



Response to Australian Government Early Years Strategy Discussion Paper

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Introduction

Carers Australia welcomes the opportunity to provide input into the Discussion Paper for the Australian Government Early Years Strategy (the Strategy). Carers Australia mirrors the view of Minister Rishworth published within the [Discussion Paper](#), that “Every child deserves the opportunity for the best start to life; a chance to achieve their goals and dreams.” This strategy is of great importance not only to children and families around Australia, but also to the proportion of Australia’s 2.65 million carers¹ that provide care to children under 5 who are experiencing disability, developmental delay or showing signs of developmental delay.

As recognised within the Strategy’s Discussion Paper, the first five years are critical within the development of a child and the importance of positive experiences, relationships and environments during this time cannot be overstated. However, in order to provide these requirements carers and families must be given adequate support, specifically in the circumstances of disability or developmental delay.

Additionally, Carers Australia believes that the Strategy’s development and purpose should be viewed holistically. Enriching a child’s wellbeing, education, health, safety, and development throughout the early years are key for lifelong success, however this enrichment and support must be provided at every stage of their lives. Without this many Australian children will be set up for failure. The Early Years Strategy should be accompanied by commitments and actions to ensure that the systems and environments that children enter beyond age five, such as primary schooling and community activities, continue to provide support and guidance.

This submission will provide responses to all questions outlined within the Strategy Discussion Paper. We have focused on addressing ways in which the Strategy can better ensure that the needs of children with disability or developmental delay are met, and that carers are recognised and supported to meet the Strategy’s vision.

Questions

QUESTION 1. Do you have any comments on the proposed structure of the Strategy?

Carers Australia supports the proposed structure of the Strategy that is outlined within the Discussion Paper.

QUESTION 2. What vision should our nation have for Australia’s youngest children?

Carers Australia believes that the Early Years Strategy vision should recognise the rights and freedoms of Australia’s children, and that all Australian’s have a role in addressing the challenges and providing ongoing support in achieving the best outcomes for children in the early years and beyond.

We stress the importance of recognising that the early years are the start of a child’s development and this strategy, and any relevant policies or programs, must acknowledge that this Strategy is the first stage of a development. Children are deserving of support and access to opportunity during all stages.

This is especially relevant for young carers, of which there are approximately 235,000 aged 11-25 years in Australia², who are at risk of disengagement or who have disengaged from school or education

¹ Carers Australia uses the term ‘carer’ as defined by the Commonwealth Carer Recognition Act 2010 (the Act), where it should not be used broadly and without context to describe a paid care worker, volunteer, foster carer or a family member or friend who is not a carer. The terms ‘informal carer’, ‘unpaid carer’ or ‘family and friend carer’ are also often used by organisations, government and the community to describe a carer. Carers Australia may use these terms to assist in providing context and to differentiate between other types of care.

² A Report for Carers Australia, Caring Costs Us (2022), [accessed online](#)

opportunities due to caring responsibilities. Additionally, many young carers report³ a lack of sleep, ongoing stress and mental health issues which affects their motivation or ability to get up in the morning or go to school, and that their care responsibilities restrict their ability to achieve their potential, socialise with friends, participate in extra-curricular activities, and build a sense of belonging.

The long-term benefits of enrichment and support in the early years will only be achieved if the needs of children are met consistently. As such, the vision of the Strategy must acknowledge life after the early years.

QUESTION 3. What mix of outcomes are the most important to include in the Strategy?

Carers Australia supports the inclusion of example outcomes listed within the Discussion Paper. We believe that outcomes should align with international human rights frameworks including the [Declaration of the Rights of the Child](#) and the [Convention on the Rights of Persons with Disabilities](#). Outcomes should not only acknowledge an individual's rights of equality and non-discrimination, but must also recognise that some children, or groups of children, must be protected and supported in an equitable manner.

Outcomes should recognise that families and carers are primary partners in the delivery of this Strategy and as such, have a right to access support and resources to fulfil their role in childcare. Outcomes that reference this must recognise varying familial and care dynamics including **mentioning carers explicitly for the role they have in the provision of care, support and advocacy for children facing disadvantage due to disability or developmental delay.**

Furthermore, communities must be supported in the development and maintenance of child-safe and child-positive attitudes, behaviours and services; thus being standard setters in enabling ongoing support and guidance for future generations.

QUESTION 4. What specific areas/policy priorities should be included in the Strategy and why?

QUESTION 5. What could the Commonwealth do to improve outcomes for children—particularly those who are born or raised in more vulnerable and/or disadvantaged circumstances?

QUESTION 6. What areas do you think the Commonwealth could focus on to improve coordination and collaboration in developing policies for children and families?

Carers Australia agrees with the decision to include addressing and breaking down silos that exist within the coordination and delivery of services by the Australian Government, and that addressing this issue is a priority.

Additionally, **we recommend the inclusion of service and support provision, specifically those related to early childhood intervention, be considered as a priority.** Carers of children with complex needs have limited options when it comes to accessing childcare for young children, with many carers reporting not being able to access such services or have the option to return to work until their child enters the public school system. The Strategy Discussion Paper raises the importance of the first 1,000 days, and the consequences if a gap emerges and is not closed within the first 5 years of life. A lack of access for children with high care needs to childcare programs which support their development and individual needs, is such a gap.

³ Moore T et al (2019). 'No space in my brain to learn: Young carers and their engagement with education: an analysis of applications to the Carers Australia bursary program 2017-2018'. University of South Australia for Carers Australia [\[accessed online\]](#)

Furthermore, there are increasing issues regarding the cost, availability and accessibility of healthcare for children. Waitlists for pediatricians within the public health system are becoming increasingly significant, in some cases wait times are extending over 24 months for an initial appointment. Carers Australia has heard that some carers resort to obtaining a diagnosis for their child through the private system, the cost of which has been reported as up to \$5,000-\$6,000 just for diagnosis. Even for private pediatricians, waitlists can be long, and due to demand many pediatricians are either not accepting bookings, or only accepting restricted or condition-specific bookings.

In addition to the strain that carers face in navigating the healthcare system, they also deal with the subsequent stress to meet the complex needs of the child in their care until services can be accessed. For many carers the financial burden can be detrimental, with 2018 data indicating that primary carers were nearly twice as likely to be in the lowest income quintile than non-carers (14.5% compared to 8.3%) and half as likely to be in the highest income quintile (9.4% of carers compared to 18.1% of non-carers).⁴ They were also twice as likely to rely on a Government pension or allowance than non-carers. The 2022 Carer Wellbeing Survey found that, in the 12 months to March/April 2022, 54.4% of carers experienced at least one significant financial stress event, such as being unable to pay bills on time, going without meals, or having to ask for financial assistance, compared to 32.2% of Australian adults.⁵

Case Study – Shelley from WA

Shelley, a carer for a young child with autism, obtained a diagnosis for the child through the private health system in Western Australia at a total cost of approximately \$5,400.

Following this, when pursuing care planning Shelley was advised that her child's pediatrician would be leaving their practice and was subsequently left without a pediatrician and placed back on the public waitlist by her GP. She also pursued sourcing a new private pediatrician. When Shelley received a follow-up notice through the public health system the wait time for an initial appointment was over 24 months.

Whilst pursuing options within the private system, many of the private pediatricians Shelley found were not accepting bookings, most others were only accepting restricted or condition-specific bookings. Of the few that were accepting bookings, Shelley described the online reviews of these services as problematic, citing multiple mentions of dissatisfied patient experience or shortened appointments.

Feedback acquired by Carers Australia highlights that Shelley's experience is not unique, and the issues she faced are only exacerbated in regional and rural areas around Australia.

As such, Carers Australia recommends the following target areas and methods to improve outcomes for children, and coordination and collaboration in Commonwealth policies for children and families.

1. Increased support, including respite, for carers and families of children facing greater disadvantages such as children with disability, developmental delay, or complex needs.

Carers are currently filling the gap with childcare, where the existing childcare system does not provide for them. Children with complex needs face limited access to the childcare system. This can be due to a range of issues such as un- or undereducated staff, problematic, anti-social or violent behaviours from the child, or inadequate or inaccessible facilities for children with complex health or care needs. Where the system does not meet the needs of the child, the carer is carrying the burden. This became extremely prevalent in the face of the COVID-19 pandemic. In 2021 72% of carers reported an increased intensity in their caring responsibilities due to COVID-19, with almost half (49.6%) reporting that this is long-term.⁶ Carers cannot be expected to enrich the lives of the children they care for within a system that does not support them.

⁴ Australian Bureau of Statistics (ABS), Survey of Disability, Ageing and Carers, 2018, [\[accessed here\]](#)

⁵ University of Canberra, Caring for Yourself and Others, 2022 Carer Wellbeing Survey (commissioned by Carers Australia), [\[accessed here\]](#)

⁶ Op.cit (5)

Case Study – Carer from Victoria

The challenges for us is that my son is non-verbal and he doesn't have a lot of comprehension either. He's doing lots of things that are anti-social, he's spitting and runs off as well. We've got a disability sticker too going to all the therapies. Everything's constant. There is no break for us at all. If we sit down and have a break when he's around he starts throwing stuff over the fence, like his shoes, anything he can think of. Every day is a challenge, and it gets to a point that I ask myself 'Why do I even wake up?' It's not getting any better. For normal children when they grow up, they get better. But for children with disabilities, like my son who is six, they grow up and they get harder. They're heavier, they're stronger.

We've put our daughter, who just turned two, into childcare just to give me a break because she's showing signs of delays as well. Only recently did I apply for the NDIS yesterday for her and I've already got a million appointments. It's getting to all the appointments, dealing with all the therapists. They don't really understand. They see them for 45 minutes once a fortnight or once a week, charge you an arm and a leg, and to be honest, I don't really know what they do. They're supposed to be doing things, but one of ours is about toilet training. My son at six, is not toilet trained and that's one of the goals. At the end of the day, if your child's not going to do what they're supposed to do, a therapist isn't going to do anything. We've been potty training since he was 18 months old, and he is now six years old. We're constantly doing it. And yes, he's getting there, but not from the therapist, from the parents.

I'm not going to be going to work ever again. I'm dealing with children that have high needs. I used to have a six-figure income and now I get \$137 a fortnight. And yes, we're over the threshold for our pension, but I can't work. I can't go to work. I'm not sure how that's fair on us that we can't work because we've got children with special needs and now, we're down to \$137 a fortnight.

I go to quite a few parent support groups, I find the majority of them go to normal schools, and they have got challenges, but they have completely different challenges. It's really hard to relate to people whose kids are verbal, toilet trained and can dress themselves and wash themselves. And yes, they've got challenges, but I find it challenging to relate. I just have a cup of tea and have a bikkie.

Carers Australia has continuously advocated for greater support for Australia's carers and we encourage consultation and co-design with carers when developing policies for children and families.

2. Ensuring that childcare and early childhood education is available and affordable to all families, including for children with high care needs

In aligning this Strategy with existing initiatives and frameworks, including those listed in Attached B of the Discussion Paper, we must ensure that all Australian's have access to childcare and early childhood education services. Expanding accessibility and education requirements for these services will enable greater participation of disabled children in society from day one. Acknowledging the responsibility of society to meet the needs of disabled peoples and fostering attitudes of inclusivity are fundamental aspects of Australia's Disability Strategy. Enabling change and setting standards within early childhood settings can be used as a fundamental step in reaching a more inclusive Australia.

As part of this outcome, Carers Australia supports recommends the Strategy include a review of existing childcare system, including the current Childcare subsidy, to ensure that childcare is affordable for families and carers of children with higher-care needs.

3. Increased accountability and transparency

As noted within the Discussion Paper, there are existing silos that limit the coordination of Government programs and policies, impacting the performance and outcomes for both Government, families and carers, and children.

Carers Australia's members routinely provide feedback highlighting the lack of communication or guidance provided by Government services. Much of the feedback refers to a lack of guidance around who is responsible for provision of support for children with disability, whether it be the NDIS, health, or social services. As children age, education enters the picture too.

To address these issues, this Strategy should outline a path towards transparent reporting standards for relevant stakeholders. Making them accountable not only for their responsibilities but for their performance too.

QUESTION 7. What principles should be included in the Strategy?

Carers Australia recognises the advantages of the 'child and family centred' approach that is discussed within the Discussion Paper, however the described approach ignores the unique reality that carers face in meeting the needs of a child with disability or developmental delay.

The relationship between a child and their carer must be principally recognised within this Strategy. Carers are partners in care and this role should be recognised and respected, as stated within the Commonwealth [Carer Recognition Act 2010](#) (Cth). We acknowledge and appreciate the role of parents and families, yet an individual is not a carer under the terms of the Carer Recognition Act merely because they are a parent or other relative of an individual who requires care.⁷

Without targeted recognition those providing care for children with disability or high care needs may not seek access to resources, support and services targeted for themselves and other individuals providing care. Recognising carers as an individual cohort and as important partners in care enables them to access support services and identify pathways to carer networks.

Additionally, guiding principles should recognise the lived experience of children with disabilities, their families, and carers, across the service system and over time. This lived experience encompasses increasing and complex interactions with services systems across government and industry sectors. This journey, like those faced by children with other diverse needs or backgrounds, is unique and important and failure to sufficiently recognise or integrate this will severely restrain potential future development and growth of these children.

As mentioned earlier, the Early Years Strategy must be accompanied by policies, programs and reforms that better improve inclusivity and accessibility beyond early childhood. Recognising and mapping the interactions and realities of system interaction for children with disabilities and their carers from the onset will enable government, industry, and community to provide greater opportunity for societies most disadvantaged.

QUESTION 8. Are there gaps in existing frameworks or other research or evidence that need to be considered for the development of the Strategy?

The research and findings of the [Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability](#) should be considered as integral in any considerations that are made regarding the experiences and outcomes of children with disability. As such, we strongly recommend that the findings are used to inform the development of the Early Years Strategy. Furthermore, the findings from the [National Disability Insurance Scheme \(NDIS\) Review](#), which are due by October 2023, will enable the Strategy to

⁷Australian Commonwealth Government, [Carer Recognition Act 2010](#) (Cth)

better understand the ongoing systemic barriers provide insight into how greater cross-system interaction can be achieved.

Carers Australia notes the lack of carer related research or evidence within Attachment A of the Discussion Paper. As highlighted throughout this response, carer recognition and support are vital to the success of this Strategy and many other existing frameworks, specifically through their efforts to address barriers faced by individuals in need of care.

We recommend the Strategy consider research undertaken by Carers Australia, specifically [Caring for Others and Yourself](#), which is a report based on the findings of the 2022 Carer Wellbeing Survey. The survey is a collaboration between Carers Australia, the Department of Social Services, and the University of Canberra. This report provides valuable insight into the barriers carers face in providing care.

About Carers Australia

Carers Australia is the national peak body representing the diversity of the 2.65 million Australians who provide unpaid care and support to family members and friends with a disability, chronic condition, mental illness or disorder, drug or alcohol problem, terminal illness, or who are frail aged.

In collaboration with our members, the peak carer organisations in each state and territory, we collectively form the National Carer Network and are an established infrastructure that represent the views of carers at the national level.

Our vision is an Australia that values and supports all carers, where all carers should have the same rights, choices, and opportunities as other Australians to enjoy optimum health, social and economic wellbeing and participate in family, social and community life, employment, and education.

This includes carers:

- Who have their own care needs
- Who are in multiple care relationships
- Who have employment and/or education commitments
- Aged under 25 years (young carers)
- Aged over 65 years, including 'grandparent carers'
- From culturally and linguistically diverse backgrounds
- Who identify as Aboriginal and Torres Strait Islander
- Who identify as lesbian, gay, bisexual, transgender, intersex (LGBTI+)
- Who are living in rural and remote Australia, and
- That are no longer in a caring role (former carers).

Carers Australia acknowledges Aboriginal and/or Torres Strait Islander peoples and communities as the traditional custodians of the land we work on and pay our respects to Elders past, present and emerging. As an inclusive organisation we celebrate people of all backgrounds, genders, sexualities, cultures, bodies, and abilities.