

Suzanne Orr, MLA
Member for Yerrabi
ACT Legislative Assembly
orr@act.gov.au
cc: JasonA.Clarke@parliament.act.gov.au

Dear Ms Orr,

Re: Consultation draft of the Carers Recognition Bill 2021

We write to provide comments on the consultation draft of the Carers Recognition Bill 2021. This feedback is a summary of issues raised during a community consultation forum on the consultation draft of the Carers Recognition Bill 2021, held online by ACTCOSS on Wednesday 3 March 2021. We again thank you for attending that forum and taking feedback.

The community consultation forum heard from community sector organisations whose clients and services would be impacted by the proposed Bill. This included service provider organisations and organisations representing people with disability. ACTCOSS received additional feedback from forum participants subsequent to the event.

We note that there have been other forums and dialogues which have specifically sought input on the Bill from peaks and organisations representing carers. We would encourage you to also closely consider the feedback from these forums.

We welcome the opportunity presented by this proposed Bill to acknowledge carers and the vital role they play in the ACT community. We are particularly keen to see investments in practical supports to enhance the wellbeing of carers. We encourage practical measures which allow carers to be recognised and supported in their workplaces and educational institutions, such as carers leave and carer-friendly policies.

We believe that the intended outcomes of the proposed Bill need to be more clearly stated. The Bill should also more clearly specify which groups of carers will be covered by the Bill and which organisations will need to undertake reporting under this Bill. Further, the Bill needs to explicitly set out how it will lead to increased practical support for carers.

Language is important and therefore in Attachment A we provide specific suggestions for wording which aims to mitigate possible perverse outcomes of the Bill. Such unintended outcomes may unwittingly remove the agency of individuals who are receiving care. We caution against statements that appear to valorise the carer's knowledge and decisions over those of the person receiving care.

Generally speaking, ACTCOSS would expect that proposals such as a Carers Recognition Act are adequately resourced. We note that the ACT Carer's Strategy 2018-28, for instance, has not been realised, nor fully funded. We question if there will be adequate resources allocated to support this Bill, for example, to cover the costs of training staff in the impacted organisations on the new reporting requirements.

Finally, the practical obligations and reporting requirements for community organisations need to be more clearly defined.

While extensive, we hope these comments will be helpful in preparing a Bill which adequately addresses the concerns of carers and those receiving care as well as those of the community sector organisation which support them.

Yours sincerely,

A handwritten signature in black ink that reads "Emma Campbell." The signature is written in a cursive, flowing style.

Dr Emma Campbell
CEO, ACTCOSS

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19 March 2021

Areas requiring clarification or further work

Below we provide specific examples where the consultation draft of the Carers Recognition Bill 2021 requires further clarification. Our comments are non-exhaustive, providing instead, an indication of some issues the proposed Bill raises:

Cover Page

“An Act for the recognition of people in care relationships and for other purposes” (p.1).

- The term “people in care relationships” is problematic. Does the proposed Bill only apply to the carer or does it also cover the person to whom care is being provided (who presumably is one half of the “care relationship”)? The word “relationship” implies a two-way exchange; however the Bill appears to pertain the carer only. (This comment also applies to the use of the term “care relationship” in **Section 5, part 2 (6) (1)**).
- What is meant by “and for other purposes”? The vagueness of this term, although unintentional, may afford scope for perverse uses of the Bill. We suggest that the aims and intent of the Bill are clearly specified and the term “and for other purposes” is removed.

Section 5

Part 2 6 (1) (a) to (e)

- Taking into account intersectional identities
“; or” could be replaced with “; and/or”

Part 6 (3) (a)

- “; or” could be replaced with “; and/or”

Section 7

“Meaning of care and carer support agency” (p. 6)

- Please provide some examples of care and carer support agencies. Under the current definition almost any publicly funded agency will qualify as a care or support agency.

Section 8

Part 3 8 (1) (a) (iii) “[A carer should be recognised as] someone with special knowledge of the person in their care” (p.7).

- The term “special knowledge” is problematic as it potentially creates a hierarchy between the carer and the person receiving care. The person being cared for may also, arguably, have ‘special’ and indeed ‘specialist’ knowledge of their own conditions. Consider removing the word “special” to just read “knowledge”. The proposed Bill cannot override privacy provisions or the rights of people with disability and others receiving care

Part 3 8 (1) (d) “[A carer should] if appropriate, have their views and cultural identity taken into account, together with the views, cultural identity, needs and best interests of the person in their care, in matters relating to the care relationship” (p.7).

- The term “best interests” has a specific meaning in legal situations (such as power of attorney) and guardianship terms and suggests a hierarchy of knowledge and power in a relationship in favor of a carer. This term should not be used in the Bill as it may interact with formal usages of the term in other matters such as power of attorney and guardianship in ways that were not intended.
- The wording “person in their care” is problematic here as it suggests ownership, perhaps replace with “person receiving care”

Part 3 8 (1) (j) to (m)

- Taking into account intersectional identities “; and” (p.8) could be replaced with “; and/or”
- Questions to consider: When and how do individuals report that they identify with a particular community? For example, would there be a consistent set of questions to be asked at the point of intake or review? What if, for example, case workers in a community organisation did not know a carer identified as part of the LGBTIQ+ community, however the carer had assumed that caseworkers knew and were later unhappy to find out that specific support services had been available which the service provider neglected to mention?

Section 9

Unless there is a guardianship order, people receiving care should be the primary voice and in any decisions and advocacy made about their welfare. However, in the proposed Bill there is an absence of the primary right of the person receiving care to express their views. For example, **Section 8 (1) (a) to (m)** lists a page of expectations to respect the carer's rights. By contrast, **Section 9 (a) and (b)** contains far less information on the "treatment of people being cared for" (p.9). The primacy of the carer's rights is contrary to the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).

A person receiving care's intersectional identity should also reflect the categories outlined for carers in **Part 3 Section 8 (1) (j) to (m)**.

"A person being cared for in a care relationship should –"
(b) (i) "have their views, needs, cultural identity taken into account ..." (p.9)
(b) (ii) "have their changing needs considered and taken into account" (p.9)

- Questions for consideration: How are changing needs assessed? How often (i.e. at regular intervals, through a review process or as issues arise)? What practical steps need to be taken to measure this has happened?

Section 10

10 (b) [A person in a care relationship should] "have their views considered in the assessment ..." (p.9)

- The choice of the wording "considered" is problematic, especially when taken with the description of the carer as having "special knowledge" (p.7). By contrast, the person to whom care is provided is described as having their views "taken into account" (p.9). Although such language is perhaps unintentional, such contrasting statements set up a potential hierarchy which could approach substitute decision making rather than a rights-based approach with supported decision making.

Section 12 Reporting obligations of care and carer support agencies

12 (1)

Please provide details on the threshold for reporting. It is important to work with service providers to provide clear and practical guidelines.

- Questions for consideration: Will community and other organisations be provided with detailed guidelines and training on reporting requirements? Will community and other organisations be given extra funding to cover the costs involved in producing reports (e.g. staffing hours)? What is the value of the proposed reports and how will the data collected be used? What will be the costs to the ACT government to monitor reporting? Would that money be better spent on measures that have a more direct benefit for carers, (for example, increased funding for carer respite services?)

Other Issues

Definition of a Carer

The definition of a carer requires further consideration.

- Questions to consider: Could someone be considered a carer if they only provide financial support? Or accommodation? Are there carers who do not consider themselves to be carers?
- Whose responsibility is it to identify as a carer to a service organisation? Do carers divulge that they are a carer? What happens when a carer self-identifies as a carer but the person receiving care does not acknowledge the carer? (This could have practical implications if a workplace grants an individual paid carers leave but the person does not actually provide care). Alternately, should the responsibility lie with the person receiving care to recognise a carer? If that is the case, what if the person receiving care refuses or does not want to notify the service agency?

- It would be useful to list practical examples of what is a reasonable length for an organisation to go to provide support to a carer (e.g. provide brochures, warm referrals).
- Finally, the Bill does not explicitly recognise young carers, nor the unique needs of this cohort.

Definition of Disability

We recommend that the Carers Recognition Bill 2021 uses the definition of disability drawn from the UNCRPD, instead of the proposed definition which is drawn from the Disability Discrimination Act 1992 (DDA). The DDA definition does not utilise the current best practice definition based on the social model of disability. The social model definition is taken from UNCRPD, which states:

“disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others.”¹

We recommend the Carers Recognition Bill 2021 uses the definition in the ACT Disability Justice Strategy which is based on the UNCRPD definition:

“Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.”²

Guardianship legislation

It is not clear how the proposed Bill relates to guardianship legislation. There is concern that the proposed Bill may contradict a person’s absolute right to make their own decisions if they are not under any order precluding them from doing so.

¹ <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/preamble.html>

² <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-1-purpose.html>

Supported Decision Making

The Bill does not actively refer to the principles of supported decision making. The Bill should reflect the fact that the ACT has moved away from substitute decision making.

Inconsistencies between this Act and other legislation/ Commonwealth agency procedures

The Bill appears to be trying to influence the operation of Commonwealth legislation including income support payments for carers. It is unclear how the ACT Government will achieve outcomes for carers through this Bill in areas of policy that are currently the remit of the Federal Government.

For example, currently Carers Allowance and the Carers Pension are only paid to non-kinship foster carers. This Bill cannot influence this Commonwealth legislation to improve outcomes for carers.

Further, providing funding directly to carers does not align with the values established in the person-centred National Disability Insurance Scheme (NDIS). In the NDIS, funding is provided to the person with disability. This is generally accepted as the preferred model. Although carers maybe be NDIS plan nominees, they do not receive payments directly.

Many organisations providing support to people with disability in the ACT, including those funded under the NDIA, or through other Commonwealth mechanisms, such as Local Area Coordinators (LACS), may encounter problems or contradictions meeting their obligations under Commonwealth legislation and meeting the obligations that this Bill would give rise to.