

Response to Australian Government Department of Social Services consultation on Developing the National Autism Strategy

Introduction

Carers of people on the autism spectrum report higher levels of psychological distress, loneliness, and dissatisfaction with their caring role than most other carers (Schirmer et al. 2023). However, they have instrumental roles in the lives of those they care for and must be supported to continue providing care in a healthy manner.

Carers Australia welcomes the development of a National Autism Strategy, however makes the following recommendations to ensure carers are considered.

- The National Autism Strategy should recognise and remain consistent with the National Carers Strategy, once developed.
- Carers Australia recommends that autism awareness and education include the important role of informal supports and communicate the role and rights of an individual as a carer.
- Accessible and accurate information for carers should be made available for all programs and services available for autistic persons.
- Mapping of respite care be included as a priority for both national, state and territory governments.
- Take into consideration the other recommendations for families and carers put forward by the Senate Select Committee on Autism, including those that are not specific to the National Autism Strategy.

This paper sets out Carers Australia's response to the [Discussion Paper](#) on the development of the National Autism Strategy (the Strategy). Carers Australia supports the Australian Government's decision to develop a person and family-centred Strategy that addresses whole-of-life needs for autistic people. As recognised in the Senate Select Committee on Autism 2022 Final Report [Services, support and life outcomes for autistic Australians](#), the wellbeing of parents and carers is critical to the success of autistic people, however "there is overwhelming evidence that support for parents and carers is currently inadequate".

In recognition of this, the development and implementation of the Strategy is of great importance not only to individuals living with autism around Australia, but also to the proportion of Australia's 2.65 million carers that provide care to a person on the autism spectrum (ABS 2019).

Carers of autistic people

Findings from the 2023 Carer Wellbeing Survey (CWS) reveal that carers of autistic people continue to report some of the worst wellbeing outcomes in comparison to other carers and the general Australian public (Schirmer et al. 2023). Notably, carers of people on the autism spectrum were among those with the highest levels of psychological distress. In addition to the impact on their wellbeing, carers of autistic

people also face increased barriers to participating in paid work and are amongst the most likely to report low levels of financial wellbeing.

Carers Australia recognises the depth of research and storytelling that has already occurred and will be used to inform the development and implementation of the Strategy. We also understand the integral role that community participation and lived experience engagement have throughout consultation. However, the role of carers and parents in the lives of autistic people cannot be understated. This was agreed by the Select Committee on Autism, it has been said by many members of autism community and it is the view of Carers Australia.

Addressing carer outcomes within the Strategy

To the extent that the Strategy intends to be holistic in addressing the whole-of-life needs for autistic people from a person and family-centered lens, there is a distinct disconnect between the priorities for action listed in the Discussion Paper, and the needs and experiences of Australian carers. This Strategy must recognise families and carers as primary partners in strategy development and delivery who have a right to access dedicated support and resources to fulfil their role as a carer. 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 autistic people.

Carers Australia notes the [recent announcement by the Australian Government](#) to develop a National Carers Strategy and recommends the National Autism Strategy recognise and remain consistent with the National Carers Strategy, once developed.

Social Inclusion

Carers play a key role in fostering social inclusivity for autistic individuals, specifically for those with high support needs. However, carers themselves also face barriers to social inclusion. The 2023 CWS found that carers of people on the autism spectrum report the highest levels of loneliness of all carers surveyed (Schirmer et al. 2023).

As part of the Strategy will focus on social inclusion for autistic people, the expectations, and limitations of carers to enable this must be recognised. As safeguards and advocates, carers and families have immense opportunity to positively contribute to autism awareness and acceptance throughout the Australian community. However, this opportunity is regularly limited or impacted because of increasing demands and decreasing support for being a carer.

Carers Australia recommends including the role of carers when raising awareness of autism. Without this acknowledgement, carers will continue to fall between the cracks and their ability to foster positive social engagement will diminish.

Furthermore, all efforts targeted at addressing housing and accommodation inclusivity must meaningfully address the needs for both carers and the people they care for. Findings from the 2023 CWS reveal that carers of autistic people were significantly less likely to report that their housing met their needs (Schirmer et al. 2023). Policy measures targeted at addressing housing inequality must ensure that social housing

is available, appropriate and accessible for both carers and occupants that may have a disability or require specific accommodations within their homes.

"I am watching my financial security slip away from me the longer I care and I know it will make me vulnerable as I age. The longer I am out of work the more I am left behind and housing security is of particular concern." - participant in the 2022 Carer Wellbeing Survey

Economic Inclusion

Expanding the accessibility of education and employment is fundamental in enabling greater participation of autistic people in society from day one. In many instances, carers are currently filling the gap with education and employment where the existing systems do not provide for them. This includes enduring the financial burden of under- or unemployment and having to provide home supervision or learning in place of school participation.

Autistic children with complex needs face limited access to childcare, while autistic adults can struggle to access education and employment. This can be due to a range of issues such as un-or undereducated staff, problematic, anti-social or violent behaviours, or inadequate or inaccessible facilities for autistic people. Where the system does not meet the needs of the individual, the carer is carrying the burden.

This became extremely prevalent during 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 (Schirmer et al. 2022). Carers should not be expected to be a positive safeguard for the person they care for within a system that does not also support them.

Education

According to the 2023 CWS, 47.1% of carers were doing less paid work than desired, compared to only 27.5% of Australian's more generally (Schirmer et al. 2023). Carers Australia's [submission](#) to the Inquiry into the National Trend of School Refusal and Related Matters, explored how the provision of inclusive school environments may decrease the amount of time needed to provide home care, supervision or learning by a carer due to inappropriate levels of support within the school.

Australia's Disability Strategy 2021-2023 highlights the importance of increasing accessibility and inclusion within school environments for people with disability. Under the [Disability Discrimination Act 1992](#) schools must make reasonable adjustments to provide access for students with disabilities to the same schooling opportunities, yet as acknowledged in the Discussion Paper there is a widespread lack of resourcing in accommodating diverse needs.

The variety and extent of accommodations needed will vary from student to student, yet the first hurdle many carers face is accessing information around requesting support. Experiences vary largely by state and region; however, carers have cited to the National Carer Network as the main reasons they remove a child from school while they 'figure it all out' as:

- lack of information,

- inconsistencies with information provided via organisations, government departments, school websites and school staff, or
- inadequate resourcing within schools.

Addressing this requires various levels of intervention and cross portfolio consideration. In addition to increased funding and resourcing, schools must promote collaborative discussions with carers and families when exploring adjustments for diverse needs. Sadly, we are frequently told of instances where there is an increasing reliance on carers and parents in 'dealing with' complex needs, and the ability to 'offload' responsibility of a child with disability. We draw attention to the fact that this denies the person their rights as recognised by the United Nations [Convention on the Rights of Persons with Disability](#) (CRPD).

Employment & Transport

Carers Australia supports the inclusion of employment and transport measures as priority areas in the development of the Strategy. However, we caution the inclusion of potential actions that are heavily dependent on the carer without further consultation. **Accessible and accurate information for carers should be made available for all programs and services available for autistic people.** These resources provide carers with increased support and understanding during times of transition, a time in which carers should be recognised and supported as a change to the routines of people with autism can often be difficult, with carers managing what can be a very stressful process.

Additionally, all employers and services providers should be accurately educated on who carers are and how to be inclusive of carers when they are, or need to be, present.

Diagnosis, services and support outcomes

Carers Australia supports the recommendations made by the Select Committee on Autism that relate to the provision of services and supports for carers. These recommendations focus on recognition, clarity and support for carers.

Carers Australia recommends that respite care be included as individual action in addition to 'Improve supports for parents and carers and service integration and coordination' under Accessing supports and services. Whilst respite care could be considered a support measure, Carers Australia is aware of the extreme barriers carers face in accessing appropriate respite care, within both the National Disability Insurance Scheme (NDIS) and the broader mainstream system and believe the problems with respite care provision must be addressed separately to other carer supports.

Having access to respite care can make a significant difference to the quality of carer's lives, and to both their wellbeing and the wellbeing of the people they care for. The 2023 CWS reported a decline in the proportion of carers who reported respite care services from 30.6% in 2021, to 27.7% in 2022 and 26.8% in 2023 (Schirmer et al. 2023).

Reasons for this decline include difficulty finding high quality services, long waiting times, lack of local service availability and lack of funding. In order to identify potential solutions to these problems, the Select Committee on Autism (2022) recommended that:

“7.92 The committee recommends that state and territory governments undertake a mapping of respite and support services for parents and work with government and non-government providers to address identified gaps in support.”

Carers Australia recognises the importance of a holistic and coordinated National Autism Strategy, that addresses all levels of government. As such, we recommend that **the mapping of respite care be included as a priority for both national, state and territory governments.**

Additionally, Carers Australia encourages the consideration of other recommendations for families and carers put forward by the Select Committee, including those that are not specific to the National Autism Strategy. These recommendations are indicative of challenges faced by carers and families throughout Australia and measures included within the Strategy should align with any changes made that sit outside the remit of the Strategy – such as the NDIS. For example, the Committee called for increased transparency and consistency in the provision of carer support under the NDIS and requested greater clarity on the operation of the ‘ordinary role of parenting principle’. These recommendations highlight the need for coordinated, accountable and fair services and support for carers across all systems.

Autism supports must be fair in the expectations placed on carers and families as advocates, navigators, and providers of care. Carers should be recognised for the role they give in the provision of care and that a carer for a child or young person is distinct from ‘parenting’. Thus, all actions to assess and support autistic people must consider the specific requirements for the carer both as an individual and within their caring role.

Conclusion

Carers of people on the autism spectrum report higher levels of psychological distress, loneliness, and dissatisfaction with their caring role than most other carers (Schirmer et al. 2023). However, they have instrumental roles in the lives of those they care for and must be supported to continue providing care in a healthy manner.

In conclusion, Carers Australia welcomes the development of a National Autism Strategy and supports the effort made thus far to recognise and include carers of autistic people in both the development and implementation of the Strategy.

We request that the Strategy make greater efforts to include carer outcomes and expectations where they are relevant, and that the Department ensures the Strategy remains consistent with the upcoming National Carers Strategy.

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.

