

CYDA's submission to the Senate Select Committee on Work and Care

“The voices of children and young people are also rarely heard when decisions are made about the issues that affect their lives.”

Australian Human Rights Commission [website](#)



Content note for the discussion of ableism

**Children and Young People with Disability Australia
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Authorised by:

Miranda Cross, Acting Policy and Research Manager

Contact details:

Children and Young People with Disability Australia

E. info@cyda.org.au

P. 03 9417 1025

W. www.cyda.org.au

Authors:

Sue Tape, Project Coordinator – Inclusive Education

Shae Hunter, Policy and Research Officer

A note on terminology:*Children and young people with disability*

The disability community has largely recognised and used inclusive language and terminology for decades. Children and Young People with Disability Australia (CYDA) uses person-first language, e.g., person with disability. However, CYDA recognises many people with disability choose to use identity-first language, e.g., disabled person.

Families and caregivers

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

Acknowledgements:

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

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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 submission to the Select Committee on Work and Care's inquiry (the Inquiry). This submission outlines the impact that combining work and care responsibilities has on children and young people with disability and their families. More specifically, we draw on the lived experience of families to highlight how fragmented and underperforming systems fail to support the needs and strengths of children and young people, thereby impacting the capacity of family and caregivers to successfully participate in both work and care.

The first section presents four case studies from members of our community. These demonstrate the tangible impacts of inadequate and inaccessible systems on enabling children and young people with disability to participate in community life on the same basis as their peers without disability. Further, they foreground the emotional, financial and administrative burden placed on family and caregivers not by children and young people with disability, but by the systems that fail to provide adequate and appropriate supports (which, in many cases they are legally required to).

The second section details specific and actionable recommendations that will better support the inclusion of children and young people with disability in service systems and community life, and as such, enable families and caregivers to successfully participate in both work and care.

The third section, the context for our recommendations, provides insight into some of the structural and systemic issues that are hindering necessary reform and entrenching disadvantage—in particular the complex, fragmented and sometimes competing service and policy environment discussed in the case studies. This section contains many references to more detailed work on these topics to enable members of the Inquiry to explore as needed.

This submission as a whole, draws on the insights and lived expertise of young people and families/caregivers who participated in our survey work, youth focus groups, and our 2022 webinars about inclusion in early childhood, co-facilitated by young people. It has also been shaped by input from CYDA staff, the majority of whom have personal and/or family experience of disability.

Summary of recommendations

Incorporate the rights of children and young people in future work and care policy development designed to benefit their families and caregivers

1. Establish a dedicated office and ministry to ensure the rights of children and young people are promoted and upheld across government

The Australian Government should develop an Office for Children and Young People with a dedicated Minister to ensure there is a consistent focus on children and young people's needs, including those with disability, across government. This Office should also be responsible for ensuring children and young people have ongoing and accessible opportunities to express their views on the issues and systems that impact their lives.

2. Initiate the 'immediate actions' in the 'Jobs and Skills Summit September 2022 Outcomes' document specific to children and young people with disability

CYDA urges the Australian Government to consider and act on broader issues from the recent [Jobs and Skills Summit](#). The outcomes document included "*Put in place a Carer Friendly Workplace Framework which includes a self-assessment tool and learning modules, for businesses to be recognised as a carer friendly workplace*". Any additional workplace frameworks and training need to be coupled with action on the government and social systems that also impact 'carer friendly' employment options.

3. Protect children and young people from the developmental, social and economic scarring effects of the COVID-19 pandemic

CYDA urges the Australian Government to prioritise the development of a National Child and Youth COVID-19 Recovery Plan to mitigate adverse social and economic impacts. Specifically, CYDA endorses [UNICEF AND ARACY's Kids at the Crossroads: Evidence and Policy to Mitigate the Effects of COVID-19 report](#) that provides immediate and longer-term recommendations across six wellbeing domains.

Reform systems that directly support and involve children and young people to enable families and caregivers to combine work and care

4. Make early childhood education and care the first step of an inclusive life

CYDA urges the Australian Government to act promptly on the [Early Childhood Targeted Action Plan](#) as outlined in [Australia's Disability Strategy 2021-2031](#) including:

- Enable early identification of disability or developmental concerns and develop clearer pathways and timely access to appropriate supports
- Strengthen the capability and capacity of key services and systems to support parents and caregivers to make informed choices about their child
- Encourage a stronger sense of inclusion and provide opportunities for parents, caregivers and children to build peer networks, including for Aboriginal and Torres Strait Islander and culturally and linguistically diverse parents and caregivers.

CYDA calls on the Australian Government to give children their best start in life. Specifically, CYDA joins calls by [The Parenthood](#), [Thrive by Five](#), [Every Child](#) and the [Centre for Policy Development](#) for the Australian Government to ensure:

- Universal access to education and care – affordable, high quality, inclusive and easy to access
- Simplification and coordination of the currently confusing and expensive array of services and schemes
- Data are collected and shared at all levels of government to improve evidence of the range and quality of early childhood services.¹³

5. Protect the educational rights of children and young people

CYDA urges the Australian Government to fund and implement a body with independent oversight to ensure that education providers – in early childhood, school, post-school and adult education settings – are meeting their legal obligations and complaints can be independently investigated, monitored and resolved.

6. Provide early support pathways and proportionate access to the NDIS to ensure equity for children and young people

The Australian Government must guarantee ongoing and sufficient funding of the NDIS to ensure equitable life opportunities for children and young people with disability. There must also be an increased focus on supporting equitable access for new entrants to not undermine its insurance principle of investing early to enhance lifelong outcomes.

Case studies

This section includes four case studies varying in length and detail, to illustrate the experiences of families, caregivers and children and young people with disability. The case studies highlight the real-life experience of combining various types of work and care and the inadequacy of work and care supports. They include a range of experiences, including types of work undertaken, impact of policies, workplace arrangements and lessons arising from COVID-19. All experiences relate to informal caring roles.

Case study 1 – Jean’s story

Note from the family in this case study:

We and our two children live a life of privilege. We live in our own home, in a suburb of a large city, close to amenities and family. We have no experience of violence, addiction or significant mental health issues. We speak English as our first language, have professional qualifications in demand and have lived in our local community for 15 years. Both our children attend inclusive and welcoming government schools. We both work in supportive workplaces, close to home and have a level of literacy that allows us to navigate the complex systems that surround us.

After a tumultuous first five years of life for our youngest child, we live a delightful and relatively ordinary life of two kids, two parents and two incomes. Both parents will be in their mid to late 50s when the children turn 18. Between now and then, we will navigate high school, first jobs, learners permits and first loves. We will also attempt to secure our family’s long-term wellbeing and financial future with work and care responsibilities.

Over the 11 years of her life so far, both her parents have adjusted their work and financial arrangements. Both her parents have made changes to how we imagined our family and our careers. These changes have not been made because of our daughter’s disability but because of the systems and the world we navigate to ensure she is loved, learning and living as typical as possible life of an 11-year-old.

Our child is a loved and loving member of our family. She is our second child. She has a rare genetic disability that impacts her physical, social, emotional, communication and cognitive engagement with everyday life. She has for the most part a very ordinary childhood. She goes to the same school as her older brother did. She attends after school hours care two days a week. She pats our dog, fights with her brother over the remote control, and raids the fridge when she’s hungry.

She is not a burden as some will have us think. She is not a problem to be fixed. She is resilient, feisty, funny and cheeky. She has life long, permanent disabilities that will mean she will need support and adjustments for the rest of her life. She has a lot to offer her peers, her family and her local community.

“When your child goes blue at home, stops breathing at 10 weeks old and you call 000, your husband’s job security or arrangements are not top of mind. You question every move and decision you have made for the last 10 weeks and what could have changed this situation. You assume that the medical professionals you did and will now interact with, will provide you with all the information and professional insight you need to be the best possible parent to this tiny girl. You don’t realise that ableism¹ will now present itself at almost every interaction you have with medical staff, employers, bureaucrats and bank managers.”

¹ See page 29 for definition of ‘ableism’

Case study 1: Topic area	My child with disability has experienced the following....	This meant...
Baby and maternity services - family and caregiver information and supports	<p>Poor education and supports: The paediatrician didn't advise us she likely had a rare genetic syndrome that required early intervention and adjustments to support her development. The possible and eventually diagnosed syndrome was noted on her day 1 medical file, as accessed via FOI.</p> <p>None of the health professionals involved in maternity care supported us to understand what care might be required for our baby.</p>	<p>We as a family were not prepared or informed as to how we could and should prepare ourselves, our finances, our home set up and our mental approach to parenting.</p> <p>When her health declined at 10 weeks old at home, we had no provision for parental or sick leave, work breaks or financial buffer for the care that could have been anticipated and was required for the first few years of life.</p>
Early childhood education and care	<p>Limited access to care: Long day care options that were supportive, safe and suitable were limited.</p>	<p>Lack of access to early education and care with her same age peers and restrictions on work options for one parent, up until kindergarten age</p>
Financial and income support	<p>Diminished earning capacity: With diminished capacity of one parent to work and pressures placed on the other parent, less money was coming in</p>	<p>Lower earnings means lower super balances and more pressure on any savings</p> <p>When your only possible source of financial planning is the house in which your own parents live and the value of their eventual estate, you have reached morbid skill level 10.</p>

Case study 1: Topic area	My child with disability has experienced the following....	This meant...
<p>Employment - options and supports</p>	<p>Restrictions on time available to work: For the first five years of life, our daughter lived in a single income house, despite both availability of jobs and capability to earn.</p> <p>Not able to return to previous earning capacity: Once our youngest child began kindergarten, I (mother) began looking for employment. I needed to be within driving distance of her to manage any issues with feeding tube use or other health related matters. The Inclusion Support Program and supports available to the kindergarten did not allow for an individual support aide but only a teacher aide, meaning that specific training and supports were not always forthcoming or viable.</p>	<p>The lack of knowledge about how to approach parenting a young baby with disability and lack of supports to navigate new systems and services, meant no opportunity to also seek employment. One income meant we relied on grandparents to care for our older child so we could keep the one job we did have. I only saw my 18-month-old child on weekends for weeks at a time as we navigated hospital stays and visiting hours.</p> <p>I had been out of the work force for five years. My professional qualification was out of date and out of reach for a parent who shared a hefty 2007 era mortgage. I took a part time role for less than half of what I was earning 5 years prior. I had a 5-year gap in my superannuation contributions.</p>
<p>Health</p>	<p>Poor experience with health staff: Experiences of discrimination and ableism have meant lengthy wait times for services and barriers to accessing services and supports</p> <p>Public and private health admissions and services: over the last 11 years we have navigated the public and private systems punctuated with a key theme of limited communication between the two systems. Our child has at one time been under the care of the following (not exhaustive list):</p> <ol style="list-style-type: none"> 1. GP 2. Paediatrician 3. Neurologist 4. Cardiologist 5. Endocrinologist 6. Respiratory and Sleep physician 7. Ear Nose and Throat specialist 8. Gastroenterologist 9. Orthopaedic surgeon 	<p>Our child has been unable to have bone density scans since 2017 because the state-based children’s hospital medical imaging department is unwilling to make reasonable adjustments for a patient who uses augmented and assistive communication and has an intellectual disability.</p> <p>There is no one health person who has carriage or knowledge of our child. We as parents are required to hold and communicate the knowledge – medical and otherwise – between professionals and systems.</p> <p>The 15 listed professionals correspond by letter with each other before and after appointments as part of the referral process. This is often the extent of the communication and there is no one case manager – other than her parents.</p>

Case study 1: Topic area	My child with disability has experienced the following....	This meant...
	10. Plastic surgeon 11. Dietician 12. Speech therapist 13. Physiotherapist 14. Occupational therapist 15. Paediatric dentist	
Education	<p>Siblings expected to be at the same school: We have two children who are three school years apart. Our son had been at school for three full school years before his sister started school, and our daughter Jean* had been front and present at the school that whole time – pickups, drop offs, on my lap at concerts, playing with the other children at the local pool during holidays and birthday parties, noisy like all little sisters at the Christmas assembly, etc.</p> <p>Inclusive education: Jean got to this place, year 4 at her local school, because she turned up on day 1, excited, dressed in the same uniform, with her Dad carrying her bag, her things named, and ready to learn. She was welcomed, her needs were anticipated and planned for, and everyone had high expectations of her – academically and socially.</p>	<p>Considerable time and energy spent on advocating with school and others for all of the components of physical, social and curriculum inclusion: In the year before Jean started school, therapists, doctors and other professionals peppered conversations with questions about school preparation and planning. Those questions appeared to be focused on how Jean would ‘cope’ and what level of effort the school might go to for her ‘benefit’.</p> <p>Fortunately, our conversations with the school team were different. Almost all of the conversations started with the question “Is Jean excited to start school?” Meetings and kindy visits were organised that looked at what Jean was up to, what she enjoyed about kindy, what sorts of adjustments helped her to interact with her kindy classmates and what goals were we working on at home. I asked a cross section of staff from school, kindy, then Disability Services Team, external therapy, and the Department transition team, to join together for a meeting in a local coffee shop. It was the first time any had experienced this, and it seemed to me to create a sense of excitement and collegiality that they were all to be part of Jean’s transition to Prep.</p> <p>These and other subsequent conversations didn’t avoid the mundane arrangements that needed to be made and didn’t skirt around Jean’s disability.</p>

Case study 1: Topic area	My child with disability has experienced the following....	This meant...
		Now in grade 4 and an older brother in high school, I would spend at least 3 hours a week advocating for or organising educational adjustments for our child. Based on the lack of connection to the other systems in her life, I don't expect this will ever change. 320 weeks to go.
NDIS	<p>Straightforward plan: Transition to NDIS at age 7 from previous Disability Services model. Currently on 4th NDIS plan.</p> <p>Arduous regular process: Before school and with over six years of early intervention and medical trauma under her belt, Jean appeared wary of and weary with adults and their expectations of her to repeat the same linear development milestone driven tasks over and over with the same expected outcome. We were also tired of explaining that Jean didn't appear to measure her happiness or quality of life by whether she would respond to her name, eat certain food, or say B for ball. People and professionals who were focused on frameworks and forms missed that B is for bath, formula was her saviour, she knows what her name is, and if you are over the age of 20, you are merely a means to an end and should not assume you are her friend.</p>	<p>Straightforward plan: Our child's NDIS plan is relatively straightforward, and we self-manage.</p> <p>Arduous regular process: The paperwork, the people and the process are all completely different to those completed under Health, Education, Inclusion Support Program, and kindy. For every plan we are required to prove again that our daughter has a permanent, lifelong disability – physical and intellectual. She has a rare genetic syndrome that is not an acquired disability and for which she has experienced over 500 sessions of early intervention either physiotherapy, speech therapy and occupational therapy.</p>

“The overall NDIS plan value has remained at similar levels for the last five years and meets all of the current needs. This level of stability is due to our close management of it and in spite of a fairly horrendous transition process. We have never had the same NDIS person from plan to plan and each review requires telling “her story” over again. The lost work time spent engaging with this system is far above the value of any services or supports received or frankly, needed.”

*name changed to protect privacy

Case study 2 – Theo’s story

(written by a parent imagining his point of view)

My name is Theo* and I am 6.5 years old, and I live with my two mums and my little sister. I love machines, animals and spending time on my grandparent’s farm when I have a chance. I’m autistic (with a PDA² profile), I have ADHD, and I also have anxiety and a tic disorder. My highly sensitive nervous system, the level and availability of certain chemicals in my brain and the structure of its neural pathways, means that I find many environments in my world extremely difficult to manage. My ‘behaviours’ are what most people focus on, because they make me seem different to most other kids my age, but they are only a tiny reflection of what is going on inside my brain and my body. My family knows that my behaviours are signals that I need support to manage myself and my environment.

Before I was born my Mama worked full-time at a university doing research and then completed her PhD when I was a baby, hoping to go back to working in research. My Mummy worked full-time in a community sector organisation. As my support needs increased from the age of 2.5, my Mama has not been able to continue her career in the way that she thought, and my Mummy decided to quit her job and start a business so that she could work flexibly to be available for the tricky moments in our household.

I love having both my parents around, but I can tell that they are stressed because they are grumpy and frustrated, and this makes it even harder to regulate my emotions. My Mama decided to take on a new role two days a week once I had started school. Now on Tuesdays and Wednesdays when I’m having trouble with school drop off, I can see that she needs to leave to get to work and this makes me sad and anxious. I told her that this makes me feel like she doesn’t want me anymore. They arranged for a babysitter to pick me up from school these two days but because I’ve had a lot of trouble adjusting to this, my mums now pick me up one day each and then work after I go to bed to make up for their missed hours.

I often need my Mama to stay at school in the mornings until I feel safe and settled, then I have an easier day and learn more. I need a calm grown-up to scaffold my social interactions at school each day, especially during recess and lunchtime, but the funding in the education system means that fewer teachers are available during these times. It’s really tricky to navigate these times and I sometimes get into altercations with other children because I can’t understand what is going on socially. Usually when this happens, I need one of my parents to pick me up early because the social demands and sensory environment exceed my ability to cope, and I have a meltdown. I feel ashamed and embarrassed when this happens and I need someone, preferably one of my mums, to protect my dignity and help me regulate. I wish school was a place that could support me to stay regulated so I could stay there longer and learn more.

Mama says we use the phrase ‘flip your lid’ for good reason—when we are in distress our prefrontal cortex, or the lid on our brain, becomes disconnected from the instinctive and emotional parts of our brain and we don’t have access to language and reasoning. Most grown-ups I interact with each day don’t understand brain-body science or neurodivergence. Their behaviourist lens means they think I choose to act this way when my system is in overwhelm. They don’t seem to see the bruise on the side of my face from hitting myself out of overwhelm and frustration and wonder why anyone would choose to do this. My Mama gets really frustrated that some of the services and systems we encounter each day say that they are ‘trauma informed’ or ‘autism friendly’ and then use coercive techniques to try to get kids to do something.

² Pathological Demand Avoidance. Widely understood to be a profile within autism. Further information available at: <https://www.pdasociety.org.uk/>

Each morning I wake up and my parents seem tired. They have often been awake well into the night paying NDIS bills, researching appropriate accommodations to diplomatically introduce to my school, completing the paid work they missed during the day, doing the grocery shopping (because it's difficult to get it done during the day), cooking, cleaning, meeting with my OT on telehealth, packing lunches, tending to me or my sibling if we wake up overnight, and any other number tasks that need to be done to smooth the way for me in this far from ideal world. They know that as a child with disability, I interact with systems each day that cannot (or will not) fully accommodate my needs, so they fill these gaps to try to minimise the negative impact on me.

Case study 2: Topic area	My child with disability has experienced the following....	This meant...
Early childhood education and care	Lack of training in disability and neurodivergent presentation: The day care staff where our child attended two days per week from 18 months to 3 years old were not trained to understand his behaviour and were somewhat dismissive of our concerns. We engaged an OT who performed an observation at the centre and confirmed his confusion and distress and provided some strategies. Ultimately, staff lacked the training to support him adequately, so we removed him from the centre.	<ul style="list-style-type: none"> • Delayed diagnosis and/or services • Emotional distress to the child and family • Family unable to increase hours of care meaning working hours remained restricted for one parent.
Financial and income support	Diminished earning capacity: With diminished capacity of one parent to work and pressures placed on the other parent, there is less money coming into our household than we have capacity for, if we were to have better supports and inclusive environments.	<ul style="list-style-type: none"> • Lower annual earnings • Lower superannuation balances (especially for the parent who stayed at home for longer than planned) • Less savings • Less disposable income • Restricted ability to carry out plans such as growing a business, providing additional educational opportunities or retiring early.
Employment	Restrictions on employment type and arrangements: For the first 6.5 years of life, our child lived in a single income house, despite both parents being willing and able to earn higher than average incomes (after having completed training and qualifications to allow for this). The single income was low for a period of three years as the primary income earning parent altered her work arrangements to suit homelife with a child with disability.	<ul style="list-style-type: none"> • Primary earning parent left full time role in non-profit sector to gain more flexibility and availability for the family. This significantly altered her career trajectory and meant there was a large reduction in earnings for three years until the business grew. • Primary carer parent returned to work later than planned, and only in a limited capacity due to needing to be available for extended drop offs and early pickups from school,

Case study 2: Topic area	My child with disability has experienced the following....	This meant...
		<p>additional sick days (from anxiety), regular school avoidance, and rejection of after school babysitter.</p> <ul style="list-style-type: none"> • Increased stress in the household due to financial restrictions.
Health	<p>Lack of training for health staff: A plaster technician at a major children’s hospital with limited understanding of neurobiological and trauma origins of behaviour rushed through a procedure without explaining it properly or building rapport. Our child was in pain and frightened and then had an extremely large distress response a few weeks later when it was time for the plaster to be removed. It took three separate visits before the plaster was successfully removed. On the third visit his Occupational Therapist was present and he had to be sedated in a day procedure unit for the plaster to be removed.</p> <p>This is just one of many examples of our interactions with the healthcare system.</p>	<ul style="list-style-type: none"> • Financial cost to healthcare system of specialist staff for additional visits plus administration costs of investigating the resulting parent complaint. • Financial cost to family of the additional 7-10 hours spent at the hospital instead of being in paid employment, the many hours spent advocating for the child and lodging feedback in an attempt to improve the system, and \$60 in car parking. • The financial cost of the Occupational Therapist (\$600) from our child’s NDIS plan – displacing other therapy; plus the additional therapy to deal with the trauma of the incident. • Health and wellbeing cost to the family, emotional distress to our child and family, and ongoing difficulty in supporting and advocating for our child through medical procedures.
Education	<p>Outdated approaches in school system limit inclusivity: Positive behaviour support framework used in our child’s school to understand and manage student behaviour. It’s system of incentives, rewards, consequences and modification strategies fails to account for the structural and chemical differences in the nervous systems of neurodivergent children or those with trauma backgrounds. Despite numerous meetings and sharing resources to demonstrate a different approach, staff fall back on the dominant paradigm of behaviourism, choosing from number of techniques to ‘manage’ our child without considering the context of his internal experience. His neurobiology means he</p>	<ul style="list-style-type: none"> • After a number of incidents where behavioural techniques are used, he refuses to go to school one to two days a week and getting to school is stressful every day • When he is there, he’s anxious and dysregulated and misses valuable educational instruction which leads to additional resource inputs required by parents to advocate for his right to access education on an equal basis to his peers • Learning at a slower rate to peers and poor feelings of self-worth • Both parents taking time out of paid employment and family/leisure time to attend school to settle our child, meet with teachers, research

Case study 2: Topic area	My child with disability has experienced the following....	This meant...
	is highly reactive to feeling managed and quite often escalates prompting more techniques and meltdowns.	<p>approaches and techniques for adjustments and accommodations</p> <ul style="list-style-type: none"> • Emotional overwhelm due to additional hours required to advocate for our child's rights.
NDIS	<p>Inappropriate support from disability insurance: Following a period of time (COVID-19 lockdown in Victoria, March to May 2020) when our child was extremely dysregulated for majority of each day for weeks in a row, we contacted the NDIS to understand our ability to access assistance at home and get respite. We explained that we limited in our access to support from friends and family due to the pandemic conditions at the time. The NDIS informed us that when a child with disability is under 15 years old, the family is not entitled to respite because all tasks relating to the child can be classed as 'parental responsibility'.</p>	<ul style="list-style-type: none"> • Economic loss to household due to one parent not being able to do any paid work during this period and the other needing to be available due to safety concerns for both children. • Extreme emotional distress, poor mental health, and caregiver fatigue and burnout. • Compounding emotional distress for our child whose caregivers are tired, angry and resentful due to lack of adequate supports. • Pressure on the mental health system due to requiring additional telehealth sessions. • Increase in level of vulnerability of the whole family system impacting long term wellbeing. • Funding for subsequent NDIS plan was required to double, in part due to the emotional 'fallout' from inadequate support in previous plan.

*name changed to protect privacy

Case study 3 – Blake's* story

Case study 3: Topic area	My child with disability has experienced the following....	This meant...
Social and emotional – family and friends	Hyper vigilance around safety due to past domestic/family violence. Home bound due to child's Agoraphobia fears (might get out into the community once a week with him, if possible, can sometimes walk the dogs).	Solo parent gets cranky or mad and always tired and falls asleep in the chair. Forget to start dinner and there's always "stuff" everywhere!
Health	Constant researching supports and advocacy efforts. Diagnosed health issues	Reaching parent/carer burnout.... again

Case study 3: Topic area	My child with disability has experienced the following....	This meant...
Education	Huge hours advocating for my child's needs to be met in educational settings	Home educating via Distance education
Financial and income support	Needs school, Family Law Court and NDIS to recognise the intersection between Domestic and Family Violence and Disability, and acceptance of 'in the best interests of the child' should actually involve the child's input.	Impact on quality of relationships, education, self-care, ability to care, sleep, available income options, dependent on government payments, lack of energy to engage.
NDIS and disability support services	Cannot apply for NDIS funding for supports for me (even though diagnosed) because of abusive ex, and the very real fear of the family law court ruling custody with the other parent if child's father knew and used it against me in court.	I dare say my son also feels I am always distracted, busy, and asking him to 'hang on a minute'. I always seem to be speaking with therapists as we navigate my PDA'er (PDA – pathological demand avoidance)

*name changed to protect privacy

Case study 4

".... this topic has resonated a bit harder than I expected. Basically, when I carefully raised the topic with my kid (15 year old autistic non-binary magnificent kid), it turns out my kid feels a bit guilty that 'I need to help them too much' - they are also old enough to be thinking about money, and I think they are aware that me and dad both working part time (due to caring responsibilities) has an impact on what we have... and then we are all tired... and then there is the issue of part time work, and being excluded from career pathways [Professional with Masters], and I am now looking at not being able to continue in a relatively senior role because I'll no longer be able to be part time."

Mother, NSW, via direct message to CYDA team member with permission to use.

The key themes that emerged from these case studies – difficulties interacting with systems not meeting their legal obligations to children and young people, displaced economic and career opportunities for parents/caregivers who fill the gaps in these systems, and long term family wellbeing impacts from this additional labour – are addressed in next two sections of this submission, with detailed recommendations and context.

Detailed recommendations to the Senate Select Committee

This section provides further detail on each recommendation. It includes references to research, reports or previous submissions. Acting on these recommendations and furthering the work in this area, will better support the inclusion of children and young people with disability in service systems and community life, and as such, enable families and caregivers to participate in both work and care.

Incorporate the rights of children and young people in future work and care policy development designed to benefit their families and caregivers

1. Establish a dedicated office and ministry to ensure the rights of children and young people are promoted and upheld across government

Recommendation

The Australian Government should develop an Office for Children and Young People with a dedicated Minister to ensure there is a consistent focus on children and young people's needs, including those with disability, across government. This Office should also be responsible for ensuring children and young people have ongoing and accessible opportunities to express their views on the issues and systems that impact their lives.

For government policy and programs to reflect the contemporary child and young person's experience, there must be clear inclusion and consideration of the rights of children. As such, we urge the inclusion of the Convention on the Rights of People with Disability (CRPD) as one of the underpinning principles of this Office.

This convention clearly stipulates the non-negotiable standards and rights of children which must be upheld by our governments, and flow through to 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.³

We wish to highlight Article 7(3) of the CRPD which 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 governments commit to supporting – and funding – the disability advocacy sector's important role in realising the government's obligations as signatories of the CRPD.

Children and young people with disability are often overlooked in policy and service development. In child and youth-specific policies, the distinct needs and strengths of children and young people with

³ 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>

disability are unrecognised. Similarly, this cohort's rights and developmental and social needs are also commonly absent from disability-specific policies.

At its core, our community's needs are missing from policy because their voices are not being considered in policy development. Across departments and portfolios, there are few mechanisms that support children and young people with disability to express their views and be heard. Without genuinely including them, the Australian Government ultimately risks investing in initiatives and strategies that will not be effective for the nearly one in 10 Australian children and young people with disability⁴ and/or failing to provide targeted supports when it's most necessary.

Comments from young people within the CYDA community (2020):

"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."

"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."

The lack of representation of children and young people in policy development is further compounded by the lack of any oversight of the departments and portfolios whose work directly impacts their lives. CYDA argues that readily available data for this cohort is either non-existent or misrepresented. There should be a focus on transparency of information across systems and jurisdictions to ensure the experiences and outcomes of children and young people are adequately recognised.

Sadly, we saw the consequences of not including children and young people in policy development and the absence of authoritative body within government representing their interests play out in Australia's COVID-19 crisis responses.

In early 2020, CYDA ran a national survey⁵ of children, young people and their families and caregivers on their experiences during the COVID-19 pandemic. The survey found that existing inequalities were exacerbated during the crisis for the community, and that systems failed to respond to their needs.⁶ Findings include:

- Children and young people left without essential goods that are necessary because of their conditions
- Lack of appropriate and targeted information about COVID-19
- Barriers to accessing crucial supports and services, including in health and education.

Researchers have also analysed the development of a COVID-19 policy response for people with disability in Australia, including the failures of the Australian Government to include the community's

⁴ 7.6% of children aged 0–14 years and 9.3% of young people aged 15–24 years have disability; 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/reports/people-with-disability-in-australia/prevalence-of-disability)

⁵ The survey was conducted from 16 March to 23 April 2020 and had 697 responses. The majority (93 per cent) of respondents were a family member of a child or young person with disability.

⁶ Dickinson, H., Yates, S. (2020) *More than isolated: The experience of children and young people with disability and their families during the COVID-19 pandemic*. Report prepared for Children and Young People with Disability Australia (CYDA), Melbourne

needs in initial actions and rapid policy responses.⁷ Identified barriers to developing disability-inclusive policy included:

- The lack interactive processes in and between governments
 - Challenges linking up across departments and portfolios
 - Lack of clarity of responsibility for planning and actioning policies to protect people with disability
- Absence of a whole of government disability advisory process or structure that spanned across systems.

Establishing an Office for Children and Young People within the Department of Prime Minister and Cabinet that works across government to monitor the portfolio's obligations to meet the rights of children and young people and provide expert advice and guidance in improving systems, will help to address the aforementioned issues. The Office should also have a targeted focus and understanding of different intersectional needs and strengths of children and young people – including, but not limited to, disability.

Further, a fundamental component of this Office should be developing a formal and ongoing engagement framework to amplify the voices of children and young people across government. This framework must incorporate different activities and approaches to ensure children and young people from all different backgrounds, with different communication access needs and strengths can participate in a way that is safe and empowering.

2. Initiate the 'immediate actions' in the 'Jobs and Skills Summit September 2022 Outcomes' document specific to children and young people with disability

Recommendation

CYDA urges the Australian Government to consider and act on broader issues from the recent [Jobs and Skills Summit](#). The outcomes document included "*Put in place a Carer Friendly Workplace Framework which includes a self-assessment tool and learning modules, for businesses to be recognised as a carer friendly workplace*".¹ Any additional workplace frameworks and training need to be coupled with action on the government and social systems that also impact 'carer friendly' employment options.

"Carer friendly workplaces" are one important aspect of combining work and care and frameworks and accreditation programs do currently exist ([example from Carers NSW](#)) to support this outcome. To improve the lives of children and young people, their families and caregivers need to be better supported to navigate the systems and services that play a critical role in development across the lifespan. Core systems including health, education, social services and housing are often complex and hard to navigate for those under time and financial pressure to combine work and care.

CYDA notes that the [Carer Recognition Act 2010](#) does not include mention of the policies, practices and support services that are needed to support the combination of work and care, nor any process of evaluation or improvement. Each workplace or employer is expected to follow the minimum expectations of the [National Employment Standards](#) in respect of paid and unpaid carer leave. Employees and employers are then required to navigate guidance and or awards on [flexible](#)

⁷ Green, C., Carey, G., & Dickinson, H. (2021). *Barriers and enablers in the development of a COVID-19 policy response for people with disability in Australia*. Melbourne: Centre of Research Excellence in Disability and Health.

[working arrangements](#), to enact further work and care combinations. The current national network ([NDIS](#) and [Carer Gateway](#)) that provide information to families and caregivers do not have the mandate or remit to support individuals in advocating for changes with employers and are not supported to advocate for changes to systems across the Australian Government or state and territory based health or education places.

3. Protect children and young people from the developmental, social and economic scarring effects of the COVID-19 pandemic

Recommendation

CYDA urges the Australian Government to prioritise the development of a National Child and Youth COVID-19 Recovery Plan to mitigate adverse social and economic impacts. Specifically, CYDA endorses [UNICEF](#) AND [ARACY](#)'s *Kids at the Crossroads: Evidence and Policy to Mitigate the Effects of COVID-19* report that provides immediate and longer-term recommendations across six wellbeing domains ¹².

As the COVID pandemic advanced, children and young people's lives were turned upside down during pivotal developmental and life stages. Their learning and education was interrupted, they were socially isolated from their peers, incurred the stress of household economic pressures and were pushed out of employment.

As COVID restrictions were implemented, children and young people with disability, and other marginalised young people, faced additional challenges because of an inadequate government response. Research⁸ prepared for CYDA demonstrated that children and young people with disability were more at-risk during the global pandemic, not because of their impairment, but because of discriminatory, limited, or inappropriate policy strategies.

Comments from CYDA's community during early stages of the COVID-19 crisis (2020):

*"I am a disabled young person with no family support. I work as a freelancer because traditional employment is inaccessible. My work is being cancelled, but there's no support for dealing with this lost income because freelancers don't have anywhere to get sick pay, and we're falling through the cracks."*⁹

*"As a student with a highly modified program there has been no attempt by the school to make learning accessible. While I am capable of developing a suitable program the majority of parents at our school with students requiring adjustments are not. I worry about the effect the break in these students learning that this will cause'."*¹⁰

A joint report authored by UNICEF and the Australian Research Alliance for Children and Youth (ARACY) has found that not only have existing inequities for some groups of children and young people been further entrenched throughout COVID-19 disruptions, but without intervention, children and young people will feel the impacts for their lifetime as disadvantages will continue to be widened.¹¹

⁸ Dickinson, H., & Yates, S. (2020). *More than isolated: The experience of children and young people with disability and their families during the COVID-19 pandemic*. Available at [covid_report_compressed_1.pdf \(cyda.org.au\)](#)

⁹ *ibid.*

¹⁰ *ibid.*

¹¹ Harris, D., Seriamlu, S. Dakin, P. & Sollis, K. (2021). *Kids at the Crossroads: Evidence and Policy to Mitigate the Effects of COVID-19*. ARACY. Available at [Kids-at-The-Crossroads-UNICEF-Australia-ARACY.pdf](#)

Reform systems that directly support and involve children and young people to enable families and caregivers to combine work and care

4. Make early childhood education and care the first step of an inclusive life

Recommendations

CYDA urges the Australian Government to act promptly on the [Early Childhood Targeted Action Plan](#) as outlined in [Australia's Disability Strategy 2021-2031](#) including:

- Enable early identification of disability or developmental concerns and develop clearer pathways and timely access to appropriate supports
- Strengthen the capability and capacity of key services and systems to support parents and caregivers to make informed choices about their child
- Encourage a stronger sense of inclusion and provide opportunities for parents, carers and children to build peer networks, including for Aboriginal and Torres Strait Islander and culturally and linguistically diverse parents and caregivers.

CYDA calls on the Australian Government to give children their best start in life. Specifically, CYDA joins calls by [The Parenthood](#), [Thrive by Five](#), [Every Child](#) and the [Centre for Policy Development](#) for the Australian Government to ensure:

- Universal access to education and care – affordable, high quality, inclusive and easy to access
- Simplification and coordination of the currently confusing and expensive array of services and schemes
- Data are collected and shared at all levels of government to improve evidence of the range and quality of early childhood services.¹³

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

Dependent on the support, engagement and experiences children and their families/caregivers and communities receive during early years, this life stage can bring both opportunity and risk.¹² Tragically, we know that many children are not able to access equitable or adequate support. Specifically, not every child currently has access to high quality, affordable and inclusive Early Childhood Education and Care and Outside School Hours Care. As result, more than one in five Australian children enter primary school 'developmentally vulnerable'.¹³ This is in addition to the children who already have a diagnosed disability.

Therefore, the Australian Government must invest in:

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

¹² Thrive by Five & The Minderoo Foundation. (2017). *Time to Act: Investing in our children and our future*. Available at [TB5 Time2Act 20170119_FNL_Digital-p.pdf \(minderoo.org\)](#)

¹³ Australian Early Development Census. *Australian Early Development Census National Report 2018: A Snapshot of Early Childhood Development in Australia*. Department of Education and Training. Available at [AEDC 2018 National Report.pdf](#)

Too many do not meet National Quality Standard (NQS). According to National Quality Framework Snapshot June 2020, 17.7 per cent of centres did not meet the NQS, rising to 18.4 per cent for long day care (excluding preschools).¹⁴

Affordability: Australia's early learning centres are also some of the most expensive in the Organisation for Economic Co-operation and Development (OECD). According to the *Household, Income and Labour Dynamics in Australia (HILDA)* Survey, approximately 27 per cent of household income is absorbed by childcare.¹⁵ These costs have more than doubled since 2002.¹⁶

Inclusion: The COVID-19 pandemic has exposed the fragilities and inequalities in a range of service systems for children with disability and their families.¹⁷ [Australia's Disability Strategy](#) recognises that high quality early childhood education sets children up with the foundations for success and that inclusion must begin from the earliest ages with a focus on access and participation of all children in early childhood education and care.¹⁸

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

5. Protect the educational rights of children and young people

Recommendation

CYDA urges the Australian Government to fund and implement a body with independent oversight to ensure that education providers – in early childhood, school, post-school and adult education settings – are meeting their legal obligations and complaints can be independently investigated, monitored and resolved.

The [Disability Standards for Education](#) (DSE) have been in place for 17 years and the [Disability Discrimination Act](#) (DDA) since 1992. Neither the DDA, the DSE or any state or territory based polices ensure an equitable and quality education for students with disability.

As children with disability begin their 13-year school journey, families and caregivers need greater access to advocacy outside of the NDIS, including individual advocacy for families and young people with disability. Further investment from the Australian Government for independent disability advocacy will ensure students have their rights to inclusive education upheld and families/caregivers can more successfully manage the work and care balance with the time they previously spent on advocacy.

¹⁴ Australian Children's Education and Care Quality Authority. (2020). *NQF Snapshot: Q2 2020*. Available at [NQF Snapshot Q2 2020.pdf \(acecqa.gov.au\)](#)

¹⁵ Ruppner, L. (2019). *HILDA findings on Australian families' experience of childcare should be a call-to-arms for government*. Available at [HILDA findings on Australian families' experience of childcare should be a call-to-arms for government \(unimelb.edu.au\)](#)

¹⁶ *ibid.*

¹⁷ Dickinson, H., Yates, S. (2020). *More than isolated: The experience of children and young people with disability and their families during the COVID-19 pandemic*. Report prepared for Children and Young People with Disability Australia (CYDA), Melbourne

¹⁸ Commonwealth of Australia. (2021). [Australia's Disability Strategy 2021-2031](#)

Applying to each jurisdiction, the *Disability Discrimination Act* (DDA) and the Disability Standards for Education (DSE) are intended to protect students with disability from discrimination in education settings. More specifically, the DSE clarify and set out the obligations of educational authorities, institutions and providers under the DDA.¹⁹ These obligations include, but are not limited to, enrolment, participation, curriculum development and student support services.²⁰

Despite the presence of these protections, we know from our community that providers and institutions often do not meet their obligations and students' education rights are unlawfully withheld. Students are being denied enrolment and not being provided necessary and reasonable adjustments that support them to participate in their education on an equal basis as their peers.

“Basically, I got told I could take extra time in an assignment, and that’s the only accommodation ... Extra time seemed like such a Band-Aid measure, to say, ‘OK, we’re not prepared to do anything to make this less inaccessible for you. So, we’re going to keep it being inaccessible, but give you more time to try and account for that.’ When, obviously, the damage that inaccessibility causes is untold, and that cannot possibly be done if they gave me all the time in the world.”

— Young person (2021)

In October 2020, the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (Disability Royal Commission) held a public hearing on the barriers experienced by students with disability ‘in accessing and obtaining a safe, quality and inclusive school education and consequent life course impacts.’ Many children and young people, families and caregivers, and organisations advocates – including CYDA – gave evidence of instances where student’s rights were not upheld. In the subsequent Commissioner’s report, it was concluded that:

“Existing laws and policies governing enrolment of students with disability, reasonable adjustments, the use of exclusionary discipline and restraints do not impose sufficient oversight of the practices employed in schools. As a consequence it can be difficult to hold educators accountable for their decisions and ensure they meet the obligations set out under the DDA.”²¹

Further, the Commissioner’s report commented that “Regulations must be accompanied by oversight mechanisms if they are to be effective. These mechanisms include independent complaints processes and data collection and analysis.”²²

¹⁹ Murray, S. (2021). *Legislation and Regulation in Australia: Children and young people with disability in primary and secondary education settings*. Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability.
²⁰ *ibid.*

²¹ Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. (2021). *Barriers experienced by students with disability in accessing and obtaining a safe, quality and inclusive school education and consequent life course impacts*. Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, p. 34.

²² *ibid.*, p. 44.

6. Provide early support pathways and proportionate access to the NDIS to ensure equity for children and young people

Recommendation

The Australian Government must guarantee ongoing and sufficient funding of the NDIS so children and young people have equitable opportunities and the insurance principle of investing early to enhance lifelong outcomes will not be undermined.

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.

Children and young people make up more than half (58 per cent) of all National Disability Insurance Scheme (NDIS) participants.²³ While acknowledging that the world-first and still relatively new Scheme has many areas for ongoing development improvement, we hear from our community that when the NDIS is good – it's great. It has allowed many children and young people to access supports they need to participate in activities and communities in line with their interests and aspirations.

Comments from young people within the CYDA community (2020):

“Having easy access to supports and the technology and equipment you need is really important. I think things have improved with the NDIS and I hope they improve further.”

“I also found that since I joined the NDIS, having support workers is really healthy. My parents wouldn't always listen to me ... so having support workers helped me gain independence.”

Knowing the immense value of the NDIS, the public and political debate around its ongoing funding has been incredibly distressing for the disability community. Leaked documents from the NDIA, use of cost-cutting taskforces, forceful attempts to introduce discriminatory and inappropriate access requirements, and cases of reducing individual's plans without notice or explanation, have all contributed to a feeling of distrust and unease around intentions for the future of the NDIS.

CYDA share these concerns. We are particularly concerned that access to the NDIS will be restricted, and children and young people's plans will be reduced during crucial development and life stages. Mainstream services do not currently provide inclusive, safe and adequate support for people with disability. Without the NDIS, many children and young people's quality of life will be impacted, and they be left without the supports they need to flourish in their education, employment and social lives.

The NDIS has reached a critical juncture in meeting the needs of children and young people. Since first being legislated in 2013, many adults with disability have now had opportunity to access the NDIS. It is time for the focus to shift toward new entrants into the scheme and fully establish an early childhood approach with clear and simplified access to the NDIS. It is integral that children have access to timely support during early development stages.

²³ As at June 2022; NDIA. (2022). *Explore data*. Available at <https://data.ndis.gov.au/explore-data>

Context for CYDA’s recommendations

On a daily basis, children and young people with disability and their families and caregivers, navigate a complex, fragmented and sometimes competing service and policy environment. In this section we provide insight into some of the structural and systemic issues that are preventing necessary reform and entrenching disadvantage. We have also included references to more detailed work on these topics to enable members of the Inquiry to explore as needed.

Data and terminology

Families and caregivers of children and young people with disability juggle caring responsibilities and, like other Australians, a multitude of other responsibilities – raising children, working, and earning enough to feed, house and keep themselves and loved ones safe. In this section, we have provided an overview of terms used (and navigated by families) and some of the data available.

a) Navigating terminology

Care & attention

The Australian Government Social Security Guide uses the term care and attention as the act of a carer providing at least some additional care and attention to a person because of a disability or severe medical condition that would not be required if they did not have a disability.²⁴

Impact: The lived experience of care and attention is not limited to the definition of policy or programs and many families and young people provide feedback to CYDA that the pressures of meeting tight definitions and entry requirements takes time away from work, family and other responsibilities.

Informal and formal supports

The National Disability Insurance Scheme explains formal supports as supports participants have to book and pay for and informal supports as the supports participants get from the people around them, for example family, friends, neighbours²⁵.

Impact: On 30 June 2022, there were 309,899 participants of the NDIS aged 0-24²⁶. The 2018 ABS Survey of Disability, Ageing and Carers showed an estimate of 647,600 0–24-year-olds with reported disability²⁷. More than 300,000 children and young people with disability have families and caregivers who navigate caregiving with no paid supports or services available via a NDIS plan. “...under the current eligibility requirements of the NDIS, only 10% of the total population of people with disability in Australia can access the scheme.”²⁸ Families and caregivers explain to CYDA that wait times to access the NDIS are stressful and once a plan is provided, finding suitable supports and services is also a further consideration.

²⁴ Australian Government. (2022). *Guides to Social Policy Law*. Social Security Guide Version 1.297 - Released 15 August 2022. Available at: <https://guides.dss.gov.au/social-security-guide/1/1>

²⁵ National Disability Insurance Agency. (2022). *NDIS Glossary*. Available at: <https://www.ndis.gov.au/about-us/glossary#>

²⁶ NDIS. (2022). *Participant Data*. Available at: <https://data.ndis.gov.au/explore-data>

²⁷ Australian Bureau of Statistics, (2018). *Survey of Disability, Ageing and Carers*. Available at: <https://www.abs.gov.au/statistics/health/disability/disability-ageing-and-carers-australia-summary-findings/2018/44300do010.xls> Table 3.1

²⁸ Fisher, RK. (2019). *Understanding the NDIS: many eligible people with disabilities are likely to miss out*. The Conversation.

Carer and caree

The Australian Government Social Security Guide define a caree as a person receiving a substantial level of care and a carer (care provider) as a person who is providing a substantial level of care to a caree.

Impact: Families and care models are dynamic and composed in various ways, changing over time as children and young people with disability change. Where programs and funding, supports and services are built around the notion of the one carer and one caree household, limitations are placed on the entire family system. For example, a family may share care responsibilities across grandparents, siblings, neighbours and paid supports during school term and may need to vary this approach during school holidays in the absence of accessible vacation care. Carer's allowance or payments are not flexible in this same way and vacation care and [Child Care Subsidy](#), is connected to the child and family, rather than other informal supports. Ultimately families are balancing job security, caring responsibilities and family dynamics across multiple systems – education, health, NDIS, etc with no support to navigate those systems or maintain the capacity of informal supports.

b) Improving data collection and information sharing

Efficient and effective data collection is a key policy priority for CYDA, and it is essential for improving outcomes for Australia's children and young people with disability. As a representative organisation, we use multiple avenues to understand the experiences of children and young people so we can best provide an informed voice on the social issues important to them. One of these avenues is the use of desk top research methods to gather data. However, often CYDA is unable to ascertain information specific to children and young people with disability because many data sets are aggregated at a more macro level, lacking the granularity needed to understand children and young people with disability. As noted in Australia's Disability Strategy 2021–2031, a range of stakeholders need to "...work together to develop a comprehensive data strategy in 2022. This will ensure data needed to measure outcomes for people with disability is collected, shared and progressively improved".²⁹

Impact: Without high-quality data, there are limited opportunities to develop evidence-based approaches to protect children and young people and monitor existing and new interventions.³⁰ CYDA has found that data collection in general for children and young people with disability across the systems they interact with is also inadequate or not collected comprehensively.

c) Work, care and disability

According to the Productivity Commission, not only is paid employment a source of income that provides access to resources for families and caregivers, but stable employment can provide the financial security, confidence and socialisation that allows families to maximise opportunities for their children to gain higher levels of educational attainment and earning capacity in the future³¹.

Impact: "My partner works in what could be described as a male dominated profession and the idea that he would take leave (paid or unpaid) to support the care of our child has been met with laughter, derision and refusal. His current employer is unaware of our child's disability because he found people did not understand our situation and it was easier that way."

²⁹ Commonwealth of Australia (Department of Social Services). (2021). *Australia's Disability Strategy 2021-2031*. Available at: <https://www.disabilitygateway.gov.au/document/3106>

³⁰ 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)

³¹ Productivity Commission. (2018). *Rising Inequality? A stocktake of the evidence*. Available at: <https://www.pc.gov.au/research/completed/rising-inequality/rising-inequality.pdf>

d) Work, care, disability and gender

CYDA notes that it is difficult to discuss work, care and disability in Australia without exploring the dimensions of gender. Although young males are more likely to have a need for assistance than young females in the first half of the lifespan, particularly between the ages of 5-24 years³², it is girls and women who are disproportionately impacted by caregiver responsibilities and the flow on lack of economic opportunities³³.

As of 2020, there were 2.8 million people providing unpaid care in Australia with 57% of these people being women³⁴. Economic modelling has shown that the cost of replacing the 2.2 billion hours of informal care in Australia each year would be \$77.7 billion³⁵. By providing the majority of unpaid care, women participate less in paid employment, are less likely to take on professional development opportunities, and more likely to experience discrimination, need to take leave, and have to stop work all together³⁶.

Women and girls are also more likely to spend significant amounts of time having their disability unrecognised or misdiagnosed, leading to inadequate and inappropriate services³⁷. Moreover, the stigma and discrimination that occurs in relation to their intersectional identities, is also more likely to disproportionately marginalise them compared to their male counterparts. For instance, only 37% of NDIS participants are women and this number is far less when looking at indigenous, culturally and linguistically diverse, geographical remoteness, or LGBTIQ+ identity³⁸

Impact: As outlined by Women with Disabilities Australia in their 2022 Election Platform, “...*Australian legislative and policy frameworks consistently fail to apply a gender lens. Similarly, gender related policies, programs and services consistently fail to apply an appropriate disability lens.*”³⁹

e) Work, care, disability and educational participation

In 2021, those aged three years and over, with a need for assistance were less likely to be attending an educational institution than those without a need for assistance (14.9% compared with 27.5%), with some notable differences across age groups. Children and young people with disability in Australia are increasingly likely to be home educated by families and caregivers (predominantly women), the majority of whom receive no financial assistance and reported significant income losses⁴⁰.

³² Australian Bureau of Statistics, (2022), *Profile of people with a core need for assistance in Australia Information on need for assistance, Disability and carers: Census, 2021*

Available at: <https://www.abs.gov.au/articles/profile-people-core-need-assistance-australia>

³³ Australian Government. (2022). *Gender equality and caring*. Available at: <https://www.wgea.gov.au/gender-equality-and-caring>

³⁴ Deloitte. (2020). *The Value of Informal Care*. Available at: <https://www2.deloitte.com/content/dam/Deloitte/au/Documents/Economics/deloitte-au-dae-value-of-informal-care-310820.pdf>

³⁵ Ibid

³⁶ Australian Government. (2022). *Gender equality and caring*. Available at: <https://www.wgea.gov.au/gender-equality-and-caring>

³⁷ Yates Et. Al. (2021). *Women's experiences of accessing individualized disability supports: gender inequality and Australia's National Disability Insurance Scheme*. International Journal for Equity in Health. Available at: <https://equityhealth.biomedcentral.com/articles/10.1186/s12939-021-01571-7>

³⁸ National Women's Alliances and Disabled People's Organisations Australia. (2019). *The Status of Women and Girls with Disability in Australia*. Available at: <https://wwda.org.au/wp-content/uploads/2020/06/The-Status-of-Women-and-Girls-with-Disability-Asutralia.pdf>

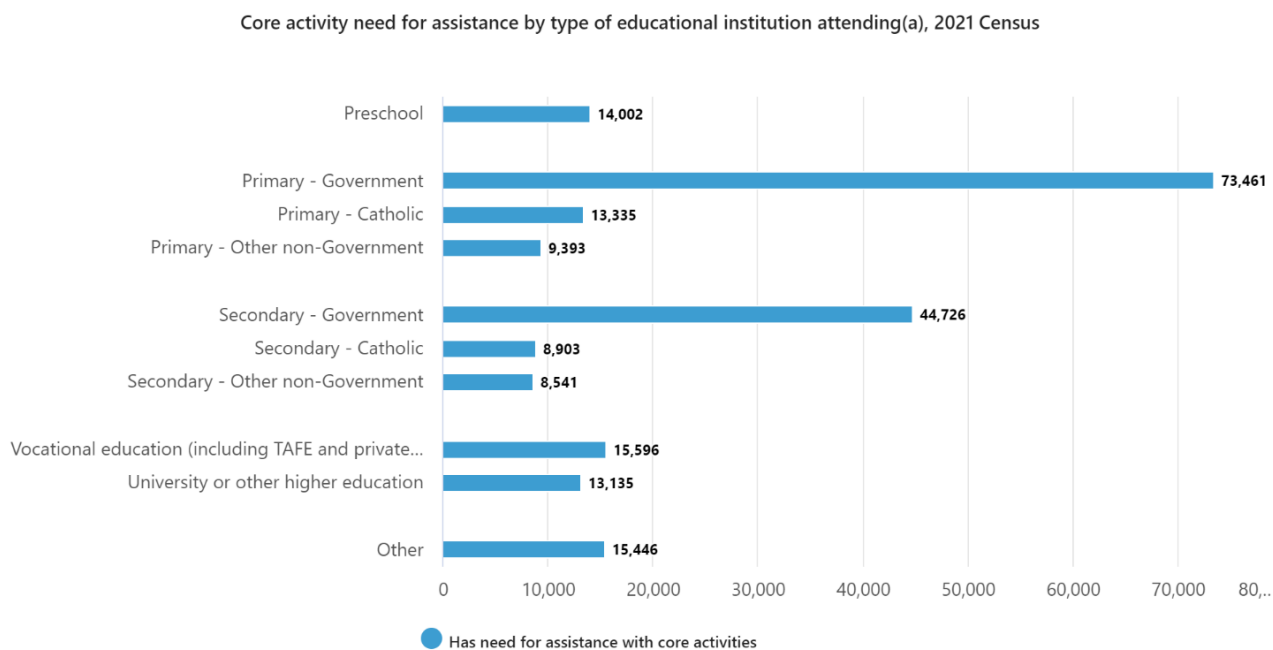
³⁹ Women with Disabilities Australia. (2022). *WWDA's Federal Election Platform 2022*. Available at: <https://wwda.org.au/publication/wwda-election-platform-2022/>

⁴⁰ Slater Et. Al. (2022). *Reasons for home educating in Australia: who and why?*. Educational Review. Available at: <https://www.tandfonline.com/doi/full/10.1080/00131911.2020.1728232>

According to census data from 2021, government funded primary schools far exceeded other educational settings in terms of numbers of individuals requiring assistance (see Figure 1 below)⁴¹.

Impact: Children and young people experience compounded disadvantage in that many educational institutions are not fulfilling the requirements of the Disability Discrimination Act 1992, and the Disability Standards for Education 2005, to support people with disability⁴², and consequently their families and caregivers economically disadvantaged by the time taken out of employment to fill these gaps.

Figure 1 Core activity need for assistance by type of educational institution attending



(a) Based on place of usual residence. Count of person attending an education institution who require a need for assistance with core activities. Excludes overseas visitors. Source: Core activity need for assistance (ASSNP), Type of educational institution attending (TYPP)

Source: Australian Bureau of Statistics, Disability and carers: Census 2021

f) Work, care, disability and health

The 2020 report prepared by Deloitte Access Economics, *The Value of Informal Care in 2020*⁴³, highlighted that the ABS Survey of Disability, Ageing and Carers (SDAC) reported on core activities (mobility, self-care or communication) or non-core activities (such as health care, household chores and meal preparation), but only those hours spent caring above that which would be regularly required are included.

The SDAC also identified that approximately 141,000 people aged 5-24 years old, with ‘a profound or severe core activity limitation’, needed assistance with health care (compared to 227,036 in NDIS participants of the same groups⁴⁴).

⁴¹ Australian Bureau of Statistics, (2021), Disability and carers: Census, *Information on core activity need for assistance* Available at: <https://www.abs.gov.au/statistics/health/disability/disability-and-carers-census/2021>

⁴² De Bruin. (2020). *Disability royal commission: People living with disability paint a bleak picture of education exclusion and neglect*. Monash University. Available at: <https://lens.monash.edu/@education/2020/10/21/1381561/education-failing-people-with-disability>

⁴³ Deloitte Access Economics. (2020). *The value of informal care in 2020*. For Carers Australia. Available at: https://www.carersaustralia.com.au/wp-content/uploads/2020/07/FINAL-Value-of-Informal-Care-22-May-2020_No-CIC.pdf

⁴⁴ NDIS. (2022). *Participant Data*. Available at: <https://data.ndis.gov.au/explore-data>

Impact: “Before children I worked in a profession that had to account for time spent in 6-minute increments, 5 days a week, 48 weeks a year, for 16 years. If I look at my child’s time spent in hospitals receiving emergency or planned healthcare or seeing a doctor, I know that the time spent booking, navigating forms, confirming appointments, organising referrals, sharing information readily available in a system I can’t access, following up doctors for information needed by another doctor, making claims for reimbursement from two separate systems, explaining my child’s pre-existing conditions noted in the file in front of the doctor, and answering questions about services and supports the child is entitled to, was greater than the time spent receiving care. **Navigating the systems is harder than navigating the disability of my child.**”

g) [Work, care and the ‘polished pathway’](#)

Systems that families and caregivers navigate in the early years of a child’s life can be difficult and families tell CYDA that they never really understand the impact of decisions they make so early in their child’s life. The most obvious of these is the education choices they make on behalf of their child.

The polished pathway refers to the experiences of young people with disability in employment, education, and housing and how these experiences have the potential to impact their own, and their family’s ability to participate in paid employment.

*“The polished pathway refers to the way people with an intellectual disability face significantly fewer barriers to segregated environments, including education, housing and employment.... At each stage in the life of a person with an intellectual disability, the barriers to an included life must be removed. There are a number of key points on a student’s journey where families face difficult decisions about education and are often pushed towards more segregated options. There is a lack of independent information, advocacy and support for students with an intellectual disability and families.”*⁴⁵

Inclusion Australia explains:

“At each part of the lives of people with an intellectual disability, family, friends and supports play a pivotal role in diverting them from the polished pathway into segregated employment. They are a crucial factor in whether a person with intellectual disability will enter open or self-employment. But they need more information about what is possible and access to peer expertise. To sustain both open and self-employment, support from family, friends and supporters is essential and is needed long term. But currently, very little resourcing exists that focuses on this sustainability of informal supports”⁴⁶

Impact: More independent information is needed, accompanied by individual advocacy support, to ensure that families and caregivers of young children with disability are offered inclusive opportunities additional to those represented on the polished pathway.

Ableism and societal beliefs

⁴⁵ The experience of children and young people with disability in different education settings, Inclusion Australia position paper for Disability Royal Commission Public Hearing 24: June 6-10, 2022 <https://www.inclusionaustralia.org.au/wp-content/uploads/2022/06/Inclusive-education-for-students-with-an-intellectual-disability-IA-Position-Paper.pdf>

⁴⁶ Inclusion Australia. (2022). *DES Reform submission*, https://www.inclusionaustralia.org.au/wp-content/uploads/2022/02/Our-Submissions_2022_02_Submission-on-Disability-Employment-System-Reform.pdf

h) Explaining ableism

Ableism is a term increasingly used to describe the process by which people are excluded, viewed and treated as 'not one of us'. Ableism is used in the same way as 'racism' and 'sexism' to describe the process of negatively stereotyping individuals or groups on the basis of a perceived 'difference' and, often, discriminating based on such stereotypes at individual and systemic levels.⁴⁷

The Early Years Catalyst initiative reported as recently as August 2022, young children and their families, face embedded narratives and deep systemic forces. CYDA believes the following are particularly relevant to the Select Committee's work:⁴⁸

- Deeply held societal beliefs including:
 - We are a society that is prepared to live with poverty
 - Families are a no-go zone
 - Parenting comes naturally
 - What's not normal is 'other' (the exception)
 - There are good mothers and bad mothers
- Care logic including:
 - Care (being human) is a burden on society (read economy)
 - Care is women's work / belongs in the shadows
 - Erosion of the village
 - Reductionism more powerful than care, connection & trust

i) Impact on early development and care

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

- Societal fear, aversion to disability and poverty
- Disability, disadvantage is your problem not ours
- Govt policies / programs are designed for the majority not the exception
- Systems reward normal and punish those who don't fit the "norm"
- Loss of benefits, tax rates, childcare costs etc makes it unaffordable to work, incentivises poverty
- Something wrong with parents that produce a child with disability or special needs
- Wider society/voters don't care if something is unfair if they are 'the other'
- We like to think Aussies are all equal – evidence to the contrary makes us uncomfortable
- We support inclusion until it challenges our views of ourselves
- They don't need same standard of support as a normal person- should be grateful for what they get
- Poor people, disabled people are not normal or mainstream or common
- Inequity and disadvantage are held in place

Impact: Fundamentally, ableism – the discriminatory and damaging attitudes, both historical and current, held by society – are at the core of violence and abuse against people with disability.

⁴⁷ Cologon, K. (2019) *Towards inclusive education: A necessary process of transformation*. Report written by Dr Kathy Cologon, Macquarie University for Children and Young People with Disability Australia (CYDA)

<https://www.cyda.org.au/resources/details/62/towards-inclusive-education-a-necessary-process-of-transformation>

⁴⁸ Fiona McKenzie and Eve Millar, 2022. Mapping the systems that influence early childhood development outcomes. Prepared by Orange Compass for the Early Years Catalyst, August 2022. <https://www.earlyyearsatalyst.org.au/field-insights/>

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

From the way we colloquially speak about disability, to the way disability is considered and represented in policy and law-making, pervasive ableist norms create a cultural acceptance of the abuse, neglect, and mistreatment of people with disability. As such, primary prevention mechanisms that create long-term community attitude change around ableism and promote understanding and respect for all people with disability, including children and young people, are crucial. The focus of Australia's Disability Strategy 2021–2031 goes some way to addressing the impact of ableism on children and young people with disability but does not specifically address the issues raised in this submission.

The policy setting in Australia

j) Human rights

As CYDA provides recommendations in submissions such as this, we ground our work in evidence and a human rights approach. This includes the impact of families and caregivers combining work and care on children and young people with disability. There are a range of international instruments that establish normative standards and principles for the treatment of children and young people with disability, including:

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

All children or young people are more than their disability, their education and more than their health. Consistent with the United Nations Convention on the Rights of the Child⁴⁹, and the CPRD, Australian children and young people with disability should feel:

- Healthy
- Safe
- Connected
- Supported
- Challenged
- Engaged

⁴⁹ Convention on the Rights of the Child, adopted and opened for signature, ratification and accession by General Assembly resolution 44/25 of 20 November 1989 entry into force 2 September 1990, in accordance with article 49, <https://www.unicef.org/child-rights-convention/convention-text>

k) Australia's Disability Strategy 2021-2031

Australia's Disability Strategy 2021–2031 is a whole-of-community response, including business, non-government and services sectors, and individuals to ensure people with disability can participate as equal members of society.

As outlined in the introductory sections of this submission, inclusive participation for children and young people with disability in services and systems is a prerequisite to the long-term wellbeing of the entire family. Put simply, families and caregivers are compromised in their ability to maintain stable paid employment when they are using their time, intellectual and emotional resources to fill the gaps left by our major public services which were designed to prevent vulnerability – health, welfare, education, disability insurance and support, and housing.

The targeted action plans contained within the strategy contain important pathways for programs and funding to deliver the objectives contained within the seven outcomes areas:

- Employment and Financial Security
- Inclusive Homes and Communities
- Safety, Rights and Justice
- Personal and Community Support
- Education and Learning
- Health and Wellbeing
- Community Attitudes

Given the clear intersectionality between many of the key issues and challenges faced by children and young people with disability, CYDA strongly urges the Select Committee For Work and Care to consider the outcome areas in the strategy to guide policy and program design in creating better outcomes for combining work and care. One area of focus may be outcome area of '*personal and community support*', policy priority 3: "*The role of informal support is acknowledged and supported*".⁵⁰

l) COVID-19 policy responses⁵¹

The COVID-19 global pandemic has had a significant impact on all Australians, but there are very good reasons why the impact might be more keenly felt by people with disability and their caregivers. People across Australia have experienced work and income disruption, supply shortages and educational difficulties. However, all of these disruptions are exacerbated for children and young people with disability and their families.

Many of those who care for children and young people with disability are constantly beset by difficult decisions and precariously balancing work, play, care and education to provide the best possible lives for those under their care. Many people can only manage these things when the world is operating as it normally does – but this global pandemic (especially when immediately preceded by bushfires and subsequent floods) has thrown these precariously balanced routines off to such a degree that families are struggling to cope.

The lives of children and young people were thrown into turmoil throughout the period. This group already face multiple barriers and difficulties in accessing inclusive education, support for reasonable

⁵⁰ Commonwealth of Australia (Department of Social Services). (2021). *Australia's Disability Strategy 2021-2031*.

Available at: <https://www.disabilitygateway.gov.au/document/3106>

⁵¹ Dickinson, H., Yates, S. (2020). *More than isolated: the experience of children and young people with disability and their families during the COVID-19 pandemic*. Report prepared for Children and Young People with Disability Australia (CYDA), Melbourne.

adjustments and the same curriculum as their non-disabled peers, placing enormous pressure on them, and their families during this time.

However, these issues will not simply be solved by providing more evidence or better targeted evidence. The main message of this submission is that urgent action is needed to attend to the many inequities that people with disability and their families and caregivers face on a daily basis. Without movement on these issues, any future widespread emergencies will again produce substantial destabilisation for these households, with similarly detrimental impacts.

Children and young people with disability have been largely forgotten in government responses during the height of the COVID-19 pandemic in Australia. In our recent policy work we highlighted how Australia lacked a coherent national information strategy and response for children and young people with disability, creating and exacerbating feelings of uncertainty and distress.

Our policy work also demonstrates the inadequacy of targeted responses for children and young people with disability spanning vaccinations, education, support services and a range of other impacts.

CYDA's COVID-19 work:

- [Response](#) to the Disability Royal Commission's Omicron issues paper (2022)
- [Co-signatories on the Disability sector Omicron statement of concern](#) (2022)
- [Locked out: Vaccination discrimination for children and young people with disability](#) (2021)
- [Submission to the Disability Royal Commission: Emergency Planning and Response during COVID-19](#) (2020)
- [Not even remotely fair: Experiences of students with disability during COVID-19](#) (2020)
- [CYDA CEO, Mary Sayers Disability Royal Commission witness statement](#) (2020)
- [More than isolated: The experience of children and young people with disability and their families during the COVID-19 pandemic](#) (2020)
- [Co-signatories on Open letter to National Cabinet Immediate Actions Required for Australians with Disability in Response to Coronavirus \(COVID19\)](#) (2020)

m) Children and young people with disability as stakeholders

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.

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

At a glance we know:

- Nearly half of all young people with disability are unemployed or underemployed⁵²

⁵² 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>

- Students with disability leave school before the age of 16 at a rate nearly three times higher than that of their non-disabled counterparts⁵³ and are less likely to complete year 12 or attain a tertiary education, such as a gaining a bachelor's degree or higher⁵⁴
- 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 peers⁵⁵
- 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 disability⁵⁶
- Compared to their peers, children with disability are⁵⁷:
 - 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.

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, to name a few. This means that children and young people's voices need to be heard through participatory processes across a wide range of policy areas, and reform is needed to ensure all our service systems are accessible and inclusive for all our children.

The stakeholders, influencers and advocates:

⁵³ 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>

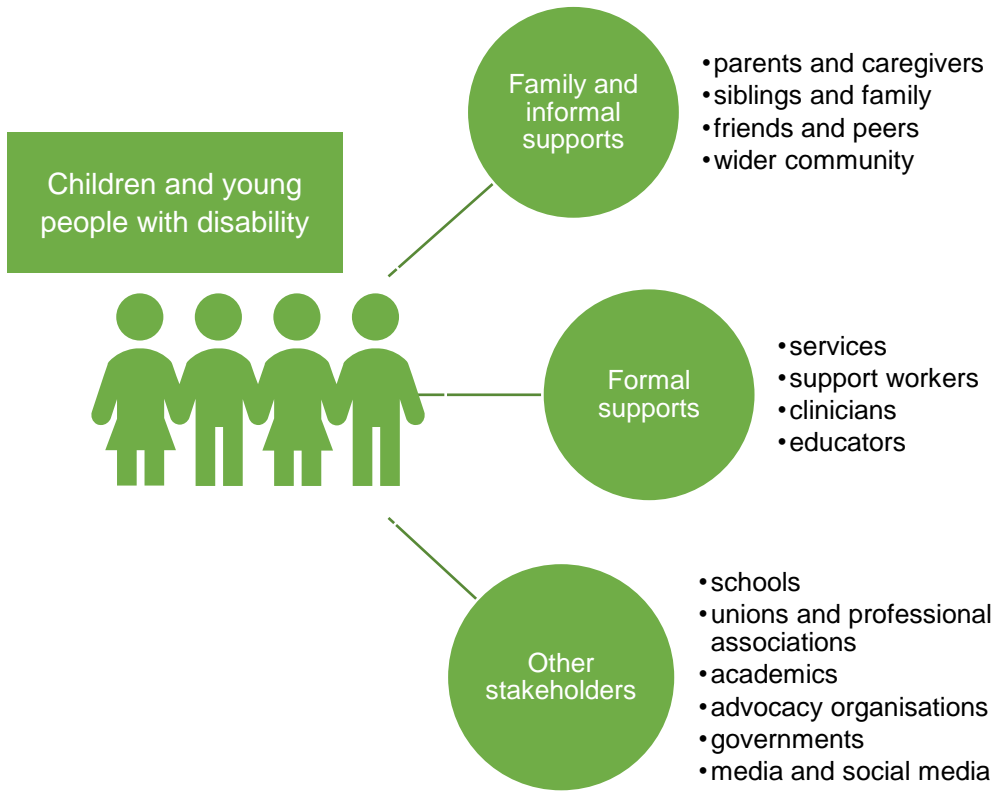
⁵⁴ AIHW. (2020). *People with disability in Australia*. Available at <https://www.aihw.gov.au/reports/disability/people-with-disability-in-australia/contents/education-and-skills/educational-attainment>

⁵⁵ 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>

⁵⁶ AIHW. (2019). *People with disability in Australia: In brief*. Available at [People with disability in Australia 2019: in brief \(Full publication:21Aug2019Edition\)\(AIHW\)](#)

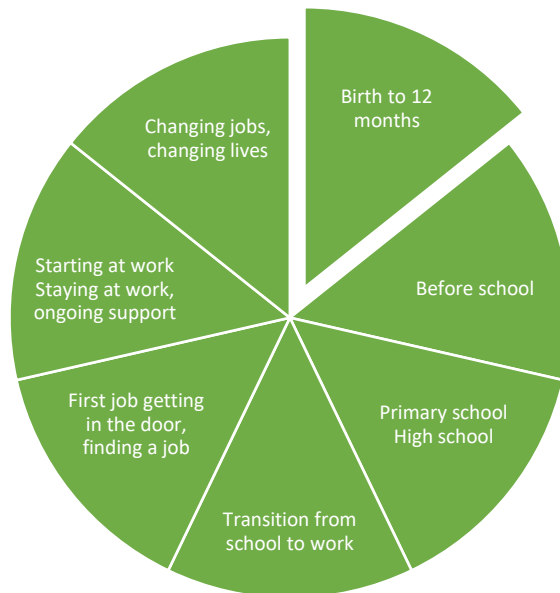
⁵⁷ Wayland, S & Hindmarsh, G. (2017). *Understanding safeguarding practices for children with disability when engaging with organisations*. Available at [Understanding safeguarding practices for children with disability when engaging with organisations | Child Family Community Australia \(aifs.gov.au\)](#)

Figure 2 The stakeholders, influencers and advocates that help support the child's experience of life



n) Agency and voice for children and young people

Figure 3 Stages of life⁵⁸



⁵⁸ Adapted from Inclusion Australia, 2022, DES Reform submission, https://www.inclusionaustralia.org.au/wp-content/uploads/2022/02/Our-Submissions_2022_02_Submission-on-Disability-Employment-System-Reform.pdf

Over the different stages of life depicted above, children and young people with disability are beholden to the adults in their lives to advocate for their best interests. Children and young people being front and centre in the decisions that affect them is a key priority for CYDA and is built into our strategic plan. Our ideal future is one in which children and young people are recognised as the agents and experts in their life, making informed decisions as they grow; are included in ways that are meaningful to them; and have their human rights upheld.

A report CYDA commissioned in 2014 showed that:

“Participation by children and young people in advocacy and change-making can not only improve and foster positive change in their own lives, but also influence the lives of others. When young people’s participation is supported, meaningful and engaged, multiple benefits accrue. Their perspectives and experiences bring a unique contribution and can result in rights-based empowerment, enacted citizenship and improved relationships. This has the potential to shape policy, to increase the relevance and responsiveness of organisations they use, and to influence change in their communities in positive ways.”⁵⁹

Participation can occur at different levels, including at a:

- Local/individual level: such as decision making and influencing change for daily living.
- Structural level: influencing change in systems, such as within education and community.
- Systemic level: influencing change at a society/policy level.⁶⁰

The report provided evidence on the many benefits stemming from the inclusion of children and young people with disability in participatory activities. These include individual benefits for young people themselves, benefits for the organisations they are involved with, for informing policy, and systemic benefits for wider communities. However, the report noted:

“There are a range of barriers that discourage, prevent or actively exclude children and young people from participating. Some of these are social and cultural barriers, such as attitudes and low expectations. Others are practical — participation processes which limit the depth and involvement of children and young people’s influence, such as one-off, adult-led consultations. These barriers to participation are magnified for children and young people with disability, particularly younger children and those with higher or more complex support needs.”⁶¹

Young people with disability rarely have opportunities to meaningfully engage with government policy development processes or consultation; and there is a long way to go to ensure these processes are genuinely inclusive and built on co-design principles.⁶² At the national level, policy impacting children and young people with disability sits across multiple policy portfolios, including:

⁵⁹ Simmons, C., Robinson, S. (2014) *Strengthening Participation of Children and Young People with Disability in Advocacy. Report prepared for Children and Young People with Disability Australia.*

<https://www.cyda.org.au/resources/details/86/strengthening-participation-of-children-and-young-people-with-disability-in-advocacy> p. 5

⁶⁰ Lord, J. E., Guernsey, K. N., Balfe, J. M., Karr, V. L., & deFranco, A. S. (2012). Human Rights. Yes! Action and Advocacy on the Rights of Persons with Disabilities. In N. Flowers (Ed.), Human Rights Education Series, Topic Book 6, 2nd Edition (2nd ed.). Minnesota: University of Minnesota Human Rights Center, BlueLaw International, LLP on behalf of One Billion Strong.

⁶¹ Simmons, C., Robinson, S. (2014), p. 33

⁶² “Co-design is a process used to create products, services and programs. It brings people in as ‘design partners’, giving a voice to those who are often excluded from the design process. Decision-making, design, information sharing and project planning are among the equal roles between trained designers and design partners.” See, Future Social Service Institute (2018), RMIT University, *What is Co-design?* <https://www.futuresocial.org/wp-content/uploads/2018/08/FSSI-CoDesign-one-pager.pdf>

- *Employment policy, services, income support* – Services Australia, Department of Social Services (DSS) and Department of Education, Skills and Employment (DESE)
- *Youth policy* – Department of Health
- *Disability services* – DSS and National Disability Insurance Agency (NDIA)
- *Abuse, neglect, child protection and juvenile justice* – DSS, NDIS Quality and Safeguards Commission, Attorney General's Department
- *First Nations policy and programming* – National Indigenous Australians Agency.

At the state and territory level there are also multiple departments and agencies, and again there is little opportunity and few formal structures for young people with disability and families and caregivers of young children to be involved. The machinery of government approaches to policy-making and program delivery for children and young people with disability create structural barriers meaning that governments generally have difficulty in holistically considering the needs of young people with disability and involving them in consultation and/or policy development.

Additionally, children and young people with disability often face barriers to participating in consultative process because of inaccessible processes (including inadequate information delivery, meeting structures, interpreters, assistive technology), and we have seen little evidence that government consultative processes are responding to these needs adequately. This concern was echoed in the Social Deck's recent consultation report to help shape the next National Disability Strategy, which confirmed young people 'do not find current mechanisms used by governments to engage on these issues appealing, suitable or easy to access'.⁶³

⁶³ 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