Carers WA

Submission to the

Australian Government

Department of Social Services

The National Autism Strategy

October 2023

About Carers WA

Carers WA is the peak body representing the needs and interests of carers in Western Australia and is part of a national network of Carers Associations. Carers provide unpaid care and support to family members and friends with disability, mental ill health, long term health conditions (including a chronic condition or terminal illness), have an alcohol or drug dependency, or who are frail aged. The person they care for may be a parent, partner, sibling, child, relative, friend or neighbour.

Caring is a significant form of unpaid work in the community and is integral to the maintenance of our aged, disability, health, mental health, and palliative care systems.

Some important facts about carers include:

- There are currently 2.65 million unpaid carers in Australia.
- There are more than 320,000 families and friends in a caring role in Western Australia.
- The replacement value of unpaid care, according to a report undertaken by Deloitte, Access Economics, "The economic value of unpaid care in Australia in 2020" is estimated at $77.9 billion per annum.

Carers WA acknowledges the Traditional Owners of country throughout Australia and recognises their continuing connection to land, waters and community. We pay our respects to them and their cultures; and to Elders both past and present.

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1.0 Introduction

Carers WA welcomes the opportunity to provide feedback to the federal Department of Social Services (the Department), in response to its discussion paper on *What we have heard: moving towards development of a National Autism Strategy.*

2.0 What does a National Autism Strategy need to achieve?

> ‘Not even my extended family understand how hard it is, so how can anyone else in the wider community get it. I have some friends who are in similar situations, and they are my support, we tend to lean on each other. But there is no awareness of the toll it takes on career, marriage, and divorce, being alienated, feeling blamed for kids’ behaviour when they don’t understand autism. I would love to see more awareness of asking if a carer is ok and acknowledging what they do. The general population might assist more if they knew how hard it can be. Thanks for giving us this opportunity to speak up.’
>
> – feedback from a carer.

2.1 Aware and accessible Early Childhood Services

> ‘Due to my autistic son’s complex nervous system disability and manifestation of this behaviourally, he has been terminated from two childcare centres. I am trying to maintain employment and juggle his care and this is significantly challenging as the NDIS do not recognise this as a point for support, claiming childcare is a parental responsibility. Though there are no suitable options for him to attend childcare.’
>
> – feedback from a carer

As outlined in Recommendation 22 of the Select Committee on Autism’s Final Report[1], a National Autism Strategy needs to achieve recognition of the vital role that families, parents and carers play in supporting an individual with autism. This is particularly of importance for the carers of children and young people with autism, as well as ensuring widespread awareness in early childhood services to further early diagnosis and early intervention – for both the child with autism and the carer. It has been shown that delays in diagnosis can result in children not benefitting from appropriate early intervention.[2] However, this can be also true of carers who are not connected to carer services early in their caring role, with carers often only making contact with these services once a crisis occurs or they experience burnout.

Carers of children with autism can have limited options when it comes to accessing childcare for young children, with many carers reporting not being able to access such services or having the option to return to work until their child enters the public school system.

Increased options are recommended to be provided for more accessible childcare and school holiday programs, as well as options to increase support for these services, either through the NDIS or an outside medium such as reform to the childcare subsidy. This would in turn support impacted carers of children with autism to have the option of returning to the workforce earlier than when their child enters the school system, as well as provide increased opportunities for carers to participate in other economic, social and community

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[1] (Senate Select Committee on Autism, 2022)

[2] (Senate Select Committee on Autism, 2022)

opportunities. The importance of supporting carers through such an outcome is outlined within the *Carers Recognition Act 2010* and *The Statement for Australia's Carers*.

1. Increased options are recommended to be provided for more accessible childcare and school holiday programs, as well as options to increase support for these services, either through the NDIS or an outside medium such as reform to the childcare subsidy.
2. A focus be included in the National Autism Strategy on strengthening referral pathways for carers to carer services, including from early childhood services. i.e. Childcare and early learning centres; child health nurses and parent centres; etc.

2.2 Ease of Service Navigation

What does recognition mean to WA carers?

'Appropriate acknowledgement, which is then practically demonstrated in actual needed support, and not just financially but also in regards to carer health and wellbeing and importantly with navigating the system (as we are dealing with multiple 'households' and everything associated with them - our own and the person we care for). Timely access to services, more efficient and streamlined processes, information in one spot (the amount of times I've had conflicting info or been provided with info on services from other people that is not obvious on any website anywhere), better access to respite care. All of this assists the carer to continue with working as well - this for me is my sole income (I have no other family support). I have steadily reduced my work hours and need to reduce these further which I'm not sure work will accommodate - and this has not only reduced by income but my superannuation too.' – feedback from a carer

A lack of integration between and across services contributes to a primary issue that both carers and consumers experience, this being navigation of services. In WA regional areas in particular, constant movements in staff, services and funding – add another layer of complexity to navigation of services. This is on top of other region-specific issues such as thin markets and remoteness.

This issue is so prevalent that Carers WA has developed a Through the Maze Experiential Simulation Training, to build awareness amongst students and service providers. The purpose of this training is to provide participants with a deeper understanding and insight into some of the challenges and barriers carers and consumers face throughout their journey/roles. Real life scenarios are used to throw the participant into the world of a consumer or carer in navigating services, followed by a deeper discussion at the conclusion of the activity. This activity, which is also provided as a Carers WA staff induction activity, results in participants experiencing an extreme moment of clarity and understanding, of what consumers and carers have to deal with every single day with accessing and navigating services.

3. An increased focus is recommended on reducing complexity in system navigation, particularly for informal carers who will be navigating multiple complex systems at once to ensure their child is as supported as possible.

2.3 Improvements in early diagnosis and intervention

In WA, costs of even general healthcare for families are can often be high, with significant reductions in the number of general practitioners (GPs) who are bulk billing and high costs of private specialists. Carers report that GPs which used to bulk bill for concession card holders, have now moved to policies such as having gap fees for concession card holders aged 16-64.

Public waitlists for paediatricians in WA can be significant, extending over 24 months wait-time for an initial appointment. Carers report resorting to obtaining a diagnosis for their child through the private system, but the cost of this is high, with costs reported of $5,000-$6,000 just for diagnosis.

Even for private paediatricians, waitlists can be long, and due to demand many paediatricians are either not accepting bookings, or only accepting restricted or condition-specific bookings.

These difficulties and costs associated with obtaining a diagnosis for a child, as well as wait times for other public health services, circumnavigate the benefits of early intervention. Although it may have been identified that a child may need some extra supports, the two years they spend on a waitlist waiting for diagnosis or regular services, is two extra years they are falling behind.

4. It is recommended that reforms be investigated to alleviate these wait times and costs of specialists for children.

2.4 Regional and Remote areas as a priority

The discussion paper outlines a range of areas of focus regarding intersectional (overlapping) disadvantage or discrimination, which are experienced by people with autism. However, locality is not included within these areas of focus, nor are regional and remote areas considered as a priority area. Given that 28% of the Australian population resides in regional areas, or 7 million people,[3] this priority area is vital.

In WA in particular, 24% of carers are in crisis, resulting in higher psychological distress, a greater impact of their caring role on work, more care tasks, lower social support, recognition, work-life balance and self-efficacy[4]. This is particularly prevalent in WA regional areas, in the midst of heightened and pronounced challenges which carers in regional areas have in accessing services and support for themselves and those they care for, along with issues with housing and transport.

5. Locality, carers and people with autism living in regional and remote areas be included in the National Autism Strategy as a particular focus area.

2.5 The extent of parental responsibility

> ‘Being supported in other areas so that I can focus on my caring role, e.g. funding for cleaning, maintenance, so that I can spend more time with the person I care for. Recognition that my caring role is not the same as standard parental responsibility and goes much, much further than that. Understanding that I need respite away from the person I care for sometimes.’
>
> – feedback from a carer

Recommendation 23 of the Select Committee on Autism’s Final Report discusses ‘working with stakeholders and experts to clarify the operation of the ‘ordinary role of parenting’

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[3] (Australian Institute of Health and Welfare, 2023)

[4] (SAGE Design & Advisory, 2023)

principle',[5] recognising the significant additional responsibilities borne by parents and carers of autistic individuals.'

Carers also often report not being recognised for the additional role they have, above that of a parental role, as well as running into these difficulties when seeking funding through the NDIS. This recognition needs to be reflected within the National Autism Strategy, with clear differentiation and definition between a parent and a carer.

6. Realisation of Recommendation 23 of the Select Committee on Autism's Final Report within the NDIS and the National Autism Strategy.
7. Clear differentiation and definition between a parent and a carer within the National Autism Strategy.

7.0 Conclusion

Should the Department require any further information regarding the comments included within this submission, or assistance from the perspective of WA carers, Carers WA would be delighted to assist. Please contact the Carers WA Policy Team at policy@carerswa.asn.au.

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[5] (Senate Select Committee on Autism, 2022)

Bibliography

Australian Institute of Health and Welfare. (2023, September). Rural and remote health. Australia. Retrieved from https://www.aihw.gov.au/reports/rural-remote-australians/rural-and-remote-health

SAGE Design & Advisory. (2023). *2022 National Carer Survey.* Unpublished.

Senate Select Committee on Autism. (2022). *Services, supports and life outcomes for autistic Australians.* Canberra: Parliament of Australia. Retrieved from https://parlinfo.aph.gov.au/parlInfo/download/committees/reportsen/024412/toc_pdf/Services,supportandlifeoutcomesforautisticAustralians.pdf;fileType=application%2Fpdf