Carers WA

Submission to the

Australian Government Department of Social Services

A New Act to Replace the Disability Services Act 1986

February 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.

Enquiries

Carissa Gautam

Systemic Policy Officer

Policy@carerswa.asn.au

Carers WA

182 Lord Street

PERTH WA 60000

Phone: 1300 227 377

Fax: (08) 9228 7488

Email: info@carerswa.asn.au

Table of Contents

1.0 Introduction

Carers WA appreciates the opportunity to provide feedback to the Department of Social Services, in response to the Consultation Paper: A New Act to Replace the *Disability Services Act 1986*.

We welcome the prospect of a new Act to better support the rights of and improve outcomes for people with disability and their carers and families, where the person with disability has chosen to have them involved in their care.

This submission provides feedback in response to questions raised within the consultation paper and expands on areas of importance to informal carers. These comments are informed by ongoing feedback from WA carers.

2.0 General Feedback

2.1 Do you agree with the proposed objects for the new Act? What other objects should be included in the new Act?

Carers WA supports the proposed objects for the new Act, but recommends they include provision for ensuring the informal supports/carers of the person with disability are also well supported.

Carers play a significant role in supporting many people with disability, often at a great personal cost and detriment to their own wellbeing, particularly when they are not themselves adequately supported.

This is of particular importance for carers who provide care to one or more people with higher care needs or for an extended period of time, for which their caring roles comes at a significant personal cost. For carers who are in their caring role for a prolonged period, the most impacted 10% will lose at least $940,000 in lifetime income and $444,500 in retirement savings[1]. The 2022 Carer Wellbeing Survey also revealed that carers who had a higher care load (46.3%) undertook less work than they wanted to, had poorer wellbeing than other carers, and were amongst the least likely groups to have accessed support from family and friends in the last 12 months[2].

Overall, carers have significantly higher rates of psychological distress than the average Australian. Over half of carers have poor wellbeing, compared to 25.4% of adult Australians. Only 17.1% of carers report having good health, compared to 47.9% for the average Australian[3]. Financial wellbeing is also impacted, with an average reduction of $175,000 in superannuation and $392,500 in lifetime earnings for primary carers by age 67. On average, for every year someone is a primary carer there will be a reduction of $17,700 in superannuation and $39,600 in lifetime earnings that they would have made if not in a caring role[4].

Further, the value of this care has been valued by Deloitte Access Economics at $77.9 billion per year[5]. However, despite this value, carers continue to face a lack of recognition, inclusion and support. This needs to be addressed throughout the new Act.

---

[1] (Furnival & Cullen, 2022)

[2] (Schirmer, Mylek, & Miranti, 2022)

[3] (Schirmer, Mylek, & Miranti, 2022)

[4] (Furnival & Cullen, 2022)

[5] (Deloitte Access Economics, 2020)

To help achieve this recognition, Carers WA recommends the following inclusions identified in red below to the proposed objects for the new Act:

- *a) in conjunction with other laws, give effect to Australia's obligations under the Convention on the Rights of Persons with Disabilities done at New York on 13 December 2006 ([2008] ATS 12)*
- *b) support the independence and social and economic participation of people with disability*
- *c) provide supports and services which empower people with disability to maintain and increase their social and economic participation, including by:*
  - *i. participating on an equal basis in their communities of choice*
  - *ii. increasing independence and seeking meaningful opportunities for employment, education, and development*
  - *iii. understanding and enjoying their inherent human rights and fundamental freedoms*
  - *iv. ensuring informal carers are also supported in their caring role and provided opportunities for employment, education, development and social connection.*
- *d) ensure that supports and services provided:*
  - *i. are planned, developed, implemented and reviewed in conjunction with people with disability*
  - *ii. are timely, effective, innovative and high quality*
  - *iii. are locally available and accessible*
- *e) increase public awareness, understanding and acceptance of people with disability.*
- *f) Increase public awareness and recognition of the role informal carers can play for people with disability.*

2.1.1 Ensuring supports and services are timely, locally available and accessible

Carers WA recommends the new Act include a commitment to ensure supports and services are timely, locally available and accessible; with inbuilt flexibility to respond to thin markets and emerging challenges to service availability and access.

2.1.2 Carer Access to Respite

Informal carers experience increased and heightened levels of social isolation, loneliness, psychological distress, as well as ill health and low wellbeing. The impacts of caring have worsened due to the COVID-19 pandemic, particularly in remote and regional areas, as well as for people who provide care for or are part of high-risk groups such as people with disability[6]. Access to respite for an informal carer can help carers to have a healthy level of wellbeing[7], and better maintain and thrive in their caring role. Despite this, many barriers exist which hinder carers being able to access an appropriate level of respite services.

Access to services, including respite services, is a particular challenge for carers in both regional and metropolitan areas of WA, although remote areas exacerbate these issues. Carers WA recently conducted a research project in response to feedback from service providers and carers in the regions regarding a lack of respite facilities in regional areas, staff shortages, and difficulty in meeting demand. The need for improved regional service offerings is further demonstrated by recent reports from Carers WA's outreach teams of concerning shortfalls of some services in WA regional areas. Preliminary data from the research project indicates issues including:

- Respite access, availability, duration and staffing levels.
- Regional barriers to accessing services, including access to phones, local funding for carer supports, language barriers, culturally appropriate services and transport.
- Having access to appropriately trained staff.
- Staff shortages, particularly in in-home and aged care staffing.
- Need for locally available and accessible community supports (in addition to those provided through the Carer Gateway). E.g. Local peer support networks; flexible respite; funding to increase rural and remote access (including transport and travel for support staff); and a high care respite program in the Mid-West.
- Wait times and demand for services.
- Awareness of the challenges faced by people living in rural/remote areas, such as: increased transport costs and availability, access to technology (internet, phones and computers), resource availability, education and access to local supports.
- Need for increased funding: for high care consumers and for staff training to recognise stress in carers.

---

[6] (Schirmer, Mylek, & Miranti, 2022)

[7] (Schirmer, Mylek, & Miranti, 2022)

Carers WA outreach teams travelling to regional parts of WA have also reported a serious lack of availability of services, as well as staff shortages and system complexity contributing to a lack of services (especially respite). These reports are further detailed in the case studies in Appendix 1.

2.1.3 The 2022 Carer Wellbeing Survey – Access to services, including respite

Respondents to the Carer Wellbeing Survey 2022 reported at least one negative impact as a result of the COVID-19 pandemic. Over 70% of respondents had reduced their own social interaction to protect the people they cared for and increased their caregiving responsibilities. Similar numbers found it harder to get appointments and maintain treatment and/or therapy for those they cared for. The majority of respondents also reported reduced access to both formal support services and support from family and friends[8].

Barriers to accessing support in general reported included a lack of funding for services through the NDIS, My Aged Care or other support packages (65.9%); difficulty finding high quality services (69.3%); complicated application processes (69.5%); long waiting times to access services (66.9%); lack of local service availability (64.0%); difficulty affording services (64.2%); staff turnover amongst service providers (63.0%); and poor coordination between services (61.9%)[9].

For different types of support, the majority of carers reported having poor access to in-home overnight respite care (80.6%); overnight respite care out of home (73.9%); day respite care out of home (65.7%); and in-home day respite care (61.8%). For the 27.7% of carers who had access to respite care, peer support and financial support over the past year, these carers were found to be significantly more likely to have healthy levels of wellbeing. Respondents who most commonly accessed respite care were caring for a person with dementia (43.5%), with high assistance needs (41.7%) or old-age frailty (34.7%), and by carers aged 75 and over (40.3%)[10]. Access to a sufficient level of respite for carers in turn helps them to thrive and have longevity in their caring role, which is also of benefit for people with disability.

These figures are demonstrative of the demand for respite care by older carers and of carers of older people, which would have likely been used by more carers if there had not been the barriers to access as outlined above. They also show the benefit of respite services.

---

[8] (Schirmer, Mylek, & Miranti, 2022)

[9] (Schirmer, Mylek, & Miranti, 2022)

[10] (Schirmer, Mylek, & Miranti, 2022)

2.1.4 Definitions within the new Act

In addition to these inclusions, as the *Disability Services Act 1986* does not presently have a definition for informal supports or carers, Carers WA also recommends the inclusion of these definitions within section 6A of the new Act as per the below:

Informal supports *means a person who provides unpaid and informal support to a person with disability. This is inclusive of a person who is a carer within the meaning of the Carers Recognition Act 2010 and National Disability Insurance Scheme Act 2013.*

Carer *means an individual who:*

a) provides personal care, support and assistance to another individual who needs it because that other individual is a person with disability; and
b) does not provide the care, support and assistance:
    i. under a contract of service or a contract for the provision of services; or
    ii. in the course of doing voluntary work for a charitable, welfare or community organisation; or
    iii. as part of the requirements of a course of education or training.

(As stated within the National Disability Insurance Scheme Act 2013).

2.2 Do you agree with the proposed approach to the target group? How do you think the target group should be defined?

While Carers WA is supportive of the use of a social model of disability within the new Act, we recommend going beyond this to use of the human rights model of disability within the Act. This is defined as:

'The human rights model of disability views disability as a human rights issue and is similar to the social model, however, it extends upon just focusing on the environment. It recognizes disability as a natural part of human diversity which should be respected and supported and considers the views of people with disability as essential, acknowledging they are experts in their own lives. The model maintains that people with disability have the same rights as anyone else and should be given the right of equal opportunities and full participation in society, and any additional supports required to do this is not humanity or charity, but a basic human right.'[11]

We also recommend that the human rights model of disability also be reflected within the approach for defining the target group within the new Act, as well as recognition of people with disability who are experiencing physical, psychosocial and intellectual barriers to full and effective participation in society.

Carers WA supports including identification of people with particular identities or characteristics who may experience additional elements of disadvantage or discrimination, including Aboriginal and Torres Strait Islander peoples, LGBTIQA+ people and people from culturally and linguistically diverse backgrounds. However, we also recommend the inclusion within this approach of people with disability who undertake certain roles which result in them experiencing disadvantage and discrimination, such as the role of a carer.

Over one-third (37.4%) of primary carers have disability, more than double the rate of non-carers (15.3%)[12]. Further, 46% of carers have one or more disabilities, health conditions or injuries that restrict their everyday activities. Carers often also do not have a choice becoming a carer, and also have lower wellbeing, as well as diminished economic and financial security than non-carers[13]. For carers who have disability, the caring role also further exacerbates disadvantage and discrimination, which also needs to be recognised within the new Act.

---

[11] (Retief & Letsosa, 2018)

[12] (ABS, 2019)

[13] (Centre for Change Governance and NATSEM, University of Canberra, 2021)

2.3 Do you agree with our suggested principles for avoiding duplication and requiring coordination? What other principles do you think should apply?

Carers WA supports in theory the suggested principles for use when someone is separately eligible for services and supports from NDIS or from state and territory sources, and appreciates the Department's efforts to improve clarity for agencies and providers for when this situation occurs. However, we are concerned how these principles would operate in practice, and request further clarity be provided to this respect through supporting guidelines.

Carers have reported frustrations with a lack of clarity leading to difficulties in getting services and necessary equipment funded. The carer in the case study below had a highly stressful and prolonged experience in getting a CPAP machine funded for her son's life-threatening sleep apnea.

2.3.1 Case Study 1

Susan is a carer for her son Sean*, who has very severe obstructive sleep apnea and a complex heart and spine condition. Susan had a prolonged and difficult experience which she termed 'CPAP hell' in getting an appropriate replacement funded for Sean's Continuous Positive Air Pressure (CPAP) machine after it was damaged.*

Sean requires a CPAP machine to support his sleep apnea overnight, but due to a lack of maintenance of the machine by his support workers and the workers not having the machine packed adequately while it was being transported, the machine was damaged beyond repair. This was following some previous issues with the provider not assisting with hygiene of the machine and timely replacement of consumables.

Sean had gotten this CPAP machine when he was assessed by a hospital sleep specialist, where he was diagnosed with severe sleep apnea and provided with a machine specially calibrated to his needs and funded through the former WA Disability Services Commission. Sean has funding through the NDIS for CPAP maintenance or consumables related to the machine. As Sean had NDIS funding, the state health department would not fund another machine.

When Susan requested that some of Sean's NDIS CPAP repair and maintenance funding be used to purchase a replacement CPAP machine, the NDIA directed her to get an OT assessment. Susan was not able to find an OT with the skills needed for a CPAP assessment, and appealed this requirement, on the basis that a specialist sleep clinic had already assessed Sean. To back this up, Susan obtained a diagnostic report from the original hospital sleep clinic lab technician and a quote with the recommended CPAP machine, equipment and cleaning consumables. The urgency for an appropriately calibrated machine was further increased when, despite being able to use temporary CPAP machines through a loan machine and rental during this process, Sean's support worker had to wake him up when he had cyanosis.

The pharmacy through which the rental CPAP machine was provided then was not able to claim for the cost of the rental machine, which Susan urgently contacted the NDIS Planner about. The NDIS Planner then worked with Susan to identify the most straightforward way to get a CPAP for Sean using his NDIS funding. Some funding was identified to be repurposed for the CPAP machine, for which a plan review was required, as well as making the funding Plan Managed. This meant a Plan Manager could pay for the item from Sean's plan and Susan could then purchase the CPAP from any supplier, whether they were registered as a NDIS provider or not. Susan also got a letter from Sean's cardiologist to further demonstrate the need for the new CPAP machine.

While this method was successful in getting the pharmacy paid for a new CPAP machine, the plan review process then took some time to be resolved, during which there was not funding to pay Sean's plan manager. The revised plan which was sent through was also uncorrected and not resolved of several items, including the CPAP machine funding, which Susan had to further follow up to get corrected.

2.4 Do you think the new Act should include a definition for disability? Do you have any additional comments?

Carers WA is in favour of the use of a broad social definition of disability similar to the one within the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD). The use of a definition within the Act would also assist with clarity for both people with disability, service providers and agencies for eligibility for services and applicability of the new Act. We also recommend accompanying guidelines on how to apply this definition, to ensure consistency of application in practice of this definition.

2.5 How do you think quality and safeguarding arrangements should be managed by the new Act?

Carers WA believes that clear and consistent quality and safeguarding arrangements across the disability sector, with one clear and effective avenue for complaints handling and appeals, is important for increased transparency and reduction of regulatory burden on services which would be better put toward supporting people with disability.

However, alignment of quality and safeguarding requirements to other regulatory schemes such as those under the NDIS Quality and Safeguarding Commission would not be preferred at this time, given existing issues and concerns with this system.

As such, Carers WA recommends the new Act recognise existing accreditation under similar regulatory schemes, with a proviso for future investigation and implementation of a singular quality and safeguarding arrangement for the disability sector. This is also recommended to be considered as part of the review of the NDIS as it progresses.

2.6 Do you agree with the supports and services listed in the consultation paper? What other kinds of supports and services should be included in the new Act?

Carers WA agrees with the list of supports and services proposed for inclusion within the new Act, but also recommends the addition of supports and services for informal supports/carers, as well as data collection, privacy and security.

2.6.1 Informal supports/carers

Inclusion of supports and services for informal supports, such as ensuring carers are being referred onto the Carer Gateway and state or territory Carer Associations, and talking to carers to ensure they are also being adequately supported, which subsequently enables them to remain in and thrive in their caring role.

2.6.2 Data collection, privacy and security

Ensuring that any data collected is kept private and secure, especially personal health and medical data, is recommended to be included under the new Act as an essential service. The recent data breaches within Optus and Medibank, and subsequent data leaks, are demonstrative of the need for this to be embedded in the new Act.

Further, any data collection undertaken is recommended to be for a clear purpose which is communicated clearly to and agreed with by the person with disability and their chosen carer. Collection and long-term retention of client data for no clear and communicated purpose, without adequate data security, puts people with disability at undue risk of recurrences of the Optus and Medibank data breaches.

2.7 Do you consider it necessary to retain separate provisions for employment services and rehabilitation employment programs, or could they be combined?

Carers WA recommends that separate provisions be retained for employment services and rehabilitation employment program. Clients of each program often have unique and differing needs and challenges, which we do not believe would benefit from the combining of the programs. This is in addition to the differing focuses of each program, with rehabilitation employment services offering a more short-term, recovery focussed role; and employment services operating with more of a long-term duration and focus.

2.8 Summary of Recommendations

- The proposed objects for the new Act include provision for ensuring the informal supports/carers of the person with disability are also well supported.
- The inclusions identified in Section 2.1 of this submission be made to the proposed objects for the new Act.
- The new Act include a commitment to ensure supports and services are timely, locally available and accessible; with inbuilt flexibility to respond to thin markets and emerging challenges to service availability and access.
- The inclusion of definitions for 'informal supports' and 'carer' within section 6A of the new Act, as specified in Section 2.1.4 of this submission.
- Use of the human rights model of disability within the Act, including recognition of people with disability:
    - Who are experiencing physical, psychosocial and intellectual barriers to full and effective participation in society.
    - Who are also carers.
    - Identifying people who may experience additional elements of disadvantage or discrimination, including Aboriginal and Torres Strait Islander peoples, LGBTIQA+ people and people from culturally and linguistically diverse backgrounds.
- Further clarity be provided on how the proposed principles for use when someone is separately eligible for services and supports from NDIS or from state and territory sources, will operate in practice.
- Accompanying guidelines be developed on how to apply the proposed definition of disability within the Act, to ensure consistency of application in practice of this definition.
- Carers WA recommends the new Act recognise existing accreditation under similar regulatory schemes for quality and safeguarding, with a proviso for future investigation and implementation of a singular quality and safeguarding arrangement for the disability sector. This is also recommended to be considered as part of the review of the NDIS as it progresses.
- Carers WA agrees with the list of supports and services proposed for inclusion within the new Act, but also recommends the addition of supports and services for informal supports/carers, as well as data collection, privacy and security.
- Separate provisions be retained for employment services and rehabilitation employment programs.

3.0 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 Carissa Gautam from Carers WA at policy@carerswa.asn.au.

Appendix One: Access to Respite

Case Study 1: Access to respite services in Geraldton

One of Carers WA's outreach teams recently travelled to Geraldton engage with service providers, health practitioners and carers in the region to provide information and support on carer services in the region. During this trip and throughout their discussions, a serious lack of availability of services was reported, as well as staff shortages and system complexity contributing to a lack of services (especially respite). These findings were consistent with those of the regional provider survey outlined in Section 2.1 of this submission, as well as recent experiences of other Carers WA outreach teams in regional areas.

Below are some summaries of the conversations had regarding different types of service provision in the Geraldton region (as communicated to Carers WA):

<u>Respite</u>

Respite options are severely limited in Geraldton and the Midwest as a whole.

Low level/flexible respite:

This entails either a support worker going to the home to support the client or taking them out into the community, in order to give the carer a break. Flexible respite is on average only for a 2 hour block of time. Only four agencies were identified as having availability for flexible respite, with one other providing different forms of respite such as cottage respite (overnight) for low-level care. Another agency also provided mobile respite for up to 24 days (24/7 care), but this service books up quickly and only has one staff member who can provide it.

High level/residential respite:

Carers WA was informed there is only one high level respite bed available for the whole of the Mid-West Region (285,000 square kilometres), which is booked up several months in advance. If an emergency happens and the bed is needed for a permanent resident of the facility this respite bed is prioritised for those residents and respite bookings cancelled at short notice, requiring the person to go back on the waitlist.

Permanent residential care:

Only three residential aged care facilities are available in Geraldton. All three of these have extensive waitlists, averaging around 48+ applicants waiting for a bed.

As a result, families who are under significant carer stress may bring their loved one to the hospital as a last resort, where they are often admitted as a Care Awaiting Placement (CAP) patient, where they may wait in hospital for an extensive period of time (weeks/months) waiting for a bed to become available at a nursing home. During this time, their health may deteriorate, decondition and mental health decline, as they are limited in how much they do while on the ward – hence placing more pressure on an already over-stretched health service.

Case Study 2: Service Provision in Broome

Another of Carers WA's outreach teams also recently visited Broome, during which a meeting with local service providers was held that revealed similar and additional issues contributing to thin markets in service provision. These included:

- A lack of suitable and affordable housing, meaning both community members and workers cannot find a suitable place to live. This is coupled with a lack of staffing, with many services at capacity, with either no opportunities for new staff due to funding, staff retention or limited housing options.
- A great need for respite, but with limited options due to limited services, staffing and funding to pay for respite and transport.

References

ABS. (2019). *Disability, Ageing and Carers, Australia: Summary of Findings.* Australian Bureau of Statistics. Retrieved from https://www.abs.gov.au/statistics/health/disability/disability-ageing-and-carers-australia-summary-findings/latest-release#data-download

Centre for Change Governance and NATSEM, University of Canberra. (2021). *Caring for Others and Yourself: The 2021 Carer Wellbeing Survey.* Turner, ACT: Carers Australia Limited. Retrieved from https://www.carersaustralia.com.au/wp-content/uploads/2021/10/211011_Carer-Wellbeing-Survey_Final.pdf

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

Furnival, A., & Cullen, D. (2022). *Caring Costs Us: The economic impact on lifetime income and retirement savings of informal carers.* Evaluate. Turner, ACT: Carers Australia. Retrieved from https://www.carersaustralia.com.au/wp-content/uploads/2022/04/Final-Economic-impact-income-and-retirement-Evaluate-Report-March-2022.pdf

Government of Australia. (2010). *Carer Recognition Act 2010.* Canberra: Government of Australia. Retrieved from https://www.legislation.gov.au/Details/C2010A00123

Retief, M., & Letsosa, R. (2018, March 6). Models of disability: A brief overview. *Theological Studies, 74*(1), 1-8. doi:https://doi.org/10.4102/hts.v74i1.4738

Schirmer, J., Mylek, M., & Miranti, R. (2022). *Caring for others and yourself: 2022 Carer Wellbeing Survey.* Canberra: Carers Australia & University of Canberra.