

Mr Andrew Snedden
Secretary to the Standing Committee on Health and Community Wellbeing
ACT Legislative Assembly
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Monday 16 August 2021

Dear Andrew,

Hearing with regards to the Carers Recognition Bill 2021

I am writing to provide some further responses to two of the questions that I was asked by Committee members during the hearing into the Carers' Recognition Bill on 27 July 2021.

1. **How we can co-design carer policies for people who are carers and themselves have a disability?**

Co-designing is in effect a process of sharing power with people with lived experience (in relation to carer policy, this would typically be: lived experience of being an informal (family or friend) carer of another person). Carers as a group though are very diverse, and there are certainly carers who also themselves are people with disability, and it is important that carer policies are attuned to this.

In terms of how to practically co-design carer policies that also are suitable for those with a disability: I would suggest – as part of forming the group to participate in a co-design process, that there is an especial effort to seek to ensure diversity and especially include carers who themselves have disability, as part of the process (along with any support that might be needed for them to participate) and alongside others with say other types of expertise. The actual process of how the co-design happens (in person meetings, online meetings, whether information is disseminated outside the group for feedback etc), should be decided by that group, in a way that is inclusive of all.

I note also that it might also be necessary to supplement the co-design process, with other ways that the voices of carers with lived experience of disability could have their voices included in the design process as well as with professional expertise from people who work with/have expertise in working with carers and people with disability around having their rights upheld.

The reason I note that the process might need to be supplemented – as whilst technically in principle it would be possible to draw together a group of carers that themselves have a disability to participate in a co-design process: practically: it would be interesting to see how many carers who

are also people with disability would have the time/scope and would choose to be able to participate in a full co-design process of that type (given that the experience of being a carer takes time, also that life with a disability (and negotiating the myriads of systemic barriers that people face, as well as the impacts of impairment, as well as whatever else is happening in life (family, work, study, health etc) also takes time.

True co-design of policies involves sharing power the entire way through the design through to the end product (in this case the establishment of the final policy) and we would encourage this occurring to the greatest degree reasonable and practicable.

In writing the above: it is challenging to develop a policy that captures all eventualities. As such – we remind that policies can develop over time, and that even final policies can be adjusted (via reasonable adjustments) should this be required to meet the needs of a carer with disability.

2. You mentioned within your submission that the bill needs to distinguish between the rights to support the carers themselves and their rights in terms of their role caring for another person. Can you elaborate on that and on where you think the bill misses it being distinguished?

Carers (and the people receiving care) have rights both as individuals, and also with regards to the caring relationship. The current bill distinguishes between these in the way it is structured.

Section 8: Care relationship principles – treatment of carers

Section 9: Care relationship principles – treatment of people receiving care.

Both Section 8 and Section 9 should include information about rights in terms of the care relationship. In our view, and as per our last submission, section 9 could be further strengthened in terms of both the rights of the person being cared for, and also that same person's rights in relation to the care relationship (as outlined in our last letter).

We recognise that the exercise of balancing rights is a complex and nuanced one, and commend Ms Orr and all those involved, in achieving what has been achieved with this bill to date. We recognise that this distinction has been captured much more carefully in the later as opposed to earlier drafts, and thank you for the efforts involved in achieving this.

I would otherwise refer you to the answer that I had provided to this question during the hearing.

Please do not hesitate to contact me, however, should any further elaboration or information be required.

Yours sincerely,

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