

RECOGNISING AND PROMOTING RIGHTS: CHILDREN AND YOUNG PEOPLE WITH DISABILITY

A REPORT ON A FAMILIES AUSTRALIA

**'BUILDING STRONGER AUSTRALIAN FAMILIES' POLICY
FORUM**

(DELIVERED VIA WEBINAR)

24 MARCH 2021

in partnership with

**CHILDREN AND YOUNG PEOPLE WITH DISABILITY
AUSTRALIA**



**Children and Young People
with Disability Australia**

Building Stronger Australian Families
What do they need to thrive?

Families Australia
AN INITIATIVE OF

About Families Australia

Families Australia is a national, not-for-profit, peak organisation that strives to improve the wellbeing of Australian families, especially those experiencing vulnerability and marginalisation. We do this by providing policy advice to the Australian Government and Parliament on behalf of more than 800 member organisations around Australia.

Families Australia's member organisations provide services in urban, rural and remote locations across Australia. These organisations operate in a diverse range of fields such as family support, child protection, domestic violence, disability, education, grandparent/kinship care, foster care, mental health, and youth work.

Our work is organised around three important ideas, namely, that Australia will be a fairer and more equitable and compassionate nation if we better protect and value children, if all families irrespective of their form are strengthened, and if there are genuine and lasting improvements in the wellbeing of Aboriginal and Torres Strait Islander peoples.

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Background

Families Australia's policy forums were initiated in 2015 and bring together key people from government, the community sector and the research community to consider how best to advance the wellbeing of Australian families now and into the future.

Editorial note

Families Australia strives to utilise inclusive language. Families Australia uses person-first language, however we recognise that language and identity is personal. This report utilises person-first language throughout, except to reflect the language used by individual speakers.

Executive Summary

One of the important pieces of national policy work currently underway is to design the successor plan for the National Framework for Protecting Australia's Children 2009-2020 (National Framework). The National Framework is an initiative of the Council of Australian Governments that seeks to make protecting Australia's children everyone's responsibility by working together better in areas of shared responsibility. The Commonwealth, State and Territory governments and the non-government sector are working collaboratively over the course of the framework to deliver better safety and wellbeing outcomes for all Australia's children.

A key learning from the current National Framework, spanning the last 12 years, is that it is vitally important to take a more inclusive approach, to genuinely and respectfully hear - and act upon - the views of children and young people in policy design and implementation. While in recent years, there has been an increase in processes and structures to better include the voices of children and young people, and promote their rights, there is still a long way to go to ensure this approach is embedded as a standard practice. In our view, including the voices of children and young people with disability in policy co-design is more distant still. It is an area that requires much greater effort and investment, as identified through the [Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability](#) (Disability Royal Commission), disability advocates and advocacy bodies.

Australia is a signatory to both the [UN Convention on the Rights of the Child](#) and the [UN Convention on the Rights of Persons with Disabilities](#) and has obligations under both instruments.

Article 12 (1) of the UN Convention on the Rights of the Child requires States Parties to *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.*

Article 7 (3) of the UN Convention on the Rights of Persons with Disabilities requires States Parties to *ensure that 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.

In support of the UN Conventions and recognising the need to do better in listening to, and acting on, the voices of children and young people with disability in policy design, Families Australia partnered with Children and Young People with Disability Australia (CYDA), the national representative organisation for children and young people with disability, to deliver this policy forum. The forum was timely, given work underway to develop the successor plan to the National Framework for Protecting Australia's Children (2009-2020), consultations on the successor for the National Plan to Reduce Violence Against Women and their Children (2011 – 2022), the work of the Disability Royal Commission and the development of the new National Disability Strategy.

CYDA developed a briefing paper to inform the forum and this should be read in conjunction with this summary report. The paper, at **Attachment A**, set the context for the forum discussion, described the key issues impacting the effectiveness of disability and broader policy for children and young people with disability, and identified opportunities for change.

Forum presenters included, as keynote speakers, two participants from CYDA's National Youth Disability Leadership Program – [Gi Brown \(they/him\)](#) and [Chloe Polglaze \(she/her\)](#) – and [Liana Buchanan \(she/her\)](#), Victoria's Principal Commissioner for Children and Young People; [Mary Sayers \(she/her\)](#), CEO, CYDA and [Dr Brian Babington \(he/him\)](#), CEO, Families Australia. The forum was facilitated by [Natalie Wade \(she/her\)](#), a respected disability rights lawyer and advocate. Forum participants included representatives from Commonwealth and State and Territory governments, non-government organisations, academic institutions and research, and private corporations across multiple sectors including social and community services, children's services, and disability policy and services. A number of participants attended from organisations working specifically with children and young people.

The forum explored a range of barriers to inclusion in policy and program design, including systemic, medical and educational ableism; failures in recognising and upholding the rights of children and young people with disability - in all their diversity - across multiple systems including safeguarding and child protection; lack of voice for children and young people with disability at all stages of the policy-making process, including implementation; siloed approaches that fail to recognise the intersectionality of disability; lack of data, and the negative – deficit focused - framing that often surrounds children and young people with disability across multiple settings. Lived experience speakers shared their personal experiences and the impacts of these failures including on their own identity and intersectionality, their fundamental human rights, the personal and financial costs of navigating complex and fragmented systems, inequality and inequity and on risk identification and the effectiveness of system responses.

A number of opportunities were also discussed. A key message from all speakers related to the interaction and intersections children and young people with disability have with many systems and structures across their life course - both disability and non-disability specific. Additionally, speakers noted the extremely fragmented processes for developing policy for children and young people with disability, with different responsibilities across the national and state and territory systems.

Strategies and safeguards that fail to recognise and encompass the strengths and needs of children and young people with disability will not be inclusive or effective. Secondly, in order to promote these strengths and needs in policy and program design, children and young people and their representative organisations must be given an equal seat at the policy-making table, at every stage. There was a call for a fundamental shift in expectations to ensure that co-design of disability-specific and non-disability policy and programs embeds evidence and information from those with lived experience. This shift however, needs to ensure opportunities for participation were accompanied by concrete actions to empower and **enable** children and young people with disability - to not only take those opportunities but to contribute meaningfully and to their maximum potential. This includes providing support for preparation and skills development, meeting individualised accessibility and inclusion needs as standard protocol, appropriate remuneration, and utilising systems and structures where children and young people are already present, as emphasised by CYDA as a peak body for children and young people with disability. Of equal emphasis was the need to actively listen, to act on what children and young people with disability say, and to be accountable through ongoing communication and feedback loops. Finally, placing human rights at the centre of all policy development and design and recognising the complex, broad and intersectional nature of disability, and of children and young people with disability, was seen as crucial.

It is noted that this Forum was held two weeks prior to the meeting of Community Services Ministers (CSM) on 9 April. It is very encouraging that CSM announced children and young people with disability and/or their parents/carers with disability will be an additional priority group under the target cohort for the successor plan to the National Framework.

The Forum

This policy forum sought to elevate issues around safeguarding and policy gaps for children and young people with disability across a range of portfolios and professions and build understanding of the rights, safeguarding risks and gaps for children and young people with disability in national public policy settings. Three speakers shared their lived and professional experience and insights to address safeguarding and policy gaps for children and young people with disability. Chloe Polglaze and Gi Brown were participants in CYDA's National Youth Disability Leadership Program that supports young people with disability to gain a greater understanding of leadership, identify leadership goals, develop leadership values and aspirations, and learn how to implement these skills. Liana Buchanan is the Principal Commissioner for Children and Young People in Victoria and also sits as a part-time Commissioner of the Victorian Law Reform Commission. She has a background in oversight and system reform for people experiencing disadvantage, with a strong focus on family violence and sexual assault. Mary Sayers, CEO CYDA and Dr Brian Babington, CEO Families Australia, also spoke to their experience of policy development and program design and participated in an audience Q and A.

Summary of Presentations by key speakers

Chloe Polglaze spoke of her experience as a young person at the policy intersections of disability (including the National Disability Insurance Scheme), identity, higher education and social security.

She spoke of her experience as a university student, as well as her roles with the University's Academic Board and its Student Association. Her presentation focused on the consequences and negative impacts for young people with disability when policy does not recognise and promote their rights. In particular, she highlighted the impacts of rigid systems, such as tertiary education, where administrative processes lack flexibility and fail to understand the diversity of needs and accommodations that young people with disability have. For Chloe, this failure to understand and make appropriate accommodations for her in one instance resulted in an invasion of privacy that she felt would not be acceptable for a non-disabled person.

'We spend so much time self-advocating, many of us make a joke about how being a disabled person in university is an extra subject in its own right.'

'If I wasn't on the Board to raise the issue of disabled students who need this flexibility, we simply wouldn't have been considered.'

Chloe also discussed the impacts of the [Higher Education Support Amendment \(Job-ready Graduates and Supporting Regional and Remote Students\) Bill 2020](#), in particular the provision that requires a student to maintain an overall pass rate of 50 per cent to remain eligible for Commonwealth assistance¹. She argued that this provision fails to give due consideration to the needs and circumstances of young people with disability. While she acknowledged the Bill allows for exemptions, Chloe took exception to this approach, highlighting the administrative and emotional burden this places on the individual who is already experiencing distress and who then has to prove their eligibility.

'Policy is made with exemptions that put the burden of proof onto us instead of just considering us. It's lazy policy-making. An exemption isn't enough. Just consider us instead of putting the burden on to us.'

Another area of focus for Chloe was the intersection between the welfare system and the higher education system and her experience of this intersection that positioned her as 'disabled but not disabled enough'. As one example, she spoke of the legislation that required her to be moved from Youth Allowance due to [Allowable Time Provisions](#), on to JobSeeker and the perversity of this decision given she is on track to complete her Bachelor of Engineering with Honours in three months' time. She also highlighted the lack of information provided to her as a recipient of JobSeeker with disability and the outcome she achieved 'by chance' that exempted her from full mutual obligation requirements. Chloe pointed to this example as one where the system was not supporting her to achieve her tertiary

¹ <https://www.legislation.gov.au/Details/C2020B00096/Explanatory%20Memorandum/Text>

qualification but rather, was working against her and exacerbating issues such as poverty and disadvantage.

'The reality is that the current system is further disabling us. We are running ourselves further disabled trying to fight it.'

'I was told that finding a job was the utmost priority and if uni interfered with getting a job, I would have to drop out. Yet another cog in the system working against me and my future.'

Chloe's final point was in relation to the intersection of disability and health policy. She discussed issues regarding affordability and the inadequacy of access packages that fail to recognise the complexity and severity of many conditions – of being 'priced out' of treatments and being further disabled as a result. The difficulties of finding services that bulk bill and that also specialise in disability were described and Chloe spoke powerfully of the personal impacts and toll this situation is having.

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

In closing, Chloe lamented on systems and policy that appear to be developed around underlying assumptions of dishonesty by applicants and recipients and the additional burden such approaches place on young people with disability.

'We have to prove to some high, high standard that we aren't lying.... Yes, you have to think a bit harder and yes, you have to put in the work to consult with disabled youth. But these work arounds... Not only are they not good enough but they're actively harming us.'

Gi Brown was the second young speaker who shared their lived experience of medical, educational and systemic ableism, and of a system they felt was discriminatory and de-humanising. Gi spoke of the difficulties they encountered when seeking medical intervention and a diagnosis - of their sense of being degraded by professionals who lacked the capability to effectively treat young people with disability. Gi also described the adverse impacts of late diagnosis and late intervention on his health and wellbeing, on access to services and the significant financial implications. Gi advocated for better training for medical professionals working with patients with disability and for rights-based approaches to be more effectively embedded in practice.

'Medical professionals have a lack of education in how to care for disabled people and so instead they become defensive. The education medical professionals is given is so blanket it fails to recognise that young disabled people are not monolithic, we're not static and we have complex needs that need to be approached as such.'

Gi also spoke of their experience as a disabled young person in mainstream education system that he feel is not built to accommodate children and young people with disability. Gi argued that this system does not provide adequate support for students with disability to enable their participation and does not effectively promote the skills and abilities of students with disability. Instead, Gi described it as a system driven by rubrics and processes that students with disability, in all their diversity, need to try and fit into.

'...because I am unable to write essays the way that this curriculum wants me to, I begin to suffer. There needs to be more leniency for students like me and for disabled students who are not like me too. There needs to be consideration for all disabled students because it is your curriculum, it is your education policies that are failing us, not us failing the curriculum.'

Gi argued the education system is oriented to segregation of disabled students into special education streams rather than to accommodating and including them fully in the mainstream. Gi emphasised the benefits of accommodating children with disability in mainstream education, using their sibling who attends a mainstream school part-time as a case example.

'All of a sudden he really began to thrive and gain opportunities all because he could start going to a mainstream school.'

'Many ...students have never encountered a disabled person in their life, especially not an intellectually disabled person. These mainstream students will continue to grow up with a lack of knowledge on disability, with stigmas, stereotypes and ableism because they are also denied the opportunity and right to inclusion.'

Gi also spoke about the National Disability Insurance Scheme (NDIS) in relation to its ongoing development and need for it to progress alongside people with disability, particularly in relation to governance – alluding to the harm known publicly that has been experienced by members of the scheme and also exposed through the Disability Royal Commission. Gi argued the care and support workforce under the NDIS need better training and governance processes to ensure they are able to provide high quality care and safeguarding and uphold human rights.

'...we need to be informed, reviewed and involved to ensure the NDIS is focusing on the people it serves instead of the money and bureaucracy it manages.'

Gi concluded his presentation with a discussion about identity and the importance of policy being written and implemented with young people with disability to ensure it recognises and protects the many intersections that comprise their identity – whether that be First Nations, gender diversity, sexuality, cultural and linguistic diversity, intellectual and/or physical disability, low socio-economic status, those suffering from mental illness or chronic illness and those who are drug dependent. Gi argued that without young people with disability and their representative organisations having a seat at the policy-making table, policy will continue to fail them.

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

Liana Buchanan also presented as a key speaker and, noting the work underway to develop the successor plan for the National Framework, focused her discussion on the right to safety for children and young people with disability. She drew on the various functions she performs at the Victorian Commission for Children and Young People, including overseeing child protection and out-of-home care services, reviewing services to children when they die after being involved with child protection before their death, and administering the Reportable Conduct Scheme. A particular emphasis was given to the particular consequences for children with disability where their parent/s are unable to provide them with care and to meet their needs. Analysis conducted by the Commission into child deaths exposed a high number of system and service failures - risk assessments undertaken by child protection assessments that failed to factor in the needs of the child as related to their disability/ies; of services working in silos, of service providers making false assumptions about the capacity and capability of the carer and not seeking out information about the child's full range of needs.

'And the bottom line is that service fragmentation meant no one agency fully understood the extent of risk for those children or the extent of harm being experienced by those children and no-one took responsibility for addressing it. These children lived with at best poor quality of life because of these service silos issues.'

Liana also spoke about these issues being exacerbated by the NDIS where safety issues for children and young people with disability are not of a sufficiently high focus.

Other themes covered by Liana included the invisibility of children and young people, particularly those with disability, in policies and strategies that affect their lives, resulting in their needs and issues not being effectively addressed; poor data collection that reinforces poorer policy outcomes as decision-makers lack accurate and meaningful information and knowledge; and lack of voice for children and

young people with disability who are often overlooked in both micro (practice) and macro (policy) level processes.

It means systemically we can't understand and provide the support that is needed because we simply are not identifying who those children and young people are.'

'...if you are providing a service for children and young people with disability, if you're developing policy wherever you are in government that in some way affects children and young people with disability, if you're designing service responses that will impact them...you're not doing your job unless you build in a process to make sure you get their input and you hear and act on their expertise.'

Mary Sayers and Dr Brian Babington introduced the second hour of the forum and led into the general discussion. Mary emphasised the need to ensure the rights and safeguards of children and young people with disability are included in all national plans and policies. She advocated for a change in the way references to children and young people with disability are framed in policy, with a move away from a 'vulnerability' frame to one that recognises their rights and inherent strengths. She reinforced the intersectionality and diversity of disability that needs to be better recognised in policy-making and implementation and the need to engage children and young people with disability and their representative organisations more directly and in all stages of the policy process.

'If we only conceptualise children and young people with disability in a service paradigm, rather than looking at their human rights and how these are enabled, we will never be able to make progress.'

Mary spoke about the difficulty monitoring violence and abuse against children and young people with disability in Australia due to fragmented systems, siloed approaches, poor data and the lack of oversight bodies with adequate powers. She advocated for the Disability Royal Commission to make very strong recommendations to genuinely improve the lives and outcomes for people with disability.

Brian spoke of the resonance of the discussion with the findings of Families Australia's national consultations on the successor plan for the National Framework. Brian also called for greater involvement of children and young people with disability in policy and program design and implementation through appropriate and accountable mechanisms at all levels.

'We need, at the national level, proper mechanisms so that our policy-makers and politicians hear those voices loud and clear and frequently and those structures don't simply mean that young people come to a place like Canberra three or so times a year and say stuff and then go away and not much happens, [if] anything, but there's an accountability mechanism built in.'

He also called for action to address policy fragmentation and for far greater effort in bringing policies, plans and strategies together so they are working more effectively with each other. Brian argued this could be done by including the needs of children and young people with disability in all allied national plans and strategies across health, housing, education, care and protection and so on. In closing, he also emphasised the need for political will and an authorising environment with high level oversight to drive much needed change, through for example, the National Cabinet.

Implications for Policy and Practice

A number of key messages emerged through the general discussion and facilitated question and answer session. These included:

- A unifying, national strategy that brings together the various national plans and strategies that include children and young people with disabilities as a target group, to address the current siloed and fragmented approaches.
- We must ensure the **ongoing involvement of young people with disability in policy and program co-design** where government, non-government representatives, community members and people with lived experience, share a common table and come together as equals with a spirit of collaboration. This can be achieved by:
 - Prioritising young people with disability and their voices and involvement in government procurement processes. Funding proposals and tenders must include a budget to pay young people for their time and contribution; for accessibility requirements; for preparation undertaken by young people and their supporting organisations; and for post-briefing processes.
 - Ensuring there is adequate and appropriate representation of children and young people with disability in all forums and reference groups established to capture their voices and views.
 - Developing accessibility standards that establish a minimum baseline to ensure measures such as captioning and Auslan.
 - Requiring children and young people with disability to be present from the start of policy-making or service design and enabled by strong, safe support mechanisms that address power imbalances and maximise their engagement and participation. (The development of the policy to introduce independent assessments under the NDIS was highlighted as an example where the lack of consultation and co-design delivered policy that could cause harm to participants.)
 - Providing opportunities for young people with disability to develop the relevant skills and abilities to enable them to sit at the policy-making table and contribute as equals.
 - Better leveraging the organisations and groups that already exist and that are actively engaging children and young people with disability in decision-making.
 - Engaging older children and young people with disability and families and caregivers when seeking to include the voices of very young children and get a holistic view on how to really safeguard from every age.

- There is a need for a **strong political and policy authorising environment** that actively encourages policy people at the intersection of systems like NDIS, education, higher education, adult mental health and transitioning from care, to work more collaboratively across agencies.
 - Ensure the needs and issues for children and young people with disability are visible in all national plans and strategies that cross multiple systems.
 - This approach will recognise the complex, broad and intersectional nature of disability, and of children and young people with disability. National policy must work to reduce fragmentation and silos at all levels.
 - Include pricing signals in contracts that actively encourage organisations to collaborate and break down silos.
 - Develop leadership that inspires a cultural shift over time and the taking of risks to work with colleagues in different ways.
- Introduce government endorsed policy-making and service design standards that drive accountability and require children and young people with disability to be included as critical sources of evidence and information – of equal value to those of research, data and other evidence.
- Adopt a **rights-based approach** in all policy and service design that supports children and young people with disability to bring greater uniformity across systems.

‘They need to see the inherent value that we have and I don't know how to convince them of that because everyone dismisses our value and the fact that we do have inherent value...and it's not like you can just do one thing to fix it. It is really the attitudes that need to change....How do we get them to understand our worth?’ (Chloe)

Briefing Paper for the Families Australia and Children and Young People with Disability Australia (CYDA) Forum

Recognising and promoting rights - children and young people with disability

The current context

Children and young people with disability are often overlooked or missed in public policy. In child and youth-specific policies, the distinct needs and strengths of children and young people with disability are generally absent. Similarly, the cohort's rights and developmental and social needs are also commonly absent from disability-specific policies.

How children with disability are framed in Australian policy

A 2020 research report¹ explored how children and safety were constructed within and across relevant state and federal government policies in Australia. Altogether 56 policies were included in the analysis, including disability-specific policies. The review found that children and safety are generally framed in policies in two ways; with a focus on children needing protection from harm or as a recognition of children's rights, agency and capabilities. The authors noted that the emphasis on children's autonomy and competence was becoming increasingly evident in policy.

The review then explored specifically how children with disability and safety were framed. The review found:

- References to children with disability were minimal in national documents aimed at all children
- When children with disability were included in cross-sector policies, it was primarily in terms of their perceived vulnerability.

In the disability sector, the documents analysed predominantly call for compliance of people working with children, rather than promoting cultural conditions that recognise the importance of children's rights and relationships.

¹ 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>

The authors concluded that different “constructions of children in cross-sector and sector-specific policy have potential implications for the way that the safety and wellbeing of children and young people is attended to across contexts” and that framing children with disability “in terms of agency, rights and empowerment in sector-specific documents seems more likely to contribute to their increased wellbeing and safety, than the emphasis on vulnerability in other contexts.”²

Policies and systems do not capture the lived realities of children and young people with disability

Children and young people with disability need to be considered as children and young people first, and not defined by their disability. While some may receive specific disability supports and care, all children and young people are also located in other mainstream systems alongside their peers, including early childhood education, schools, health, employment, income support and housing. They are also included in more tertiary services including child protection services and out-of-home care, and the justice system.

Therefore, when mainstream or cross-sector specific policies ignore the 15 per cent of children and young people with disability,³ their distinct rights and needs will be missed, and programs and strategies will not be effective for and/or fail to provide targeted supports when and where most necessary.

When disability and the experiences of living with disability are included in policies, they tend to view people with a disability as a homogenous group. Recently, CYDA co-hosted the inaugural 2020 National Youth Disability Summit (NYDS), a five-day conference designed by and for young people with disability. The young participants at the NYDS shared how important it is that systems recognise and be respectful of a diverse range of identities.

One young participant commented that the “*one-size-fits-all approach*” does not represent people’s differences, comparing it to a “*blanket thrown over people with disabilities that contains stereotypes*”.

Young participants attending also shared the significance of intersectionality and how the recognition and promotion of different identities, such as ethnicity or sexual and gender diversity, in different systems is fundamental in ensuring that all young people feel safe and included. Talking about their experience in the education system, one young person shared:

² *ibid.*, p. 20.

³ 14.8% of people with disability are aged 0–24 years. AIHW. (2020). *People with disability in Australia*. Available at [People with disability in Australia, Prevalence of disability - Australian Institute of Health and Welfare \(aihw.gov.au\)](https://www.aihw.gov.au/People-with-disability-in-Australia-Prevalence-of-disability)

“I felt left out. Felt different. Felt like I don’t belong. Like the default is white, abled and heterosexual. I have experienced discrimination from teachers and lecturers, such as being told that I was ‘too sick’ to be at university, and constantly being in detention at school because the system just wasn’t designed for someone like me.”

The voices of children and young people with disability are missing from policy development

A key contributing factor why the strengths, needs and recognition of intersectional identities of children and young people with disability are missing in policies is because the cohort are generally missing in the processes that shape and design them.

Comments from young participants at the NYDS:

“Young people in particular ... are not part of the conversation about what should be in those supports or plans or policies [that affect young people]. ... People very much think, ‘I know all about young people so I can put this policy together without talking to them’, but when you do that, there are so many stories, narratives, bits of information that you miss because you are not talking to the affected person.”

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

Children and young people with disability face barriers to participating in consultative activities that inform policy and service development. The processes are often inaccessible, including inadequate information delivery, meeting structures, interpreters, and assistive technology. This was noted in the recent report commissioned by the Department of Social Services, which confirmed young people with disability “do not find current mechanisms used by governments to engage on these issues appealing, suitable or easy to access.”⁴

⁴ Social Deck. (2019). *Right to opportunity: Consultation report to help shape the next national disability strategy*. Available at https://www.dss.gov.au/sites/default/files/documents/12_2019/nds_beyond2020_fullreport-161219_0.pdf, p. 64

The opportunity for change

As they grow and develop, children and young people interact and intersect with many systems and structures — both disability and non-disability specific. When these systems and relevant government policies do not encompass the needs and strengths of children and young people with disability, the group will be further marginalised and governments will design and invest in strategies and safeguards that ultimately will not be effective.

Children and young people with disability and their representative organisations must have a seat at the table and incorporated in national public policies, plans and frameworks that span all the elements of their lives.

This call is echoed by young people who attended the NYDS. Young people are hungry for change and see themselves as being a core part of the solution; whereby they believe they can enact positive change if governments and systems invested in their skill development and provided meaningful platforms where they can be heard and exercise their lived expertise.

As noted by participants at the NYDS

“Our needs get met the best when we’re the ones that get to define what they are.”

“I believe that young people’s voices need to be heard. ... [W]e have the future ahead of us and we see the changes that need to happen. It will be silly not to give young people a voice and input in the matters that affect them.”

“Listen to young people. Because there is not a decision that is not with us at the end of the day. The mistakes made today will haunt us in the future.”