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STANDING COMMITTEE ON HEALTH AND COMMUNITY WELLBEING
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Submission Cover Sheet

Inquiry into Carers Recognition Bill 2021

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Health and Community Wellbeing Committee

ACT Legislative Assembly

Via email: LACommitteeHCW@parliament.act.gov.au

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Please see below my introduction speech for the Bill for use as a submission to the Inquiry into Carers Recognition Bill 2021.

I rise to introduce the Carers Recognition Bill 2021, along with its explanatory statement. 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.

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. Better recognition of carers and their needs will improve support to carers, which will in turn improve the health and wellbeing of carers as a group in our community.

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. Where a dispute between a carer and a person receiving care occurs, the bill is not intended to be used as a means for reconciling that individual dispute by giving one person in the care relationship more say than the other.

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. I thank everyone who provided feedback and worked collaboratively to make this bill the best it can be.



I will draw attention to some of the more significant clauses within the bill. Clause 6 defines the term “care relationship”. Importantly, the definition recognises the relationship that exists between a person providing care and a person receiving care. It is this relationship that is central to the bill. Clause 6 also defines who a carer is under the act.

Clause 7 defines the term “care and carer support agency”. Clause 8 creates a set of care relationship principles in relation to the treatment of carers. The principles detail that: a carer is to be respected as an individual and as a carer; the care responsibilities that a carer takes on need to be respected and supported; and the wellbeing of the carer is to be supported through the approach taken by the care and carer support agencies. The principles also note that certain characteristics of some carers require additional support; for example, supporting young carers with their education.

The care relationship principles in relation to the treatment of carers are essential to achieving the objectives of the bill. The principles are based on the barriers identified by carers that they experience which make it difficult to undertake their caring role and ultimately impact their own wellbeing. A key tenet underpinning the principles is that carers are individuals in their own right and with their own needs. The principles acknowledge that the caring roles carers undertake can and do impact other areas of a carer’s life in a way that people who do not have caring roles would not experience. By drawing specific attention to the areas where negativity is experienced by carers, the principles set a clear expectation of how carers should be treated so that they are valued and respected and able to carry out their caring role and maintain their own wellbeing.

Clause 9 acknowledges that people receiving care are individuals in their own right and that their rights as an individual are to be respected and upheld. The recognition of people receiving care is as integral to respecting the care relationship as that of recognising carers. It is important to acknowledge that people receiving care do not cease to have autonomy over their decisions simply by the fact that they receive care or are in a care relationship. To prevent this bill being used as a mechanism for disrespecting the rights of people receiving care, it is important that this clause be included.

Clause 10 sets out the obligations of care and carer support agencies under the bill. This clause requires a care and carer support agency to make both the agency’s employees and agents and the people receiving support from the agency aware of the care relationship principles. The agency is also required, along with its employees and agents, to uphold the care relationship principles when providing support services to people in care relationships. In addition, this clause requires care and carer support agencies to consult with carers and entities representing carers when planning, reviewing and developing support services, programs and policies that will affect people in a care relationship.



Throughout the consultations with carers, they have consistently provided feedback on the need for care and carer support agencies to provide transparency and accountability in how the objectives of the bill are realised. There was concern that if no accountability was placed on care and carer support agencies, the objectives of the bill would not be realised. By providing the publicly available report, care and carer support agencies will be clearly stating in an open manner what they have done to uphold the care relationship principles, providing for the transparency and accountability.

Clause 11 sets out the obligations of care and carer support agencies in relation to reporting. An agency must report annually on the steps they have taken to uphold the care relationship principles and the agency's obligations. For public sector support agencies, reporting is to be included in their annual report. Funded support agencies are required to report annually. This could be, for example, in their own annual report or by publishing a statement on their website.

For secondary funded support agencies, the provision of a public report is encouraged rather than required so as to balance the reporting obligations of smaller organisations. The reporting obligations provide transparency and accountability and are crucial to realising the objectives of the bill.

Clause 14 provides a regulation-making power and clause 16 creates a new carers recognition regulation. Schedule 1 creates the carers recognition regulation 21, which sets out the information required from care and carer support agencies to meet reporting obligations under section 11(3) of the act. The new regulation is taken to be notified on the same day as the act; however, the regulation does not commence until the commencement of schedule 1 of the act.

I note that a number of organisations have said they appreciate that there will be an implementation period for the bill and, as part of that, they welcome as much guidance and clarification as to their responsibilities as possible, as nobody wants to get this wrong.

In developing this bill I heard from many carers, and the word that I heard most in all of my conversations was "invisible". Carers consistently told me that they felt invisible, never heard, not respected—just nothing. This must change. It is no secret that I grew up in a family that cared. For most of my childhood, all of my adolescence and part of my adulthood, my parents were foster parents. We welcomed hundreds of children and young people into our home—sometimes for a short time, sometimes for a long time. My parents also cared for my maternal grandparents in their later years, and this gave them more insights into the challenges of caring.

In putting together this bill I had many conversations with my mum and dad, asking what they had seen change over the decades that they had been advocating for carers. When I sent my mum a text asking if she and Dad could give me a few paragraphs to add to my introduction speech on what this bill would have meant to them when they were caring, the response was that it always goes back to, "You're only carers, you don't have a brain,



you don't know what's best, or you are invisible". Later, they actually wrote a whole paragraph rather than just a text message:

Being a carer changes you forever. It adds to your life experience, but it is not easy. It changes your priorities and how you see life for both you and the person you are caring for. You put the person you are caring for first and put aside many of your own desires and wishes so that you can ensure the best possible options and outcomes for the person you are caring for. Sometimes that also means you put your life on hold 24/7 for as long as is needed. This needs to be respected by those working with both the person being cared for and their carers.

I note my parents are behind me, and while I cannot see them, they are definitely making me emotional. My mum also stated:

During the research I did in 1999-2000, carers stated across the country all they wanted was to be recognised in their role and to be respected. Many carers said the most important thing was Respect, Respect, Respect. Subsequent surveys and research continued to say the same thing. It's unfortunate that 20 years later carers are still saying the same thing, and if you look at the concerns carers are raising, little appears to have changed. This bill is long overdue in the ACT. Something like this exists in every other jurisdiction. Hopefully, it will help to move the recognition of all carers and the care relationship they are integral to into a better place in our community.

My dad said, "It's about time we had this bill to recognise all carers."

Some could say my whole life has been an education in how important this bill is. But this bill is not just about me or my family; it is about the tens of thousands of people across Canberra who provide support to so many others every single day. Today, I would like to give voice to some of those people I spoke with and who have agreed for me to share their words. During the consultation period on the draft bill, one carer said to me:

I wish to make two points, chosen from the many issues I faced as a carer for my terminally ill wife, because I suspect they will not be widely made by other carers.

Issue 1: unscheduled power outages for the seven or so months that Kathy was on 24/7 home oxygen. Our electricity provider, ACTEWAGL, included us on their register of premises in which life supporting equipment was operating. I have nothing but praise for this program and for the professional manner in which it was managed. We were given notice of all scheduled power outages with plenty of time to ensure we had sufficient oxygen cylinders. Both Kathy and I were very conscious that an unscheduled power outage could be extremely serious: for most of the time Kathy was on home oxygen, she was physically incapable of attaching herself to an oxygen cylinder; and I could not be in the house all day every day. What would happen if there was a power outage while I was absent?



I asked every authority I could think of (ambulance, police, fire brigade, ACT Health, ACT Public Service, GP) but no-one had an answer. An Uninterruptible Power Supply (UPS) was the best idea anyone had, but the ACT Government program does not fund this option. I purchased a UPS and attached the oxygen concentrator to it but found it would only power the unit for about 10 minutes. This was better than nothing but was quite inadequate. On advice from the ACT Police, I installed a key safe in the front porch and provided all emergency services with the combination. The plan was that Kathy would call 000, even before she called me, in the event of a power outage while I was absent. As events transpired, we did not have an unscheduled power outage while she was incapacitated, but I feel very strongly that a proper plan is needed for every household with life supporting equipment in place.

Issue 2: attitudes towards male carers. Although no-one said so directly, I sensed a fairly general attitude from people providing support to us that as a male I could not be expected to provide for a range of Kathy's needs; e.g. I was quizzed about why I had not asked for help with cleaning the house and other domestic chores, and I was questioned about my understanding of Kathy's personal needs such as with washing and toileting. We were married in 1973 and she made it quite clear she was more comfortable with me helping her in these deeply personal ways than she would have been with a stranger, female or male, inside our house. We both understood that in hospital she would be supported by nursing staff, but even there I regularly helped her with washing, toileting and eating. I strongly suggest that the training for service providers is enhanced to ensure they can more accurately read the competence of the carer. This specifically includes training to recognise unconscious biases (this could be modelled on programs to weed out sex and racial discrimination).

Another carer, Diamond Kary, told me:

I am a full-time primary carer for my elderly mother. I have discovered you have to develop pretty big shoulders to undertake the care of a loved one.

As a carer I have experienced loneliness, frustration and exhaustion. It is one of the hardest and most challenging things that you will ever do. It is also rewarding and a privilege, as you learn about what unconditional love really means and I am much closer to my mother as a result of this journey.

My love for her knows no bounds. It is also very important that I sometimes need a little time out to care for myself so I can give the best care that I can to my loved one. My Christian faith has also strengthened and has given me strength.

Another carer told me:

I am the carer for my adult daughter who has a severe chronic medical condition with resultant disabilities. She is also a single Mum.



As her carer I have never been asked by health or support personnel exactly what care I need to provide for her. And yet she often says that my care is just as important to her health and wellbeing as all her medications and therapies. My capacity to provide her with care has never been considered in any health or support management plans or hospital discharge planning.

My advocacy for her when engaging with the complex health and disability sectors, particularly while she is very sick and vulnerable, is often ignored and not respected.

Carer Craig Cormick summed it up:

This Bill is very important for carers as it not only brings the ACT in line with other jurisdictions but helps the lives of carers by providing some support and recognition for them in the vital work they do in caring for some of the most vulnerable people in society. Our community is stronger for such a Bill.

It would be fair to say that everyone in this place comes into it with the hope of making positive change. I know I did, and I believe that this bill will make a difference and leave the world a little bit better off than it was before for so many people across Canberra by giving carers the recognition they have long gone without.

Suzanne Orr MLA
Member for Yerrabi
Government Whip