



**Submission to the
Australian Government
Department of Social Services
The Early Years Strategy Discussion Paper
April 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 who are living with disability, mental illness, 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.

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Table of Contents

1.0 Introduction	1
2.0 General Feedback	2
2.1 Carer Recognition.....	2
2.2 Access to supports for children with disability	3
2.3 Cost, access to and availability of healthcare for children and families	4
2.5 Summary of Recommendations.....	6
Bibliography	7

1.0 Introduction

Carers WA appreciates the opportunity to provide feedback to the Department of Social Services, in response to The Early Years Strategy discussion paper.

The cost to replace the informal care provided by carers around Australia was estimated in 2020 to be \$77.9 billion per year¹.

For WA, this is estimated to be about \$6.6 billion per year, based on WA having 8.5% of Australia's carers (aged 15 years and over)². Further, this care provided often comes at a great cost to the carers own wellbeing, as well as their economic and financial security, which was recently quantified within the research report *Caring Costs Us: The economic impact on lifetime income and retirement savings of informal carers*. This report found that, on average, by age 67 primary carers will lose \$175,000 in superannuation and \$392,500 in lifetime earnings. Additionally, for every year someone is a primary carer they will lose on average \$17,700 in superannuation and \$39,600 in lifetime earnings³.

Furthermore, the results of the 2022 Carer Wellbeing Survey revealed that carers had significantly higher rates of psychological distress than the average Australian. Over half of carers had poor wellbeing, compared to 25.4% of adult Australians. Only 17.1% of carers reported having good health, compared to 47.9% for the average Australian⁴.

Informal carers of young children will be amongst those experiencing the highest impacts of a caring role, in particular due to the increased amount of time that their caring role may be for. Informal carers of young children will often not be able to return to work for longer, or take a break. They will also experience high medical costs, complex systems and long and frustrating waitlists, as they work to advocate strongly for their child, at a detriment to their own wellbeing.

For this reason, the Early Years Strategy must strongly consider informal carers and children with disability, and make investment in early intervention and early supports for both these groups. Carers WA would appreciate the opportunity for further involvement in the development of The Early Years Strategy to collaboratively work towards this outcome.

¹_(Deloitte Access Economics, 2020)

²_(ABS, 2019)

³_(Furnival & Cullen, 2022)

⁴_(Schirmer, Mylek, & Miranti, 2022)

2.0 General Feedback

2.1 Carer Recognition

Carers in WA and Australia experience barriers due to a lack of recognition of their caring role and the unique challenges which carers face. In the early childhood space, this lack of recognition often extends to informal carers being considered in conjunction with parental carers. The differentiation between a parental role and the additional challenges of an informal caring role for a child are important to make due to the need for unique supports and outcomes for the additional challenges experienced by informal carers. For example, the informal carer of a child with disability may also be their parent, who will experience a lack of access to mainstream childcare supports, which will prevent the carer from re-entering the workforce for a significantly longer period than that experienced by a standard parental carer.

To ensure recognition, clarity and awareness of carers and their rights, Carers WA recommends that informal carers and children with disability take a more central focus in The Early Years Strategy, with separate outcomes for both these groups.

Further, Carers WA also recommends that a separate definition be included in The Early Years Strategy for informal carers, which is consistent with the Australian *Carers Recognition Act 2010* ([here](#)) and 'The Statement for Australia's Carers', as per the below:

'A carer is an individual who provides unpaid personal care, support and assistance to another individual who needs it because the other individual has a disability, medical condition, mental illness or is frail and aged. A carer may be a family member or a friend. Carers have certain rights to respect, recognition, support and inclusion which CMOs should be aware of, which are further outlined in 'The Statement for Australia's Carers' included within these Standards. States and Territories may have additional legislative requirements relevant to the role and rights of carers.'

This recognition and awareness of carers and children with disability is also recommended to be enhanced in early childhood centres, through a specific outcome for 'Mandatory training to be incorporated in early childhood courses on the identification of carers'.

Further, Carers WA recommends that organisations involved in early childhood education and support be appropriately resourced for early identification and support of carers of young children. This should also include establishing and strengthening referral pathways to relevant carer support organisations in each state and territory. This is particularly of importance as carers of this age group may be in a caring role for the next 30-40 years or more.

2.2 Access to supports for children with disability

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 Early Years Strategy discussion paper raises the importance of the first 1,000 days, and the consequences for if a gap emerges and is not closed in 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.

Carers have reported that it is easier to access Carer Gateway services to support them in their caring role, while caring for children with disability, than accessing any NDIS support. At times such as school holidays where their children cannot access mainstream supports, carers are having to access respite through the Carer Gateway in order to maintain their employment. Specific cases include:

- Carer Gateway funding for a family to access in-home respite for their two young children with disability, due to a lack of appropriate options around childcare or babysitting services;
- Carer Gateway funding for a carer in a regional area to support with in-home respite for her child with disability. Their NDIS funding was already exhausted, there were no accessible or inclusive school holiday program providers in town and the carer had to work through school holidays.

Carers WA recommends increased options be provided for accessible childcare and school holiday programs for children with disability, 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 carers of children with disability 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 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*.

Carers WA also recommends an increased focus 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 Cost, access to and availability of healthcare for children and families

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.

Carers WA recommends that reforms be investigated to alleviate these wait times and costs of specialists for children.

Case Study:

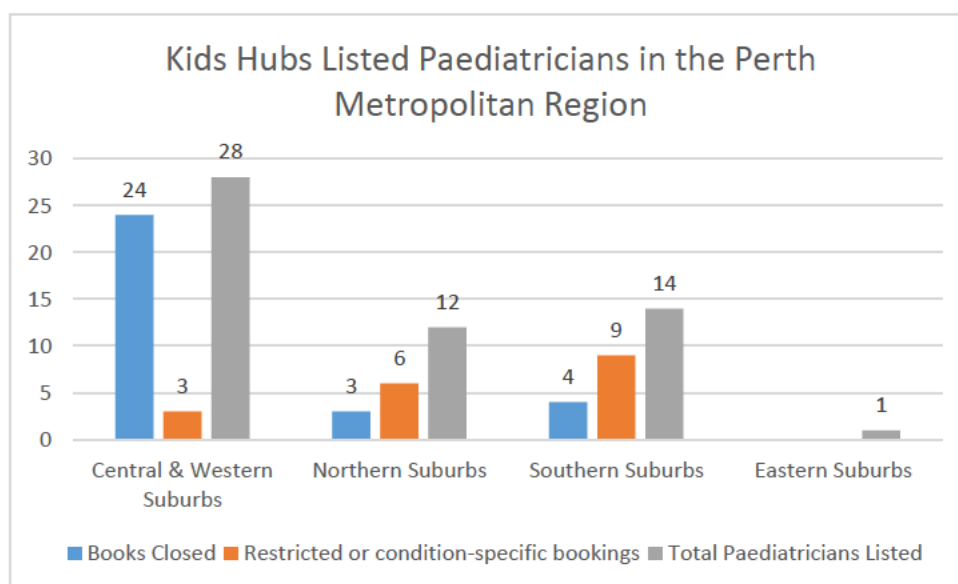
Shelley is a carer for a young child with autism, a diagnosis which was obtained through the private health system in WA at a total cost of approximately \$5,400.*

Shelley was advised that her child's paediatrician would be leaving their practice, and was subsequently left without a paediatrician and placed back on the public waitlist by her GP, while also continuing to source a private paediatrician if possible. When Shelley received a follow-up letter in the mail, the time for an initial appointment through the public health system was over 24 months.

Shelley was also provided a link to private paediatrician information through the Perth Kids Hub website, which has information around current open and closed bookings for private paediatrics in the Perth metropolitan area. Of the private paediatricians listed, a significant amount were not accepting bookings and the remainder were primarily only accepting restricted or condition-specific bookings. Of the few remaining listings for paediatricians that were accepting bookings, Shelley described the online reviews of these services mentioning them only making 15 minute appointments which in reality lasted 10 minutes, and the reviewers not feeling like their children had been properly examined.

Upon looking further at the listings in the information provided by the carer, Carers WA found that 56.4% of the Kids Hub listed paediatricians in the Perth metropolitan area, had closed books, and 32.7% were only accepting restricted or condition-specific bookings. Many of the ones that were accepting bookings also had waitlists ranging from 10 weeks to 2 years.

Kids Hubs Listed Paediatricians in the Perth Metropolitan Region			
	Books Closed	Restricted or condition-specific bookings	Total Paediatricians Listed
Central & Western Suburbs	24	3	28
Northern Suburbs	3	6	12
Southern Suburbs	4	9	14
Eastern Suburbs			1



2.5 Summary of Recommendations

1. Informal carers and children with disability take a central focus in The Early Years Strategy, with separate outcomes for both these groups.
2. A separate definition be included in The Early Years Strategy for informal carers, which is consistent with the Australian *Carers Recognition Act 2010* ([here](#)) and 'The Statement for Australia's Carers'.
3. Recognition and awareness of carers and children with disability is be enhanced in early childhood centres, through a specific outcome for 'Mandatory training to be incorporated in early childhood courses on the identification of carers'.
4. Organisations involved in early childhood education and support be appropriately resourced for early identification and support of carers of young children. This should also include establishing and strengthening referral pathways to relevant carer support organisations in each state and territory.
5. Increased options be provided for accessible childcare and school holiday programs for children with disability, 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.
6. An increased focus 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.
7. Reforms be investigated to alleviate wait times and costs of specialists for children, and to increase the prevalence of bulk billing options for concession card holders.

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