

REPORT ON INQUIRY INTO THE CARERS RECOGNITION BILL 2021

STANDING COMMITTEE ON HEALTH AND COMMUNITY WELLBEING

AUGUST 2021

REPORT 2

THE COMMITTEE

COMMITTEE MEMBERSHIP

Johnathan Davis MLA (Chair)

Elizabeth Kikkert MLA (Deputy Chair) to 30 March 2021

James Milligan MLA (Deputy Chair) from 30 March 2021 and Deputy Chair from 6 April 2021

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RESOLUTION OF ESTABLISHMENT

The ACT Legislative Assembly appointed the Standing Committee on Health and Community Wellbeing (HCW Committee) on 2 December 2020.¹

Specifically, the resolution appointing the HCW Committee provides that:

- (1) the following general-purpose standing committees be established as set out in the table below. The purpose of such committees is to enhance the scrutiny of the Executive, to examine and suggest improvements to any bills referred to it, to enable the citizens of the Territory to engage and to participate in law-making and policy review, to enable financial scrutiny of the Executive's budget proposals and to review annual reports of taxpayer funded agencies;
- (2) the committees so established may inquire and report on matters referred to it by the Assembly or matters that are considered by the committee to be of concern to the community and within the nominated areas of responsibility;
- (3) calendar and financial year annual and financial reports stand referred to the relevant standing committee for inquiry and report by 9 April of the year after the presentation of the report to the Assembly pursuant to the Annual Reports (Government Agencies) Act 2004;
- (4) notwithstanding standing order 229, only one standing committee may meet for the consideration of the inquiry into the calendar and financial year annual and financial reports at any given time;
- (5) all bills presented to the Assembly stand referred to the relevant standing committee for inquiry and report within two months from the presentation of the bill, except for those bills introduced in the last sitting week of the calendar year where the committee shall report in three months. Within 14 days of the presentation of the bill in the Assembly, the committee must decide whether or not to undertake an inquiry, and shall inform the Speaker of its decision, the Speaker must then arrange for all members to be notified. In the event that the subject matter of the bill makes it unclear which committee it should be referred to, the Speaker will determine the appropriate committee;

.....
- (7) the committees so established are required to examine the expenditure proposals contained in the main appropriation bills for the Territory and any revenue estimates proposed by the Government in the annual budget and prepare a report to the Assembly within 60 days of the presentation of the budget bills;

.....

¹ ACT Legislative Assembly, Minutes of Proceedings No. 2, pp. 17-21. (as amended 11 Feb 2021, 30 Mar 2021, and 22 Apr 2021).

- (12) each committee shall have power to consider and make use of the evidence and records of the relevant standing committee appointed during the previous Assembly;
- (13) each committee be provided with necessary staff, facilities and resources;
- (14) the foregoing provisions of this resolution, so far as they are inconsistent with the standing orders, have effect notwithstanding anything contained in the standing orders;
- (15) each general-purpose committee shall consist of three members, nominated by each of the three whips, with the chair of each such committee agreed by the members of that committee; and
- (16) nominations for membership of these committees be notified in writing to the Speaker within two hours following conclusion of the debate on the matter.

Committee	Primary Wellbeing Indicators	Areas of Responsibility
Health and Community Wellbeing	Health and Social Connection	<ul style="list-style-type: none"> • Health and health system • Justice Health • Mental Health • Homelessness and housing services • Prevention of Domestic and Family Violence • Families • Community Services

TERMS OF REFERENCE

Pursuant to clause 5 of the Resolution of Establishment for general-purpose standing committees of the 10th Assembly—the terms of reference are to inquire into and report on the referred Bill within two months from its presentation.

ACRONYMS

ACT	Australian Capital Territory
ADACAS	ACT Disability Aged and Carer Advocacy Service
AM	Member of the Order of Australia
CMHF	Canberra Mental Health Forum
HCW	Health and Community Wellbeing
HRA	<i>Human Rights Act 2004 (ACT)</i>
OAM	Medal of the Order of Australia
UC	University of Canberra

TABLE OF CONTENTS

THE COMMITTEE	I
Committee Membership	i
Secretariat	i
Contact Information.....	i
Resolution of Establishment	ii
Terms of reference.....	iii
ACRONYMS	IV
RECOMMENDATIONS	VII
1 CONDUCT OF THE INQUIRY	1
Referral of the Bill	1
2 BILL CONTEXT.....	2
Background	2
Summary of Measures the Bill is Seeking to Enact	2
Part 1 (Preliminary)	2
Part 2 (Objects and important concepts).....	2
Part 3 (Care relationship principles)	3
Part 4 (Obligations relating to care relationship principles).....	3
Part 5 (Miscellaneous).....	4
Schedule 1 (New Carers recognition Regulation).....	4
Dictionary	4
Legislative Scrutiny	5
3 VIEWS PUT TO THE COMMITTEE ON THE BILL	6
Introduction.....	6
Ms Suzanne Orr MLA.....	6
Carers ACT.....	8
University of Canberra	10
Dr Jennifer Thomson AM	11
Canberra Mental Health Forum.....	12
Ms Ros Williams OAM.....	13
ACT Disability Aged and Carer Advocacy Service	14
4 ISSUES CONSIDERED BY THE COMMITTEE AND RECOMMENDATIONS	16
Broad Support by Carers and Carers Groups	16

Definitional Issue ‘Care and Carer Support Agency’	17
Reporting Obligations—Strength and Funding Arrangements.....	17
Contribution of Bereaved Carers	18
5 COMMITTEE CONCLUSIONS	19
APPENDIX A – WITNESSES	21
27 July 2021	21
APPENDIX B – SUBMISSIONS.....	22
APPENDIX C – JURISDICTIONAL COMPARISON TABLE	23

RECOMMENDATIONS

RECOMMENDATION 1

- 4.3 The Committee recommends that the ACT Government support the Carers Recognition Bill.

RECOMMENDATION 2

- 4.4 The Committee recommends that that a supplementary explanatory memorandum for the bill discuss the impact of the bill on carer's organisations and the role of carers in advocacy and policy as well as caring.

RECOMMENDATION 3

- 4.5 The Committee recommends clarifying the wording in the Bill to provide an easy to comprehend understanding of an informal carer's connection with a care relationship.

RECOMMENDATION 4

- 4.6 The Committee recommends that consideration be given to broadening the scope of the Bill to ensure that support for carers through a support organisation (not described as an agency) is included.

RECOMMENDATION 5

- 4.7 The Committee recommends that consideration be given to including specific recognition for the needs of informal, volunteer or family carers.

RECOMMENDATION 6

- 4.9 The Committee recommends that the ACT Government as part of implementing the Bill provide advice on who is a care and carer support agency.

RECOMMENDATION 7

- 4.12 The Committee recommends that the ACT Government consider stronger and more comprehensive reporting requirements than currently in the Bill.

RECOMMENDATION 8

- 4.13 The recommends that the ACT Government support the bill including organisations' reporting obligations.

RECOMMENDATION 9

- 4.14 The Committee recommends that the scope of recognition proposed by the Bill be expanded to allow for reporting on a wider range of issues experienced by carers.

RECOMMENDATION 10

- 4.15 The Committee recommends that the ACT Government provide adequate resources to a suitable provider to produce guidance material for entities to meet their reporting requirements.

RECOMMENDATION 11

- 4.16** The Committee recommends that the ACT Government resource community organisations to support the implementation of new obligations proposed in the Bill.

RECOMMENDATION 12

- 4.17** The Committee recommends that the ACT Government develop a simple reporting tool and straightforward reporting requirements to enable compliance with reporting obligations.

RECOMMENDATION 13

- 4.19** The Committee recommends that the ACT Government recognise the contribution that bereaved carers can make when formulating policy.

1 CONDUCT OF THE INQUIRY

REFERRAL OF THE BILL

- 1.1 The Carers Recognition Bill 2021 (the Bill) was presented to the ACT Legislative Assembly (the Assembly) on 23 June 2021. Pursuant to clause 5 of the Resolution of Establishment for 10th Assembly general-purpose standing committees (the Resolution of Establishment), the Bill was referred to the Standing Committee on Health and Community Wellbeing (the Committee) for inquiry and report.
- 1.2 Pursuant to the Resolution of Establishment, all bills presented to the Assembly stand referred to the relevant standing committee for inquiry and report within two months from presentation. A standing committee has 14 days from presentation to determine whether it will undertake an inquiry into a referred bill.

COMMITTEE INQUIRY

- 1.3 The Committee resolved on 6 July 2021 to undertake an inquiry into the Bill.
- 1.4 The Committee wrote to the Speaker and Ms Suzanne Orr MLA (as the private member who introduced the Bill) on 12 July 2021 to inform each stakeholder of its decision.
- 1.5 The Committee called for submissions from the public, resulting in 6 submissions being received.
- 1.6 The Committee held a public hearing on 27 July 2021 to hear from relevant stakeholders including the private member Ms Suzanne Orr MLA.
- 1.7 The Committee met on 17 and 24 August 2021 to consider the Chair's draft report which was adopted on 24 August 2021.

2 BILL CONTEXT

BACKGROUND

- 2.1 To date, the ACT Legislative Assembly has never enacted a recognition bill of the type which the *Carers Recognition Bill 2021* belongs. The Bill, in its current form, expressly does not seek to create in any person a legal right or give rise to any civil cause of action. The objects of the Bill centre around recognition of carers as individuals and the value they bring to those they care for and the wider community. The Bill also proposes new reporting requirements against Care Relationship Principles for care and carer support agencies.
- 2.2 While new to the Territory, all other jurisdictions except Tasmania have enacted similar legislation. Though substantially similar, each jurisdiction's law varies in detail (see Appendix C).

SUMMARY OF MEASURES THE BILL IS SEEKING TO ENACT

PART 1 (PRELIMINARY)

- 2.3 Part 1 of the Bill contains provisions which are largely standard across all bills for principal Acts in the Territory including the sections entitled Name of Act, Commencement, Dictionary, and Notes. The Bill's commencement provision (proposed section 2) would see its substantive provisions commence by written notice from the Executive or by default commencement (6 months after its notification day).

PART 2 (OBJECTS AND IMPORTANT CONCEPTS)

- 2.4 Proposed section 5 (Objects of Act) sets out the objects of the Act which relate to recognition of carers and care relationships, the differing needs of people in those relationships, and the value care relationships to the community. Proposed section 5 also states the objects to enact Care Relationship Principles and to create annual reporting requirements against those principles for entities defined as *care and carer support agencies*.
- 2.5 Proposed section 6 defines 'care relationship' and by extension 'carer'. The Bill provides that a regulation may further that definition section 6 (2). Proposed section 6 (4) limits the definition to exclude paid carers, organised volunteers (other than an approved kinship and foster care organisation), and occupational trainees.

- 2.6 Proposed section 7 defines '*care and carer support agency*' to include a public sector support agency, a government funded support agency, or a secondarily funded support agency (meaning an agency which is funded by a government funded support agency). Proposed subsection 7 (d) allows for a regulation to prescribe other entities as meeting the definition.

PART 3 (CARE RELATIONSHIP PRINCIPLES)

- 2.7 Proposed section 8 sets out the Care Relation Principles (the principles) which are the central element of the Bill. Proposed subsection 8 (1) pars (a) to (g) relate to carers being recognised as individuals in their own right, who should be supported, acknowledged for their efforts, and have their views and identity considered in relevant decision making. Proposed subsection (1) (h) relates to support agencies making carers aware of the principles and taking them into account in their planning and operation. Proposed subsection 8 (1) pars (i) to (m) relate to elements of a carer's identity such as age, indigenous status, LGBTIQ+ status, cultural diversity, and disability taken into account and acknowledge in decision making. Proposed subsection 8 (2) is a provides a definition of *Aboriginal or Torres Strait Islander person* for the section.
- 2.8 Proposed section 9 states that a person receiving care should also have their individual rights recognised.

PART 4 (OBLIGATIONS RELATING TO CARE RELATIONSHIP PRINCIPLES)

- 2.9 Proposed section 10 sets out proposed obligations of care and carer support agencies relating to the *Care Relationship Principles* (from proposed section 8). The first obligation is to take measures to ensure carers and agency staff are aware of and understand the principles. The second obligation is to ensure that agencies consult with carers and their representative entities in program development and alterations to service and consider the principles as they relate to internal human resources policies.
- 2.10 Proposed section 11 would create an annual reporting requirement for care and carer support agencies on their obligations in proposed section 10, including on relevant progress and steps taken. Relevant government agencies must report this in their annual report. Government funded agencies must make the report publicly available and secondary funded agency should consider doing so. Proposed subsection 11 (2) contains a typographical error—the mention of '*care and care support agency*' is understood to be a reference to the defined term '*care and carer support agency*' from proposed section 7.

PART 5 (MISCELLANEOUS)

- 2.11 Proposed section 12 (Legal rights not affected) expressly states that the Assembly would not, if passed, intend for the Bill to create any legal right, or give raise to any civil action.
- 2.12 Proposed section 13 stipulates that where the Bill is inconsistent with another territory law, that law should take precedent over the Bill (except for the reporting obligations in proposed section 11).
- 2.13 Proposed section 14 allows the Minister to make a regulation for the Bill. The proposed Regulation is made by proposed section 16 and is included in schedule 1 of the Bill.
- 2.14 Proposed section 15 requires that the operation of the Bill, if made, be reported on to the Legislative Assembly by the government after 5 years.
- 2.15 Proposed section 16 would, if enacted, make the Regulation proposed in Schedule 1.

SCHEDULE 1 (NEW CARERS RECOGNITION REGULATION)

- 2.16 Schedule 1 sets out a new Regulation for the making under proposed section 16 (as though made under proposed section 14).
- 2.17 Clauses 1 to 3 contain provisions which are largely standard across all regulations for making in the Territory including Name of Regulation, Dictionary, and Notes. The proposed Regulation does not include a 'Commencement' as its commencement is provided for by the Bill (proposed section 16).

DICTIONARY

- 2.18 The dictionary contains defined terms and signpost definitions to definitions throughout the Bill and external statutes.

LEGISLATIVE SCRUTINY

- 2.19 The Carers Recognition Bill 2021 was reported on by the Standing Committee on Justice and Community Safety (Legislative Scrutiny Role) in Scrutiny Report 7, released 27 July 2021².

In relation to the care relationship principles and their mentions of elements of carer's identities, such as cultural diversity, the report states;

...The Bill will therefore draw a distinction between carers and non-carers, and within carers. However, it is not clear to the committee whether this will provide any advantage to carers included by the Bill or disadvantage others who may similarly be in need of recognition³.

- 2.20 The report notes that, in relation to obligations under the principles for care and carer support agencies, it is not clear in the Bill or its explanatory statement why the principles should apply only when developing internal human resources policies. The report notes it is also unclear why consultation with carers is obligation in instances where the person being cared for and others affected by the planning decision or review may not have to be consulted with.

- 2.21 The scrutiny report, in relation to it being unclear how the obligations imposed by the bill are intended to be enforced, states;

The Bill includes various provisions limiting the obligations imposed by the Bill. Proposed subsection 10(3) makes it clear that agencies will not be required to provide financial assistance or services to people in care relationships. Under proposed section 12, there is no intention to create in any person any legal right or give rise to any civil cause of action. Under proposed section 13, other territory legislation will prevail over any inconsistent provisions in the Bill (other than provisions relating to reporting)⁴.

- 2.22 The report notes it is unclear how the proposed obligations of agencies may impact their legal authorities relating to the provision of services. The report raises whether, for example, upholding the principles may invalidate decisions made under existing legislation in circumstances where that legislation may not be considered inconsistent with the principles.

- 2.23 The Scrutiny Committee has sought a response from Ms Orr in relation to the following issue;

The obligation to uphold the care relationship principles and report on compliance may also require an agency to inquire about potential carers and persons who they are caring for. There is no requirement for the agency to be providing carer support services to the person being cared for or to already have access to information about the carer. The Bill may therefore potentially limit the protection of privacy protected by section 12 of the HRA⁵.

² Standing Committee on Justice and Community Safety (Legislative Scrutiny Role), [Scrutiny Report 7](#), July 2021.

³ Standing Committee on Justice and Community Safety (Legislative Scrutiny Role), [Scrutiny Report 7](#), July 2021, p 1.

⁴ Standing Committee on Justice and Community Safety (Legislative Scrutiny Role), [Scrutiny Report 7](#), July 2021, p 2.

⁵ Standing Committee on Justice and Community Safety (Legislative Scrutiny Role), [Scrutiny Report 7](#), July 2021, p 2.

3 VIEWS PUT TO THE COMMITTEE ON THE BILL

INTRODUCTION

- 3.1 This chapter includes summaries of the views put to the Committee during its inquiry into the Bill. All six written submissions received by the Committee are summarised in this chapter. Individuals who gave oral evidence to the Committee are listed either under the name organisation they represented at the hearing or, if appearing in their capacity as an individual, under their name.

MS SUZANNE ORR MLA

- 3.2 Ms Suzanne Orr MLA provided a written submission to the Committee, in the form of a copy of her introduction speech delivered in the Assembly for the Bill delivered on 23 June 2021. submission states:

The bill will recognise, promote and value the role carers have within our community. The bill will put in place measures requiring certain entities and organisations to consider and adapt business practices to support the care relationship that exists between carers and the people they care for. The bill establishes a set of principles relating to supporting people in care relationships. The bill also places obligations on care and carer support agencies to uphold and report on compliance with the carer relationship principles.⁶

Carers are some of the most selfless people in our community who work very hard supporting those within our community who need care. The work of carers is generally unrecognised and carers themselves often do not receive the support that they need to carry out their caring responsibilities or to look after themselves. ... This bill is not intended to create a hierarchy between carers and those receiving care; it is about all people in the care relationship being seen, heard and respected.⁷

⁶ Ms Suzanne Orr MLA, *Submission No. 1*, p 1.

⁷ Ms Suzanne Orr MLA, *Submission No. 1*, p 1.

3.3 Ms Orr continues in detailing the role of consultation in development of the final Bill stating:

A consultation draft of the Carers Recognition Bill 2021 was released in January 2021, and several individuals and organisations provided feedback on the consultation draft. In addition, two forums were held, one with Carers ACT and one with ACTCOSS, where feedback from all of their membership was provided.⁸

3.4 Ms Orr's submission then proceeds to detail the fundamental operational elements of the Bill and the interrelationship between sections and definitions in the Bill. Following this Ms Orr provided first-hand accounts of carers including those of her parents. Ms Orr, in quoting accounts of two separate individuals, notes that most other jurisdictions have enacted similar legislation and the ACT is an outlier in this regard.⁹

3.5 In her appearance before the Committee hearing on 27 July 2021 Ms Orr MLA reiterated her reasons for presenting the Bill. In response to a question relating to the enforceability of the Bill and its obligations relating to the care relationship principles, Ms Orr MLA stated;

The principles are there. The enforcement comes through the reporting. This bill is a little bit different...in that it does have a larger reporting obligation than other jurisdictions. That is based on the feedback that we have seen in other jurisdictions, where it has been a bit of a toothless tiger. That was the feedback we got—that there needs to be some level of enforcement¹⁰.

3.6 Ms Orr explained further that;

...we had a lot of organisations saying, “We don’t want a burdensome reporting requirement.” So quite an effort and thought went into finding that balance. Where we got to was the regulation, which provides a template. A lot of the organisations said in the feedback that they want to do the right thing. They said, “It needs to be clear as to what we need to report on.”¹¹

3.7 Ms Orr stated that the regulation was based on a Victorian regulation for that State’s Carers Recognition Act which was found to be working well. Ms Orr told the Committee, in relation to who is reading and checking compliance of obligations in annual reports;

In the first instance it would be that public scrutiny. I would say that there would be a lot of carers looking at those, in the first place. ... As to the reporting, there is a review period within the bill. So government would have to have a look at whether those obligations are being met under that review. ... Through the review period, if it were not providing what some people feel it will not provide, we would need to build that

⁸ Ms Suzanne Orr MLA, *Submission No. 1*, p 1.

⁹ Ms Suzanne Orr MLA, *Submission No. 1*, p 4 and p 6.

¹⁰ *Proof Committee Hansard*, 27 July 2021, p 14.

¹¹ *Proof Committee Hansard*, 27 July 2021, p 15.

evidence base before we suddenly said that people are not going to do the right thing and we were going to put in reporting requirements that are a lot stricter ¹².

3.8 In relation to the definitions of 'care' and carer agency' Ms Orr said,

While it is still not entirely perfect, I think it is going to be very hard to legislate something that goes to every single part of the care relationship, given the care relationship is actually quite broad. ... identifying what is considered a carer and care relationship agency, and who is not, under the definition. I think that is much better done either through a guideline or through a regulation, rather than through the actual law, because these agencies will come and go. ... So, if we try to get too prescriptive in the law, I am worried that we would end up not including things in the future that should be included¹³.

CARERS ACT

3.9 In its written submission Carers ACT welcomed the introduction of the Bill and stated that having carers recognised in this way is a significant step to acknowledging the contribution they make to the community and increasing the supports, recognition, and inclusion they deserve¹⁴. Carers ACT noted the diverse range of individuals needing care and the diversity of those who provide unpaid care to them. Carers ACT expressed it believes that having a carers recognition Act will help carers to feel valued and supported in the community and will improve their health and wellbeing.

3.10 Carers ACT noted its support for the objects proposed in the Bill and the care relationship principles. Carers ACT welcomed the annual reporting requirements the Bill seeks to impose on care and carer support agencies. Carers ACT stated support for the consultation requirements included in the principles but contrasted this against a stated need for government to include additional financial support to ensure consultation is feasible, inclusive, and non-tokenistic.

3.11 Carers ACT stated that;

Carers ACT have consulted with Carers within the ACT regarding their thoughts about the Act and these are very positive, and carers are grateful for the acknowledgement. Through an online voting poll more than 99% of carers indicated support for the Act¹⁵.

¹² *Proof Committee Hansard*, 27 July 2021, pp 15-16.

¹³ *Proof Committee Hansard*, 27 July 2021, p 17.

¹⁴ Carers ACT, *Submission No. 2*.

¹⁵ Carers ACT, *Submission No. 2*, p 12.

3.12 Carers ACT noted comments it received from carers on the Bill including about recognition of those with multiple caring roles, about not being perceived as a ‘carer’ not an individual, and the stigma of and inability to access or use carer’s leave. The submission mentions the difficulty induced by foster and kinship carers being defined by different terms like ‘volunteer’ or ‘workers’ in different statutes. The submission notes comments from carers in the mental health space on expressing concern about ensuring carers of people with ‘mental disorders’ and ‘mental illnesses’ as described in the Mental Health Act 2015 are both included, as well as carers for individuals with episodic conditions.

3.13 Carers ACT noted the interpretation of the legislation may leave some ambiguity, particularly around what is ‘recognised’ in terms of carer recognition and what ‘support’ looks like.

Carers ACT stated that:

To ensure the spirit of the Bill is furthered it will take willing champions beyond just those within Carers ACT and carers themselves. It will take government and non-government organisations alike to make more deliberate consideration of what they could do to assist carers they support...¹⁶

3.14 The submission mentions the ongoing debate around adequately defining ‘carers’ in society and notes that it remains a stumbling block to accessing supports to for a range of ‘unseen’ carers and that this may limit the application of the Bill. In relation to the personal cost of caring the submission asserts that if the Bill can go even part way to alleviate some of these social, physical, emotional and financial costs it will be successful and worthwhile.

3.15 The submission from Carers ACT concludes that Carers ACT and the vast majority of carers in the ACT support the proposed Carer Recognition Act. We are pleased to see the value and worth of carers being recognised and believe that the Act will assist in ensuring that we continue to build a Canberra that Cares for Carers.

3.16 Carers ACT Chief Executive Officer Ms Lisa Kelly appeared before the committee in its public hearing. In response to a question on reporting requirements Ms Kelly stated:

I do not believe the reporting requirements in the bill are onerous compared to the reporting requirements we have for people who receive care. I think some guidance around that is what is needed.

For public agencies, again I would like to see that they are given very strong guidance and training on how to apply the principles, how to report on their application of the principles, but also how to implement remedies when they have failed to deliver properly on the principles and on the supports, when that has been demonstrated, through a lack of reporting systems or gaps in them¹⁷.

¹⁶ Carers ACT, *Submission No. 2*, p 13.

¹⁷ *Proof Committee Hansard*, 27 July 2021, p 8.

- 3.17 In response to a question on why Carers ACT recommended that there are no changes to the reporting requirements, Ms Kelly responded;

I am concerned that the reporting requirements will be taken from the bill. ...

So I have written that as the recommendation. I would like to increase them, but my base recommendation is to say that they should not be taken out, that they should not be dissolved any further than they are, that they are not onerous, and that it is a very tokenistic bill, from my perspective, without the reporting requirements included in it¹⁸.

UNIVERSITY OF CANBERRA

- 3.18 Ms Jane Diedricks, Dr Bruce Baer Arnold, and Dr Raechel Johns from the University of Canberra (UC) made a joint submission to the committee's inquiry. Their comments include that the Bill is a welcome and commendable step towards greater recognition of the significance of caring in the ACT¹⁹. That significance is often under-recognised because caring (alongside unremunerated activity within households) is often unquantified and under-valued in an environment where monetary value is construed as the meaningful metric of 'value'.²⁰
- 3.19 The submission notes the Bill acknowledges the diversity of relationships and contexts in which caring takes place and seeks to foster respect for carers and the people for whom they care as individuals rather than as objectified 'one-size-fits-all' care providers and recipients²¹.
- 3.20 The submission states that the Bill is, alongside the Human Rights Act 2004 (ACT) essentially aspirational, centred on a requirement to alert carers to the proposed Carer Principles and for organisations to report on that alerting. The submission states the Bill does not require support for carers, something that is important given the large official and scholarly literature on carer burn-out, and the exclusion regarding reporting is inappropriate²².

¹⁸ *Proof Committee Hansard*, 27 July 2021, p 10.

¹⁹ UC, *Submission No. 3*.

²⁰ UC, *Submission No. 3*, p 1.

²¹ UC, *Submission No. 3*, p 1.

²² UC, *Submission No. 3*, p 1.

- 3.21 The submission makes four recommendations to the ACT Government. One, to foster development of a coherent national carer support program, through for example intergovernmental discussion at the National Federation Reform Council Two, to actively explore what support might be provided by the ACT Government, including prioritisation of access. Three, to liaise with employer associations and other relevant groups to engender support for the more expansive definition of a carer under this Bill. Four, to aggregate and evaluate data provided through the individual reports mandated under the Bill. Reporting is a means to an end, rather than something undertaken for its own sake without any impact on policy-making and funding decisions.²³

DR JENNIFER THOMSON AM

- 3.22 Dr Jennifer Thomson AM, a retired general practitioner with experience as a carer for her daughter and past experience caring for her elderly parents, made a written submission the inquiry.
- 3.23 Dr Thomson's submission makes the following three statements in relation to the Bill:
- Clause 5(e) of the Act refers to care and care support agencies being required to uphold and report on compliance with care relationship principles. I am concerned that the definition of "care and care[r] support agencies" is not clear. The explanations provided for these terms in Clause 7 and further clarifications in the Definition section of the Act do not make it clear that organisations such as public hospitals or community health services are included in these definitions. I am presuming that ACT Health organisations are indeed considered to be "care and care support agencies" and if so, I would suggest that by way of clarification, some examples of care and care support organisations could be given (e.g. public hospital, community health service) within either Clause 7 or the Definitions Section of the Act.
 - It appears that the Act only applies to public agencies or organisations funded by public funds. This limits the effectiveness of this Act. Many of the care and support agencies providing health, aged care, disability and mental health services are private organisations and privately funded. Consideration must be given to ensuring that care relationship principles are upheld in these organisations as well, otherwise this Act will only have limited benefit.
 - I am pleased to see that the Act provides for some accountability and reporting measures for care and care support agencies. I would suggest that carers and

²³ UC, *Submission No. 3*, p 1.

organisations representing carers be included in any process of monitoring compliance with this Act and in any review process of this Act.²⁴

CANBERRA MENTAL HEALTH FORUM

- 3.24 The Canberra Mental Health Forum (CMHF) made written submission to the inquiry as prepared by Ros Williams OAM²⁵. The CMHF noted its support for both carers and those receiving care, stating that sharing of information and co-design of services and programs, as partners in care, improves wellbeing for people receiving care and carers.
- 3.25 The submission notes that not all those who meet the definition of carer necessarily identify as such and may not access services or support because of this. The submission mentions that (unpaid) carers may be the main point of continuity for people receiving care due to staff changes in care providing agencies and that their assistance may make an independent life a possibility²⁶.
- 3.26 The CMHF states a belief that the Bill is a very positive step in recognising the valuable role of carers but does suggest amendment to the Bill. The submission provides detailed recommendations for amendments in a table. The submission states, in relation to its recommended changes:

We provide some general points requesting clarification on scope and inclusions/exclusions; definitions; terminology; issues around transition of care such as discharge planning; and annual reporting. We also highlight broader concerns including:

1. The Bill only focusses on individual carers, without recognising or promoting the contribution carers, as a group, can make to policy, planning, evaluation, education/training of staff;
2. The need to ensure there is sufficient workforce funding to meet the obligation to support carers and to meet the obligations in the Bill.²⁷

- 3.27 CMHF representative Dr Alison Childs appeared before the committee during its hearing into the Bill. Dr Childs reiterated a number of particular issues which were identified in the written submission from CMHF. Dr Childs, in relation to CMHF's position on the Bill, stated:

We certainly believe that the ACT Carer Recognition Bill 2021 is a very positive step in recognising the valuable role of carers. However, we do consider that some

²⁴ Dr Jennifer Thomson AM, *Submission No. 4*.

²⁵ CMHF, *Submission No. 5*.

²⁶ CMHF, *Submission No. 5*, p 1.

²⁷ CMHF, *Submission No. 5*, p 1.

amendments would aid clarity and scope. I have included in the submission, in table 1, a list of 11 points that are pertinent, relating to the wording within the bill²⁸.

...

One point that we would like to make is that the bill generally focuses on individual carers without recognising or promoting the contribution of carers groups. Often carers are time poor, stressed and overwhelmed. In these cases, advocacy groups, reflecting different components of the population, can assist with policy, planning, evaluation, education and training. The other major issue is ensuring that there is sufficient workforce funding to meet the obligations that are included in the bill to support both the carers and the community²⁹.

- 3.28 Dr Childs also made mention of issues around inclusion of bereaved carers and system planning when people are transitioning from care. On those matters, Dr Childs deferred to Ms Williams OAM to give further detail.

MS ROS WILLIAMS OAM

- 3.29 Ms Ros Williams OAM appeared before the committee in her private capacity. Ms Williams emphasised how important she feels it is for the ACT to have a strong Carers Recognition Act in her opening statement to the committee. Ms Williams expressed the view that the legislation seems will overdue given the similar enactments in other jurisdictions and in the context of rising numbers of carers across the country. On why the Bill is needed Ms Williams stated that;

...legislation is required because carers in the ACT have great difficulty in having both their individual and collective voices and opinions heard. ... I have lost count of the numbers of distraught carers who have told me stories about being treated with disregard and being stigmatised. At times their loved ones, and sometimes the families and even our community, are being placed in danger because they have not been provided with sufficient information to enable them to provide the quality of care that their family member requires, or have sufficient back-up if things go badly.³⁰

- 3.30 Ms Williams discussed issues around discharge planning in detail, stating in part that;

The two weeks after being discharged from a mental health facility is the high danger period, and the time that a patient is most likely to be readmitted to a facility. So it is very important that this legislation is specific in listing discharge planning. ... Recent anecdotal evidence shows that often these documents are still not being completed, and rarely are families provided with a copy or have the plan discussed with them,

²⁸ *Proof Committee Hansard*, 27 July 2021, p 1.

²⁹ *Proof Committee Hansard*, 27 July 2021, p 1.

³⁰ *Proof Committee Hansard*, 27 July 2021, p 3.

even if they are nominated people. ... If a family member is being discharged into a carer's own home, that carer needs to at least have the basic information.³¹

3.31 Ms Williams told the committee that, while aware of complex issues of privacy;

Carers are often portrayed as people who want more information than they are entitled to. Generally, I do not find this to be the case. My experience is that most carers would like nothing better than for their unwell family member to manage their own health, accommodation, finances and social interactions without assistance from their families and carers, and for them to become involved only when it seems absolutely necessary.³²

3.32 Ms William recommended that the definition of 'carer' in the Bill be expanded included bereaved carers. Ms Williams detailed the reasons for this including capturing bereaved carer support agencies in the reporting requirement for the Bill, tracking of numbers of bereaved carers, and issues bereaved carers face in navigating support and coronial systems in the Territory³³.

ACT DISABILITY AGED AND CARER ADVOCACY SERVICE

3.33 The ACT Disability Aged Care and Carer Advocacy Service (ADACAS) provided a written submission to the committee³⁴. In its submission ADACAS acknowledged the importance of carers and the invaluable support they provide. ADACAS recognised and strongly endorsed the need for carers to receive the support they need as individuals and in their capacity as carers.

3.34 ADACAS emphasised a need to continue to consider the human rights of all parties in care relationships. ADACAS also emphasised the importance of the Bill not seeking to inadvertently privilege the rights of carers above others in care relationships whose rights should predominate. ADACAS stated that, in its view, the Bill also needs to seek to avoid unintended negative consequences for those in care relationships whose rights may be overlooked or inadequately considered by broader society.³⁵

3.35 ADACAS noted its participation in providing feedback on earlier drafts of the Bill and in relation to this stated;

we had asked that the bill distinguish between the rights to support the carers need for themselves ...and the carer's rights in their role of caring for another person. With the latter, it is imperative that the legislation is framed in such a way as to ensure that in

³¹ *Proof Committee Hansard*, 27 July 2021, p 3.

³² *Proof Committee Hansard*, 27 July 2021, p 4.

³³ *Proof Committee Hansard*, 27 July 2021, pp 4-5.

³⁴ ADACAS, *Submission No. 6*.

³⁵ ADACAS, *Submission No. 6*, p 1.

general, this Act is taking account of everyone's rights, and cannot be utilised once issued as a mechanism for carers to seek undue or unfair preferencing of their rights above the human rights of the person for whom they are caring. ... We are pleased to see the improvements with the current version, but repeat this comment regardless, given the importance of the topics.³⁶

3.36 The submission by ADACAS includes detailed comments on parts and clauses of the Bill. The comments cover nuance in the nature and extent of the care relationship, a request for clarification on proposed section 6 (2), nuance in the responsibility to provide support under proposed section 8, wording of proposed section 9, and obligations under part 4 including issues of funding and consultation.³⁷

3.37 Appearing before the committee in her capacity as ADACAS Systemic Advocacy Team Leader, Ms Lauren O'Brien noted the organisations excitement that the Bill is being put forward. Ms O'Brien, in response to a question on how co-design may better be used in relation to carers who themselves have disabilities, stated that;

In terms of co-designing work with carers, and with carers who are also people with disability, generally we would start by getting a group of people together that have a common interest and have support to be able to participate, when support is needed. Support to participate may also include things like respite support being available to enable people to participate. Then it is a process of trying to bring the right voices together. When I say right voices, I mean bringing a very broad cross-section of people and areas of expertise together to seek to ensure that what you end up with at the end of the design process is as strong as you can make it.³⁸

3.38 Ms O'Brien discussed current proposals for co-design work with carers and also the difficulty carers may have in engaging in policy consultation during times they would normally come into contact with care and carer organisations. Discussing the balance between carers rights and the rights of those they care for, Ms O'Brien stated;

One of the other points that ADACAS made in its submission is that there is a lot of nuance in these sorts of scenarios because there are so many situations where carers are excluded when they should not be—where carers' voices need to be heard and need to be listened to. There are also situations where, for example, there is a person with disability who is the care recipient and where the person in a particular interaction might be talking solely to the carer and ignoring the person with disability and ignoring their voice about something that is important to them.³⁹

³⁶ ADACAS, *Submission No. 6*, p 2.

³⁷ ADACAS, *Submission No. 6*, p 3.

³⁸ *Proof Committee Hansard*, 27 July 2021, p 11.

³⁹ *Proof Committee Hansard*, 27 July 2021, p 12.

4 ISSUES CONSIDERED BY THE COMMITTEE AND RECOMMENDATIONS

BROAD SUPPORT BY CARERS AND CARERS GROUPS

- 4.1 Throughout its inquiry the Committee sought to determine whether the Carers Recognition Bill 2021 was supported by carers and carer support agencies within the Territory. Through examining the views put to the Committee in written submissions, it can be shown that broad support for the passage of the Bill exists amongst stakeholders. While all submitters recommended some clarification or amendment, excluding Ms Suzanne Orr MLA who did note limitations in the Bill and drafting, all were broadly in favour of the Bill's enactment.
- 4.2 At its hearing on 27 July 2021 the Committee heard from a number of submitters and their representatives. Throughout the hearing no witnesses spoke in opposition to the passage of the Bill in their oral evidence. However, many did speak in favour of partial amendment for a variety of purposes.

Recommendation 1

- 4.3 **The Committee recommends that the ACT Government support the Carers Recognition Bill.**

Recommendation 2

- 4.4 **The Committee recommends that that a supplementary explanatory memorandum for the bill discuss the impact of the bill on carer's organisations and the role of carers in advocacy and policy as well as caring.**

Recommendation 3

- 4.5 **The Committee recommends clarifying the wording in the Bill to provide an easy to comprehend understanding of an informal carer's connection with a care relationship.**

Recommendation 4

- 4.6 **The Committee recommends that consideration be given to broadening the scope of the Bill to ensure that support for carers through a support organisation (not described as an agency) is included.**

Recommendation 5

- 4.7 The Committee recommends that consideration be given to including specific recognition for the needs of informal, volunteer or family carers.**

DEFINITIONAL ISSUE ‘CARE AND CARER SUPPORT AGENCY’

- 4.8 Throughout its inquiry the Committee was made aware of issues in understanding surrounding the definition of ‘care and carer support agency’. While noting concern about the definition provided raised by some stakeholders—considering the need for flexibility in the application of the definition over time and restrictive issues on legislative drafting—the Committee is of the view that clear messaging about the definition is needed by stakeholders from the ACT Government.

Recommendation 6

- 4.9 The Committee recommends that the ACT Government as part of implementing the Bill provide advice on who is a care and carer support agency.**

REPORTING OBLIGATIONS—STRENGTH AND FUNDING ARRANGEMENTS

- 4.10 Several views were put to the Committee in relation to the adequacy and strength of the Bill’s reporting obligations for care and carer support agencies. Views ranged from support for the obligations as drafted to wide ranging amendments to the bills reporting obligation framework. The Committee considered both points of view in its deliberations.
- 4.11 The Committee is of the View that more stringent and wider reporting requirements should be made to allow for more robust monitoring and scrutiny of the implementation of the care relationship principles by care and carer support agencies. The committee acknowledges views against increasing reporting obligations and the additional administrative burden this may bring. The Committee is however of the view that this may be addressed with appropriate funding being given to suitable provider to produce guidance material to help entities meet their reporting requirements.

Recommendation 7

- 4.12 The Committee recommends that the ACT Government consider stronger and more comprehensive reporting requirements than currently in the Bill.**

Recommendation 8

- 4.13 The recommends that the ACT Government support the bill including organisations' reporting obligations.**

Recommendation 9

- 4.14 The Committee recommends that the scope of recognition proposed by the Bill be expanded to allow for reporting on a wider range of issues experienced by carers.**

Recommendation 10

- 4.15 The Committee recommends that the ACT Government provide adequate resources to a suitable provider to produce guidance material for entities to meet their reporting requirements.**

Recommendation 11

- 4.16 The Committee recommends that the ACT Government resource community organisations to support the implementation of new obligations proposed in the Bill.**

Recommendation 12

- 4.17 The Committee recommends that the ACT Government develop a simple reporting tool and straightforward reporting requirements to enable compliance with reporting obligations.**

CONTRIBUTION OF BEREAVED CARERS

- 4.18 Throughout its inquiry views were put to the Committee highlighting a need for the recognition of bereaved carers. The Committee considered the views put to it in writing and received in oral evidence on the matter. The Committee is of the view that bereaved carers have a lived experience with caring which can offer insight into, and help to improve, policies for carer.**

Recommendation 13

- 4.19 The Committee recommends that the ACT Government recognise the contribution that bereaved carers can make when formulating policy.**

5 COMMITTEE CONCLUSIONS

- 5.1 The Carers Recognition Bill 2021, as presented by the private member Ms Suzanne Orr MLA, is the first recognition Bill of its type to be considered by the Assembly. The Committee is, however, of the view—taking into consideration the existence of similar legislation in other jurisdictions, and widespread support amongst carers and carer support agencies for the Bill—that the Bill should be supported in the Assembly.
- 5.2 The views put to the Committee have expressed a wide variety of nuance in opinion and perspective on the detail of the Bill. Despite this, broad agreement that the Bill is needed and should be passed is a unifying factor across that diversity of views. The Committee is of the view that greater consideration and guidance should be given to care and carer support agencies on definitions within the Bill.
- 5.3 The Committee is also of the view that the bills reporting obligations should be strengthened and widened and that to help reporting agencies the ACT Government ensure that clear guideline material is provided to them. The Committee heard from current and former carers and formed the view that the role and views of bereaved carers should be recognised in policy formulation by government.
- 5.4 The Committee recognises the contributions of current and former carers, including carer support agencies and bereaved carers, to the community and to their inquiry.

Johnathan Davis MLA

Chair

24 August 2021

APPENDIX A – WITNESSES

27 JULY 2021

- Dr Childs Alison, Representative, Canberra Mental Health Forum
- Ms Lisa Kelly, Chief Executive Officer, Carers ACT
- Ms Lauren O'Brien, Systemic Advisory Team Leader, ACT Disability Aged Care and Carer Advocacy Service
- Ms Suzanne Orr MLA
- Ms Ros Williams OAM

APPENDIX B – SUBMISSIONS

Submission Number	Submitter
01	Ms Suzanne Orr MLA
02	Carers ACT
03	University of Canberra
04	Dr Jennifer Thomson AM
05	Canberra Mental Health Forum
06	ACT Disability Aged and Carer Advocacy Service

APPENDIX C – JURISDICTIONAL COMPARISON

TABLE

Jurisdiction	Title of Enactment	Effective	Matters of Note
Commonwealth	<i>Carer Recognition Act 2010</i> (Cwth)	18 Nov 2010	<ul style="list-style-type: none"> - Creates 'Statement for Australian Carers'. - Creates reporting obligations for relevant commonwealth agencies. - Expressly states Act does not create legally enforceable obligations. - Does not exclude similar State and Territory laws.
New South Wales	<i>Carers (Recognition) Act 2010</i> (NSW)	19 May 2010	<ul style="list-style-type: none"> - Creates 'NSW Carers Charter'. - Establishes Advisory Council to Minister. - Creates obligations for relevant public sector agencies to consider Charter in relevant decision making. - Expressly states legal rights not affected.
Northern Territory	<i>Carers Recognition Act 2006</i> (NT)	29 Nov 2006	<ul style="list-style-type: none"> - Creates 'Northern Territory Carers Charter'. - Creates reporting obligations for relevant public sector agencies and select primary funded agencies. - Does not expressly state rights are not affected.
Queensland	<i>Carers Recognition Act 2008</i> (Qld)	4 May 2009	<ul style="list-style-type: none"> - Creates 'Queensland Carers Charter'. - Establishes Advisory Council to Minister. - Does not create a reporting obligation. - Expressly states legal rights not affected.
South Australia	<i>Carers Recognition Act 2005</i> (SA)	1 Dec 2005	<ul style="list-style-type: none"> - Creates 'South Australian Carers Charter'. - Creates reporting obligations for relevant public sector agencies and select primary funded agencies. - Does not expressly state rights are not affected.
Victoria	<i>Carers Recognition Act 2012</i> (Vic)	1 Jul 2012	<ul style="list-style-type: none"> - Creates 'Care Relationship Principles'. - Creates reporting obligations for relevant public sector agencies and select primary funded agencies. - Expressly states legal rights not affected.
Western Australia	<i>Carers Recognition Act 2004</i> (WA)	1 Jan 2004	<ul style="list-style-type: none"> - Established an Advisory Council to Minister. - Creates reporting obligations for relevant public sector agencies and select primary funded agencies to the Council. - Does not expressly state rights are not affected.