

# Submission to the Department of Health and Aged Care Consultation: Funding of Aged Care Services

## December 2024

#### **About Carers Australia**

Carers Australia is the national peak body representing the diversity of the three million<sup>1</sup> 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 represents the views of carers at the national level.

Our vision is an Australia that values and supports all carers, where all carers 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.

Our carers are diverse and include those who:

- have their own care needs
- are in multiple care relationships
- have employment and/or education commitments
- are under 25 years (young carers)
- are 65 years and over
- identify as Aboriginal and/or Torres Strait Islander
- are from culturally and linguistically diverse backgrounds (CALD)
- identify as Lesbian, Gay, Bisexual, Trans and gender diverse, Intersex, Queer, Questioning and Asexual (LGBTIQA+)

<sup>&</sup>lt;sup>1</sup> Carer's Australia - About Carers - Who is a Carer

- live in rural and remote Australia,
- are former carers (no longer in a caring role), and
- have a disability.

#### Acknowledgment of country

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.



#### For information contact:



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#### Key Concerns with the Release of the draft Funding Rules

#### Commentary on consultation

Our biggest concern with the rules is trying to work out exactly what the legislation is saying. The Rules draft document, the only document included in the invitation to make submissions on the Aged Care Engagement Hub, is largely inaccessible to consumers, carers and even to their representative organisations who are not steeped in legalese and the continuous, often cryptic cross-referencing to other legislation or other parts of the document.

The funding rules need to be presented in a format that is user friendly to the end users, including carers.

In this context we note that similar complaints were made throughout the Senate Community Affairs Committee Inquiry into the Aged Care Bill; a point that was specifically raised in the Dissenting Report from Senator Allman-Payne for the Australian Greens.<sup>2</sup>

Witnesses representing consumer interests highlighted that consultation on the Bill often seemed to be focussed on providers and their representative organisations who have access to their own expert legal advice on complex legislation. As one witness summarised:

"I don't think there has been enough consultation. We had less than two weeks, after the bill was presented to parliament, to do the submission, which for volunteer groups and advocacy groups, is really challenging. For example, I don't think there are too many lived-experience people here today. So, I think the balance, even on other webinars, is that there is more time given to providers than there is to individuals and grassroots advocacy groups."<sup>3</sup>

<sup>&</sup>lt;sup>2</sup> Parliament of Australia, Senate Standing Committee on Community Affairs, Aged Care Bill Provisions 2024, Inquiry Report – Dissenting Report, November 2024

The Inquiry Report also emphasised the importance of proper consultation on the subordinate legislation, and we support Recommendation 4 by Coalition Senators that: *"all relevant rules and subordinate legislation pertaining to the Aged Care Bill 2024 be referred to the Senate Standing Committee for Community Affairs for Inquiry and public comment".*<sup>4</sup>

However, informed "public comment" can only be properly achieved if future releases of the draft Rules are accompanied by something everyone affected can understand. This is required if government is to embrace true co-design and embed lived experience into its policy.

## **Recommendation:**

Future consultations on the Rules for the new Aged Care Act should be accompanied by:

- The Draft Rules themselves, and
- Clear, plain and assessable documents (also available in translation of key languages) which are focussed on what these rules mean for consumers and carers.

## Quarterly Rollover Credit

Carers Australia has some concerns about the impact of the Quarterly Rollover Credit of 10% of unused funds in relation respite.

While ideally carers should be able to predict and plan for periods of respite and have ready access to it, this is far from the case for many carers.

The need for respite is not always predictable and adequate funding needs to be available when that need does arise.

Indeed, advice currently available on unspent funds on the My Aged Care website singles out respite as an example of where there is merit in setting aside funds for future events.

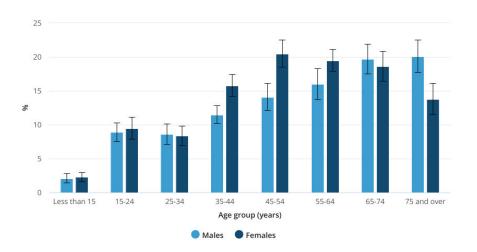
"Planning for future events - you should use a care recipient's budget to meet their current care needs.

But a care recipient can choose to set aside small amounts for future events, such as respite care.

<sup>&</sup>lt;sup>4</sup> Ibid. page 105

#### These amounts are unspent funds until the future event occurs."5

The unpredictability of when the need for respite will arise is a significant consideration for carers who are themselves over 65. As the graph below identifies (Figure one), there are many older carers who will predominantly be caring for an aged person between 65 and 74 and for people over 75.



#### Figure one: Proportion of all persons who provide informal care by age and sex<sup>6</sup>

Many of these carers will live with disabilities and health issues themselves. According to the 2022 Survey of Disability, Ageing and Carers (SDAC), 59.6% of carers over the age of 65 were categorised as having a disability of some kind.<sup>7</sup>

What this means is an increased likelihood that carers will have significant health issues which are likely to flare up unexpectedly and will need breaks from their caring role and replacement care; noting that carers are the largest providers of care and that 71.6% of people over the age of 65 receive assistance from family and friend carers.<sup>8</sup>

In such cases they are likely to need access to funded respite.

Residential respite can take weeks or even months to access and providers normally require an extended stay of some weeks which can be a deterrent for both carers and

<sup>&</sup>lt;sup>5</sup> Department of Health and Aged Care, My Aged Care website, Managing unspent funds in Home Care Packages <u>Managing unspent funds in Home Care Packages</u> | <u>Australian Government Department of</u> <u>Health and Aged Care</u>

<sup>&</sup>lt;sup>6</sup> Australian Bureau of Statistics, 2022 Survey of Disability, Ageing and Carers (SDAC), Summary of Findings, <u>Disability</u>, <u>Ageing and Carers</u>, <u>Australia: Summary of Findings</u>, <u>2022</u> | <u>Australian Bureau of Statistics</u>

<sup>&</sup>lt;sup>7</sup> Ibid. Carer data downloads

<sup>&</sup>lt;sup>8</sup> Ibid. Older People data downloads

those they care for. In 2022-23 the average length of stay per episode of residential respite was 30.2 days.<sup>9</sup>

Flexible respite – including in-home respite support, overnight in-home respite - or access to other forms of community respite will often be the most suitable option.

It will also be the case that carers need respite funding for replacement care to attend to other life matters which require their attendance for a defined period of time and which may be difficult to pre-plan for.

Carryover limits of \$1000 or 10% of unspent funds may not suffice to cover the need for replacement care when it is needed by carers.<sup>10</sup>

We are aware that providers can hold a certain amount of unspent funds in a pool to meet different exigencies, however the circumstances under which they grant access to this funding seems to be up to them.

#### **Recommendation:**

The limitations on the Quarterly Carryover provisions need to be scenario tested to ensure they are fit for purpose and the less routine and predictable elements of Support At Home services, such as respite, remain accessible at times they are needed.

<sup>&</sup>lt;sup>9</sup> Department of Health and Aged Care, 2022-23 Report on the Operation of the Aged Care Act 1997, page 41, 2022–23 Report on the Operation of the Aged Care Act 1997 - AIHW Gen

<sup>&</sup>lt;sup>10</sup> Department of Health and Age Care, September 2024 webinar, Support at Home program update, <u>support-at-home-program-update-presentation.pdf</u>

#### A snapshot of Australia's carers

There are three million<sup>[1]</sup> carers in Australia, with almost two thirds caring for someone under the age of 65<sup>5</sup>. Women make up 54% of all carers and nearly 67% <sup>5</sup> of primary carers. Carers can be any age,13% of carers are under the age of 25<sup>5</sup>, and 25% of carers are 65 years and older<sup>5</sup>. Just over 14% of the Aboriginal and Torres Strait Islander population identify as carers<sup>[2]</sup> and more than 27% of carers were born overseas<sup>1.</sup> In 2022, approximately 39% of primary carers identified as living with a disability<sup>5</sup>. The LGBTIQA+ community is 3.4%<sup>1</sup> of the caring population and just over 24% of carers live in an area of most socio-economic disadvantage<sup>1</sup>.

Being a carer is a constrained choice that impacts many aspects of a carer's life. To better understand and quantify the impact on carers, both Carers Australia, in conduction with the University of Canberra, and Carers NSW, together with State and Territory Carer Organisations, undertake detailed surveys.

Carer's Australia's conducts an annual <u>Caring for others and yourself:2024 Carer Wellbeing</u> <u>Survey (Survey)</u><sup>[3]</sup>. This year's survey had 9,000 respondents. Some key findings identified that compared to the average Australian, carers were 2.5 times as likely to report low wellbeing, are twice as likely to have psychological distress, half as likely to be in good health, and are three times more likely to experience significant financial distress.

More than 10,000 carers responded to Carers NSW 2024 biennial <u>National Carer Survey</u><sup>[i][4]</sup>. Preliminary findings from this survey have identified most carers felt they were not recognised or valued by government, and nearly one in two felt they are not recognised or valued by their community. Most noted they are not asked by service providers about their own needs as a carer and more than six in ten carers feel socially isolated.

While only 13% of Australians rely on a government pension or allowance, 40% of primary carers and 28% of non-primary carers rely on a government pension or allowance as their main source of income<sup>5</sup>. In 2020, a Deloitte Access Economics report on the value of informal care<sup>[5]</sup>, identified the economic value provided by carers in 2020 would be \$77.9 billion. The estimated earnings foregone for primary and non-primary carers at \$15.2 billion (\$11.4 billion primary carers, \$3.8 billion secondary carers). In 2022 Australian Bureau of Statistics<sup>1</sup> (ABS) identifies that approximately three in five (60.5%) of the 5.3 million people living with disability in Australia receive assistance with at least one activity of daily living, with 71.6% receiving assistance from informal carers<sup>[6]</sup>, with 42.2% receiving formal assistance daily.

<sup>&</sup>lt;sup>[1]</sup> Australian Bureau of Statistics, Survey of Disability, Ageing and Carers (SDAC) 2022

<sup>&</sup>lt;sup>[2]</sup> Australian Bureau of Statistics, Census 2021

<sup>&</sup>lt;sup>[3]</sup> Carers Australia <u>Caring for others and yourself:2024 Carer Wellbeing Survey</u>

<sup>&</sup>lt;sup>[4]</sup> Carers NSW 2024 <u>National Carer Survey</u>

<sup>&</sup>lt;sup>[5]</sup> Deloitte Access Economics (2020), The value of informal care

<sup>&</sup>lt;sup>[6]</sup> Australian Bureau of Statistics 2022