

Standing Committee on Health and Community Wellbeing
ACT Legislative Assembly
GPO Box 1020
Canberra ACT 2601
Email: LACommitteeHCW@parliament.act.gov.au

Friday 23 July 2021

Dear Colleagues,

Carers Recognition Bill 2021

ADACAS is a human-rights focussed, independent advocacy service providing individual advocacy to and working with people with disability, people who experience mental ill health, older people and carers. We have been operating in the ACT for 30 years, and more recently commenced working also with people with disability living in specific parts of NSW.

ADACAS acknowledges the importance of carers and the invaluable support that they provide. We thank Ms Suzanne Orr, MP for introducing this bill. We welcome efforts to ensure that carers are recognised and strongly endorse the need for carers to receive the supports that they need (both for themselves and their own wellbeing, but also to support them in their caring role). We also had welcomed the opportunity to work with Ms Orr and provide input (alongside other advocacy and representative agencies) as the earlier drafts of this bill were being developed, and thank you for the extent to which that feedback was incorporated into later versions.

As per our usual conventions, throughout this letter, we will use the term carers to refer specifically to informal carers (who are often family or friends of the person with disability, mental ill health and/or older person) as opposed to paid carers (who we will instead refer to as support workers) and/or volunteers linked with a particular program/ organisation (who we will refer to as volunteers).

We emphasise the need to continue considering the human rights of all parties in care relationships, and the importance of this legislation taking an approach that whilst seeking to ensure that carers (rightly) receive needed supports and acknowledgement, doesn't inadvertently privilege carers rights in situations where the rights of other/s should be predominating. In our view, this bill also needs to continue to seek to avoid unintended negative consequences for carers and for others in the care relationship, who may at times already have their rights overlooked or inadequately considered by broader society due to a combination of reasons, which can include but are not limited to: power dynamics and imbalances, lack of knowledge, or discrimination/assumptions.

In considering our response to this bill, we have been continuing to think carefully about approaches re recognising carers, and upholding carers rights and those of others in care relationships. We have additionally been reflecting on the practicalities of how services, funding and service systems work and implications.

As part of earlier feedback, we had asked that the bill distinguish between the rights to support the carers need for themselves (which is clearly imperative and very important), 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 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 recognise the complexities in finding the right wording for legislation on carer recognition, given that there are often at least two people in a care relationship, whose rights can intertwine, whose rights can affect each other, but whose rights can also at times compete. We are pleased to see the improvements with the current version, but repeat this comment regardless, given the importance of the topics.

As a related topic, but aside – We want also to acknowledge the important work that is done by our colleagues at Carers ACT – and to emphasise the continuing need for adequate funding to fully implement the Carers Strategy in the ACT.

We also wanted to bring to your attention a gap that is currently existing in terms of education, and ongoing support for people who take on the role as Enduring Power of Attorney (EPOA) or guardian – roles which many carers undertake. Education and support available should include the nature and limitations of EPOA and guardianship roles, but also should focus on supported decision-making approaches, which are widely recognised as essential in seeking to ensure that the rights of people with disability (with impaired cognitive abilities) are upheld.

Please do not hesitate to contact Lauren O'Brien, Systemic Advocacy Team Leader (lauren@adacas.org.au / 6242 5060) or myself, as per the contact details with my signature below, should there be any questions in relation to this submission.

Yours sincerely,

Wendy Prowse
CEO
ADACAS
Ceo@adacas.org.au
Phone 6242 5060 / 0417 141 049

Part 2: Objects and important concepts: Comments

Nuance in the nature and extent of the care relationship.

Part 2: Section 6: Meaning of care relationship: We liked that this draft is nuanced, in that it recognises that there are some circumstances where a person receiving care might not identify or agree that a particular person has status as a carer (in some cases might strongly insist that the person is not a carer), but that the Act can also still recognise that the other person might still be offering a level of support and/or care that is having an impact and might still need support for themselves accordingly. We note the importance of simultaneously being able to respect the views of the person receiving care and the boundaries that they are setting around involvement of other people in their care, whilst also ensuring that support is available for people that need it (even when the title carer is disputed).

Clarification: in Part 2, section 6, number 2, it is stated that: “a regulation may prescribe a relationship to be a care relationship”. We request clarification on this clause, and the situations in which it might apply. We recognise that status as a carer can be complex and can be subjective as to whether people identify as a carer (or are nominated as a carer by others). We seek clarification as to situations in which a regulation might apply. (Is this intended to cover kinship and foster carers, in situations where there are children/young people involved?)

Part 3, Section 8: Care relationship principles – treatment of carers:

In reflecting anew (with fresh eyes) on this section, we provide added feedback as follows:

Nuance re responsibility to provide support

- Clause 1g – whilst we absolutely endorse that carers should have access to support that is timely, responsive, appropriate, respectful and accessible – we propose that this clause be very slightly re-worded, so as to add the nuance that this applies in situations where support is being provided to carers? (One option to do this, could be to incorporate clause g as a sub-clause in clause h?)
- Clause 1h (ii) – if this is referring to all support services, programs or policies related to the carer and care relationship, this might be difficult to achieve. We also are conscious of the risk to carers – as if every organisation needs to seek their insights at every stage of every process, there is a high risk that carers could quickly become over-burdened by organisations’ requests (especially if these insights were being sought at times when carers were already feeling under pressure). After further reflection, we are therefore suggesting an alternative approach - could Carers ACT be funded to co-produce (or update/tailor) a best practice guide with carers that arises from this act, that organisations could then use, to seek to embed best practice approaches within systems and processes? (We will return to this suggestion later in this paper). With regards to the specific wording of this section, we would also ask - is the intent of this more about having their views considered in the approach to the direct care being provided through that service? If so, we would suggest that it be re-worded. If the intent is to speak also to the importance of the carer perspective being included in broader approaches to policy/system design etc, we strongly recommend that this be re-thought (as per our suggestion for a best practice guide). If the decision is to retain this clause, as a minimum change, we would suggest that further nuance be added in the way this section is framed, (as whilst I’d imagine that most services would seek to include carer voices/perspectives as part of assessment/ planning/ delivery/ management and review of support services, programs or

policies relating to the carer and the care relationship), that it is important that this is occurring only when this is both appropriate and practicable for all involved and we would thus recommend therefore that modifiers such as when both appropriate and practicable (or similar) are needed for this clause).

- Clauses 1i to 1m - these seem to speak to the ideals expected of the entire service systems and structures: could this be further spelt out?

Part 3, section 9: Care relationship principles – treatment of people receiving care

Current wording: “A person receiving care in a care relationship should have their rights as an individual recognised and realised.”

The care relationship principles talk of carers being provided with support that is respectful (8g). We thus recommend the word respected also be included in this section about the treatment of people receiving care, i.e. that the statement above be expanded to read: rights as an individual recognised, respected and realised. We further recommend that a statement be included in part 3, section 9, that recognises that people receiving care may also have a view on the care relationship, that acknowledges the right for this to be listened to and taken into consideration.

Part 4: Obligations relating to care relationship principles: Comments

Part 4, section 10, Obligations of care and carer support agencies relating to care relationship principles:

- Consultation and funding:

Clause 1b: as per our response to Part 3, section 8, part 1h(i)

With regards to that same clause, Part 4, section 10, clause 1 (b): whilst we agree with the principle behind requiring care and carer support agencies to consult with carers or an entity representing carers when planning or reviewing support services and programs in relation to people in care relationships provided by the agency, we note the additional work that this is likely to create predominately for Carers ACT (although as an agency that works with Carers, ADACAS could also be consulted), and ask for an assurance that there will be commensurate funding made available to support the additional work that introducing these obligations will entail.

Whilst we welcome the intent of this statement (consideration of carer needs and views), after further reflection, and as mentioned earlier in this paper – we are concerned that this approach would be both overly burdensome for carers, and also logistically prohibitive for organisations. Instead - as flagged in response to Part 3, section 8, clause 1h (ii) - ADACAS recommends that Carers ACT be funded to co-produce (with carers) best practice guidelines or standards developed from the Carer Recognition Act, so that organisations can use this as a starting point, and then that feedback to organisations from carers directly (when practicable and appropriate) can be part of a continuous improvement plan/strategy.

- **Practicalities around consultation expectations:**
Clause 2a: as mentioned above, consulting every time there are any changes (not just significant changes), with both carers and an entity representing carers is a lot to ask. Could there be further modifiers if at all possible (when appropriate and practicable, change the “and” between clauses a(i) and a(ii) to and/or, etc). Or are there other ways that a similar intent could be captured (that carers perspectives are included), in ways that would be more practicable for services to implement? (see suggestion re best practice guide).

Part 4, section 11, Obligations of care and carer support agencies:

- **Reporting arrangements:** We welcomed also the requesting for organisations to be explicit around support for carers on websites, and in annual reports, but were interested to ask about the ways in which disability service organisations (especially National Disability Services, as the peak) have responded with regards to the reporting arrangements, as we imagine some organisations might experience challenges with the requested reporting requirements.

In conclusion

Thankyou again to Ms Suzanne Orr, for her leadership and initiative in putting forward this bill for consideration, it is most appreciated.