involved in CYDA's programs.

   Whilst not specifically about the NDIS, the recommendations from the sessions covered the topic of "access to quality and safe support in all settings", which is of relevance to the NDIS safe-guarding - draft proposals.

2. **CYDA report - National Principles for Child Safe Organisations Consultation Report – Children and Young People with Disability**

   The National Principles for Child Safe Organisations set out a nationally consistent approach to promoting a culture of child safety and wellbeing within organisations. The principles give effect to the child safe standards that were recommended by the Royal Commission and bring attention to general child safety and wellbeing issues.

   CYDA's consultation report outlines key findings and recommendations to inform the development of resources that will support organisations to better keep children and young people with disability safe.

   The National Office for Child Safety (National Office) engaged Children and Young People with Disability Australia (CYDA) in mid-2022 to develop this report. The report involved extensive consultation with a range of stakeholders, including children and young people with

disability, organisations that work with children and young people with disability, and state and territory children's commissioners and guardians.

Whilst not specifically about the NDIS, the findings from this project have applicability to the NDIS safeguards proposals, especially as data was collected from NDIS providers, as well as children, young people and families.

3. **CYDA/UNSW Report - Growing Up Making Decisions Project**

Working with the Social Policy Research Centre, UNSW and Inclusion Australia, young people with disability and their families/carer-givers were interviewed by CYDA to understand what policies and practices work in supporting transition to a decision-making framework.

This project aimed to better understand how to support young people with cognitive disability in making the transition from a best interest's decision-making framework (UN Convention on the Rights of the Child) to a will, preference and rights model of decision-making (UN Convention on the Rights of Persons with Disabilities; CRPD). This project examined how young people can be supported in a way that respects and supports their evolving capacity. Many people with disability are infantilised and this can affect their transition to adulthood and beyond. Many have not been exposed to independent decision making, having to rely on caregivers through the transition. Failing to help young people build decision-making capacity can have long-term consequences for life choices and may lead to inappropriate permanent guardianship orders.

Whilst not specifically about the NDIS, the findings from this study have applicability to the NDIS safeguards proposals

CYDA's response to the Draft Proposals outlined in the consultation paper are detailed in Table 1 below

Table 1 - CYDA response to Proposals Paper

Consultation Paper Draft Proposal	CYDA's response to draft proposal	Source document #	Supporting quote from children/young people with disability/families (if applicable)	Source Document Page Reference
A participant-centred approach - participants' rights and capacity to exercise them - View the NDIS from participants' perspectives - Proactively identify and engage with risk - Be trauma-aware and healing-informed				
	Child-centred When organisations fail to be inclusive, children and young people with disability and their families are left isolated and disconnected from their community. Taking a child-centred approach that focuses on the individual is a positive way to support inclusion. The Child Safe Organisations Project report identified that there should be a shift away from the medical model of disability to the social model of disability. The social model of disability points out the way that social systems and structures create barriers that discriminate against and	2	'[W]e're pretty isolated, because of the fact that there are these barriers where clubs aren't inclusive. And so, we don't belong to any clubs, actually. No swimming club, no soccer club, no footy club, no club. Because my child has got complex communication needs and he also has challenging behaviour, and so teamwork, even when he's fully regulated, would be tricky for him. And so, we're totally excluded. It's like we're not even a citizen in our local community.' – (Parents and caregivers). '[O]ne of the biggest challenges organisations face is understanding the social and the cultural model of disability rather than viewing disability through a medical model, and understanding that there are different barriers	Pp 37,38

Consultation Paper Draft Proposal	CYDA's response to draft proposal	Source document #	Supporting quote from children/young people with disability/families (if applicable)	Source Document Page Reference
	exclude people with disability from the community.		*for different children with disabilities based on their cultural background or their gender'. – (Advocacy organisations).*	
	Rights and Risks - The process of building autonomy in decision-making is different for everyone, varying by support needs and the supports around the young person. The Growing Up Making Decisions study demonstrates that young people were supported by people they trusted and had good relationships with – with family and peer relationships being key. Young people also wanted to and needed to be allowed to make some mistakes. In terms of building or enhancing capacity, study participants highlighted the importance of active and supported long-term incremental learning. Without this, there is a risk that young people are unable to express will and preference for significant decisions in their life – in particular, where to live, who to	3	Some young people talked about their right to make mistakes, and fighting for the right to make mistakes. One young person said: *I want to have the right to mistakes. Yeah I made a lot of mistakes and I still do now. But I still want to make them. (Young person)*	Pp 43-44

Consultation Paper Draft Proposal	CYDA's response to draft proposal	Source document #	Supporting quote from children/young people with disability/families (if applicable)	Source Document Page Reference
	live with, relationships, finance, education or work. **Supporting young people to engage with risk** – An approach should include assertiveness training in the NDIS to support capacity to identify risk. For many young people, their parents and support workers helped develop their skills. For some young people, they went to specific training or sought to learn specific life skills. This included assertiveness training.		Young people also recommend sharing their experiences with others to help them learn. For example, one wrote a blog post about their experience at school which is on a disability organisation's website. Another, when asked what they would say to other young people, said '*keep it at your own pace'.* With regard to decision making and risk - young people also said what they did not like. This included: - *Surprises or being rushed* - *People deciding for them in general* - *People deciding for them for specific areas, such as 'what you're going to do for a living'* - *Not being pushed to talk about something or make a decision (Young person).*	
	Trauma-informed – Young people recommend embedding trauma-informed practice in all mainstream and disability-specific services.	2	n/a	P 17
1. **An NDIS-wide participant safeguarding strategy**				

Consultation Paper Draft Proposal	CYDA's response to draft proposal	Source document #	Supporting quote from children/young people with disability/families (if applicable)	Source Document Page Reference
- one strategic approach to participant safeguarding in the NDIS - designed with strong engagement from participants				
	One strategic approach - Any *single* approach should promote a diverse range of ways for children and young people to connect, communicate and gather (build community) to enable the sharing of knowledge and experience, especially with regard to safe-guarding access to the NDIS and non-NDIS supports. Participants from CYDA consultations spoke repeatedly of the isolating experience of being a young person with disability due to the lack of awareness by mainstream services. They claim that as the primary holder of disability knowledge and experience, young people are required to relentlessly advocate for greater understanding by	1	*"There's a real issue between the interfaces between the state and federal care, so like education like schools and stuff is one of those places that that happens because like the best example I can think of is with the NDIA's proposal for early intervention supports for children on the autism spectrum. They're proposing cutting funding by 40% when a child reaches the age of 7 because in the agreement between the state and the Federal Government the state is supposed to pick that up with schooling, but we know that doesn't happen in practice and so the Federal Government is trying to propose these decisions, they're not working collaboratively, and it just continues to leave gaps."* (Young person)	P 16

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	health professionals and service providers. Whilst this burden of self-advocacy and isolation continues, discrimination and ableism will remain unchallenged in our service system. This was particularly relevant with transitional services. According to participants, there is an additional burden associated with telling their story due to staff turnover/loss of knowledge within service providers. Participants highlighted a need for greater consistency of staff and the role of government in providing this through sustainable funding models. The divide between state and federal support systems can be challenging; leaving young people unsure of where to get help. This includes state systems deferring to the NDIS or the NDIS deferring to the education system.			

Consultation Paper Draft Proposal	CYDA's response to draft proposal	Source document #	Supporting quote from children/young people with disability/families (if applicable)	Source Document Page Reference
2. An improved and individualised approach to work with participants to understand risk and build safeguards - that reflects their needs, values, priorities and experiences				
	Reflecting needs, values, priorities, and experiences - Any approach to embedding aspects of safety relevant to children and young people with disability, should emphasise the importance of individualised approaches to addressing communication needs, building trust, supporting self-care and attending to medical tasks and emergency planning. The National Principles for Child Safe Organisations[4] have been developed to keep children and young people safe. Yet, some organisations (including the NDIS) do not adequately support children and young people with	2	*I'm in the process of meeting with all our individual coordinators who work directly with the families, and going over their national principles and the quality standards - NDIS national principles - and as part of that discussion, we talk about how important it is to not just have that communication and relationship with the family, but also with the participant that we're supporting. I think one of the other challenges is obviously communication, so kids with disabilities may not have verbal communication, they may not be able to understand the same literature and information that we provide, as an organisation.*	P 32

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[4] https://www.childsafety.gov.au/resources/national-principles-child-safe-organisations

Consultation Paper Draft Proposal	CYDA's response to draft proposal	Source document #	Supporting quote from children/young people with disability/families (if applicable)	Source Document Page Reference
	disability or fully understand what it means to keep them safe.		*So I'm currently working on some different forms of media - like video, for example, with animation - to try and educate children about who they can approach and how we manage their safety concerns.* (NDIS provider)[5]	
	Any approach should focus on key **transitional periods**: from school to university to childhood to adulthood from education to employment. Failure to recognise the individual needs of a young person within a larger life and structural context has meant that transition into adulthood remains a significant policy failure in the NDIS and related service systems. It should also focus on the intersection of disability with other key transitions, such as the development of identity and status in the LGBTQIA+ community.	3	Young people were also asked about the decisions they wanted to make in the future, during key transition periods. One young person answered 'good ones!' - Young Person with disability, Number 13 (#YP13). Young people identified a wide range of decisions they want to make in the future, including: *Getting a job, changing jobs (#YP10), starting a business* *Saving up for something, such as a new computer* *Moving out of home (#YP10), buying a house and 'having everything really properly set up' (#YP8)* *Getting a driving licence 'without my licence, I can't get a job, without a job, I can't get a house' (#YP3)* *Travelling, ranging from finding a different way to get home from work and practising that new route (#YP10) to travelling overseas*	pp. 19, 25, 26

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[5] Note: Although this is a direct quote from the consultation session with NDIS providers, it is not included in the final report

Consultation Paper Draft Proposal	CYDA's response to draft proposal	Source document #	Supporting quote from children/young people with disability/families (if applicable)	Source Document Page Reference
			• *Transitioning (gender)* • *Having a relationship and a family.*	
3. Improved safeguards deployed on an individual basis - support participants in **decision-making** - rights, dignity, risks and safety - effectively advocate for their right to be safe or to support safeguarding - effective complaints mechanisms				
	Decision- Making – approaches should align with and prepare children and young people to move from a 'best interests' decision-making framework for children as outlined in the United Nations Convention on the Rights of the Child (CRC) to a 'rights, will and preferences' framework as articulated in article 12 of the United Nations Convention on the Rights of Persons with Disabilities (CRPD). That they respect the **rights, will and preferences** of the young person, and are	3		pp.4, 9

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	proportional and **tailored to the person's circumstances.**			
	Decision making -when providing Safe-guards in the NDIS, it should be recognised (as detailed in the Growing Up Making Decisions study) that every young person has different support needs when making decisions – ranging from no support to significant support. The type of support provided also changed depending on the type or scale of the decision and the potential consequences of that decision.	3	One young person talked about the need for someone else to make decisions only in an emergency (#YP8 – in relation to diabetes). Another young person said: *My parents, they made decisions about medical and that sort of stuff, but everything else… they generally leave up to me… the usual 'parents' sort of stuff, they usually make those decisions for me, which I'm fine with.*	Pp 26, 27
	Dignity of risk - Young people with disability are particularly concerned by the failure of organisations to gain their perspective about what safety means to them. Safety, for young people, is about dignity of risk – having the right to make choices and learning from the decisions they make. Several participants from organisations discussed the difficulty they faced in balancing	2	Another balancing act raised across consultation types was around dignity of risk: *'We actually have to allow young people and children to experience risk, so we have to find a balance here between capacity building and keeping young people safe.'* – (Participant from Organisational group).	p. 9

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	processes and practices with child safety, with even ostensibly beneficial child-safe policies creating barriers to information sharing, flexible service delivery, and accessibility.			
	Improve enforcement of accessibility standards as well as the dissemination of accessibility-related information. Central to this is the implementation of **effective complaints and feedback mechanisms**.	2	Participants highlighted the burden on young people with disability to ensure that their voices are heard and their needs are met, exacerbating burnout and a likelihood of disengaging from their community or services. This was particularly evident when making complaints. This is due to a lack of accountability on the part of services and action. When speaking about their experience with taxi services, one participant noted: *"I've tried to complain a few times but I feel like it's a waste of effort and time because there's usually no action taken and nothing gets resolved and it's just, yeah, that's my experience with taxis and stuff. I did make a formal complaint, but even calling up saying "hey, this has occurred", and stuff, "Yep, yep, we'll get on to it" and no action is taken and if you know nothing is going to be done, I don't see the point of like complaining. Complain to the driver or person, complain to the organisation, I don't think they'll care, it's what is the point? "*	pp15-16