



Inquiry into the recognition of unpaid carers – Supplementary information

**McCabe Centre for Law and Cancer,
Cancer Council Victoria and
Cancer Council Australia**

6 October 2023



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Cancer Council Australia and the McCabe Centre acknowledge the traditional custodians of the lands on which we live and work. We pay respect to Aboriginal and Torres Strait Islander elders past, present and emerging and extend that respect to all other Aboriginal and Torres Strait Islander people.

Inquiry into the recognition of unpaid carers

Supplementary information

The following information is provided to supplement our joint McCabe Centre for Law and Cancer, Cancer Council Australia and Cancer Council Victoria submission to the House of Representatives Standing Committee on Social Policy and Legal Affairs *Inquiry into the recognition of unpaid carers* dated 11 August 2023, and is in response to a request to provide information about options for broadening the scope of the Act, made during our appearance at a public hearing on Wednesday 4 October 2023.

Scope of Act

We would like to see the federal Carer Recognition Act provide more tangible outcomes for carers by better promoting understanding of the significance of care relationships. Options to achieve this include broadening the scope of the Act by extending its obligations and refining its objectives to incorporate and reflect a human rights-based approach to the recognition of unpaid care.

To meet the needs of cancer carers, the Act's obligations would need to extend to policy development across the Australian healthcare system. This would require that the Act's obligations apply to a broader range of agencies and to a broader range of activities.

We note that the *Carer Recognition Act 2021* (ACT) contains obligations of broader application than the federal legislation in that they:

- expressly capture both government and funded non-government agencies and contractors providing or administering support services for people in care relationships; and
- apply to policy development.

We also note that the relevant definition in section 7 of the *Carer Recognition Act 2021* (ACT) provides the option to prescribe regulations¹ to capture any relevant entities that are not otherwise covered by the legislation. This is a useful approach that provides the flexibility to have the Act's obligations apply to other entities that may be relevant to those in unpaid caring relationships for example those that were perhaps not considered or in existence at the time the legislation was passed.

We have pasted relevant sections of the *Carer Recognition Act 2021* (ACT) below.

¹ Other Australian jurisdictions that also take this approach include New South Wales, Northern Territory, South Australia and Western Australia.

Carers Recognition Act 2021 (Australian Capital Territory) – Sect 7

Meaning of care and carer support agency

For this Act:

"care and carer support agency "means any of the following entities:

- (a) a public sector support agency;
- (b) a funded support agency;
- (c) a secondary funded support agency;
- (d) an entity prescribed by regulation.

Note Public sector support agency , funded support agency and secondary funded support agency —see the dictionary.

Carers Recognition Act 2021 (Australian Capital Territory) – Dictionary

"funded support agency "means an entity that is—

- (a) funded by a public sector support agency; and
- (b) responsible for providing a support service or program that directly impacts on people in care relationships.

...

"public sector entity" means the following:

- (a) the public service;
- (b) an entity that employs public sector members that is—
 - (i) owned or operated by the Territory; or
 - (ii) a territory instrumentality;
- (c) an entity prescribed by regulation.

Examples

- 1 Canberra Health Services
- 2 Transport Canberra

"public sector support agency "means a public sector entity that is responsible for the assessment, planning, delivery, management and review of support services, programs or policies in relation to people in care relationships.

"secondary funded support agency" means an entity contracted or funded by a funded support agency to provide a support service or program for which the funded support agency has responsibility.

In terms of the definition of carer, we reiterate our preference expressed both in our submission and during the public hearing for the approach taken in the Victorian and Australian Capital Territory (ACT) legislation, which is grounded in the multi-dimensional concept of a 'care relationship'. We consider this approach to be useful in its flexibility to:

- recognise diverse care relationships
- in its recognition that some people may not identify with the term 'carer' and may instead prefer to think of their role as part of an ongoing, reciprocal relationship
- avoid stereotypical limitations on the conception of a carer.

With reference to a definition that may encompass duties to multiple carers, we note that a range of other laws already establish frameworks to guide medical treatment decision making, substitute decision making, mental health care and advance care planning, among others.

Monitoring and compliance

The Carer Recognition Act could be more effective if compliance with obligations was improved, including reporting obligations.

Reporting on compliance as a means of enforcement can:

- create a culture of accountability and transparency
- encourage agencies to think about how they are acknowledging carers at the outset
- enable agencies to identify areas for improvement
- produce good information to support data-driven decision making.

Options to achieve this could include the introduction of monitoring through establishing a carer advisory council. We note that across Australia, carer recognition legislation in New South Wales, Queensland and Western Australia establish carer advisory councils tasked with advancing the interests of carers through making recommendations to the relevant Minister. Functions of the councils include, in Western Australia for example, to work to advance the interests of carers and promote compliance with the Carers Charter, and to make recommendations to the Minister on fostering compliance with the Carers Charter.

Clarity in drafting could also assist. Currently, much of the language in the Act regarding the obligations of public service care agencies and associated providers is not phrased in language that creates a strong obligation. We would like to see the introduction of words like ‘must’ and ‘shall’ as appears in other state and territory-based carer recognition legislation. For example, and by way of contrast while the federal legislation requires relevant agencies and providers ‘to take all practicable measures...’, the *Carer Recognition Act 2021* (ACT) requires that relevant agencies ‘must take all practicable measures...’.

Carer Gateway – model for improvement

As we noted at the public hearing on 4 October 2023, the United Kingdom has legislation in place —namely the *Care Act 2014* (UK) — establishing the right to a carer needs assessment. Enshrining a right like this into law is likely to improve the reach of Australia’s current Carer Gateway model.

As the Department of Social Services outlined in submission 70 to this Inquiry, as at 31 December 2022, less than 5% of Australian carers were registered with Carer Gateway service providers. By way of contrast, according to Carers UK, around 25% of carers surveyed in 2022 reported having a carer’s assessment or reassessment in the last 12 months in England.²

The UK *Care Act 2014* establishes duties for responsible local authorities to conduct separate assessments of the support needs of adults and their carers.

The purpose of the carer assessment is to involve the carer in identifying the outcomes the carer wishes to achieve in their daily life, and what supports could contribute to achieving these outcomes.

The assessment considers the sustainability of the caring role and the carer’s future needs for support as well as their ability and willingness to provide care now and in the future.

² Carers UK, *State of Caring 2022: A snapshot of unpaid care in the UK*, November 2022
<https://www.carersuk.org/media/ew5e4swg/cuk_state_of_caring_2022_report.pdf>.

Eligible carers are involved in the development of a support plan that outlines how the carer's needs will be met including a personal budget funded by the local authority (which can include direct payments).

Useful links

We reiterate our view expressed both in our submission and at the public hearing on 4 October 2023 that carer recognition legislation alone is unlikely to achieve significant improvements in carer recognition and/or culture change to better value the significant contribution of carers without a complementary and comprehensive system of financial and practical support including appropriate income support, tax offsets, superannuation guarantee contributions, strengthened workplace and equal opportunity protections and access to affordable allied healthcare such as mental health and social work supports.

We note that Canada provides a model for a more comprehensive system of financial support for carers, including the following:

- Carer rights protected through the [Canadian Human Rights Act](#).
- Caregiver income support to those caring for the terminally ill as well as the critically ill or injured ([Government of Canada, Employment insurance care giving benefits \(webpage\)](#))
- Job protected leave in place in provinces and territories (ranging from 5 days to 26 weeks of protected leave, depending on the jurisdiction).
- Rights to request flexible work enshrined in *Canada Labour Code* ([Government of Canada, Flexible work arrangements for federally regulated employees](#)).³
- Non-refundable tax credits for caregivers ([Government of Canada, Canada caregiver credit \(webpage\)](#)).
- Several Canadian provinces also have their own strategies and provide income support to carers and/or job protected leave (ranging from 5 days to 26 weeks of protected leave, depending on the jurisdiction).

Another example of an innovative and progressive law exists in Mexico that provides for occupational cancer leave for parents of children with cancer. Introduced in 2019, the law allows one parent to take leave of up to 28 days to support a child sick with cancer. The leave can be taken multiple times and can be extended to 364 days within a three-year period, during which time parents receive just over half of their salary and access to social security benefits. This law recognises the important role of carers and the often time intense and unpredictable nature of treatment and care for chronic diseases such as cancer.

We also draw your attention to the following submissions we have prepared recently that are relevant to this Inquiry:

³ We acknowledge that recent changes have come into effect in Australia under the *Fair Work Act 2009* (Cth) to make flexible work arrangements easier for employees to obtain, however monitoring and evaluation is required to ensure these amendments are meeting their objectives.

- Submission regarding the Productivity Commission's Position Paper: *A case for an extended unpaid carer leave entitlement?* Cancer Council Australia and McCabe Centre for Law and Cancer, 3 April 2023: https://www.pc.gov.au/data/assets/pdf_file/0007/358153/sub057-carer-leave.pdf
- Submission in support of a new national human rights framework and new national human rights act to the Parliamentary Joint Committee on Human Rights' Inquiry into Australia's Human Rights Framework, Cancer Council and McCabe Centre for Law and Cancer, 30 June 2023 (**attached**).

We once again thank the Committee for the invitation to appear before this Inquiry and for considering this Supplementary Information.