



**LEGISLATIVE ASSEMBLY FOR THE AUSTRALIAN CAPITAL
TERRITORY**

**STANDING COMMITTEE ON HEALTH
AND COMMUNITY WELLBEING**

(Reference: [Inquiry into Carers Recognition Bill 2021](#))

Members:

**MR J DAVIS (Chair)
MR J MILLIGAN (Deputy Chair)
MR M PETTERSSON**

TRANSCRIPT OF EVIDENCE

CANBERRA

TUESDAY, 27 JULY 2021

**Secretary to the committee:
Mr A Snedden (Ph: 620 50199)**

By authority of the Legislative Assembly for the Australian Capital Territory

Submissions, answers to questions on notice and other documents, including requests for clarification of the transcript of evidence, relevant to this inquiry that have been authorised for publication by the committee may be obtained from the Legislative Assembly website.

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Amended 20 May 2013

The committee met at 3.03 pm.

CHILDS, DR ALISON, Representative, Canberra Mental Health Forum
WILLIAMS, MS ROS

THE CHAIR: Good afternoon, everyone. Today the committee is holding its first public hearing on the reference of the Carers Recognition Bill 2021 to the Standing Committee on Health and Community Wellbeing. This bill is a private member's bill, which was introduced to the Assembly by Ms Suzanne Orr, MLA. The program for today is on the table at the front of the room. The committee has received and now publishes six submissions, all of which are available on the committee's website.

Today's proceedings are public and are being recorded by Hansard for transcription purposes. They are being webstreamed and broadcast live. Before we begin, I remind all witnesses of the protections and obligations entitled by parliamentary privilege, and draw your attention to the pink privilege statement, which is set out on the table. They are very important.

Before the committee starts the hearing, as part of our program today on behalf of the committee I would like to acknowledge that we are meeting on the lands of the Ngunnawal people, the traditional custodians. We respect their continuing culture and the unique contribution they make to life in our city.

I welcome our first witnesses today, Ros Williams and Alison Childs, from the Canberra Mental Health Forum. Could you please confirm, for the record, that you understand the implications of the pink privilege statement?

Dr Childs: Yes.

Ms Williams: I do.

THE CHAIR: That is wonderful. Before we proceed with questions from the committee, would you like to begin with an opening statement of up to five minutes?

Dr Childs: Yes. Thank you very much, committee, for giving us the opportunity to speak with you today. My name is Dr Alison Childs, and this is Ros Williams, who is the convenor of the Canberra Mental Forum. We have provided a short submission to you today. I will just point out that the Canberra Mental Health Forum is an independent community group with lived experience, advocating for improved mental health services. We are an active group of carers, consumers, and people with work experience in mental health services or policy development. I certainly will not be reading out all of the contents of the submission; I will just highlight a few issues and then hand over to Ms Williams to talk about some particular issues.

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 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 bill. We would like to highlight that there are some points of clarification that we request on scope and inclusions; exclusions; some things around definitions and terminology; and

issues around transitions of care, such as systemic issues such as discharge planning, which might be a gap between different care services. We also wish to raise issues around annual reporting and how we would determine that the quality of care for care recipients and carers is improving unless there is greater clarification about the outcomes of the Carer Recognition Bill.

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 community.

Within that table, one of the key points we would like to highlight is the greater clarification needed on “care support agency” and “carer support agency” and what actually is the meaning of such support. There is a very important issue around safety and the importance of safety for carers, which is listed at point 5. Also there are issues around choices, as examples, for carers. Some of the carers within our forum are now in their mid-70s, and they are still being required to care for their adult children, who might have mental health issues. This is not sustainable.

There are also issues around bereaved carers, about which Ros will continue, and there are other issues around the importance of system planning when people are transitioning from care. I also point out the importance of that interrelationship between care recipients and carers, and the importance of their interaction, rather than just focusing on the recipient. Those are the key points that I would like to make. I will hand over to Ros, now. Then, if you have questions, we can follow up on those.

THE CHAIR: Thank you.

Ms Williams: I would just like to make it very clear that I am making a personal submission today. I am not speaking on behalf of the Canberra Mental Health Forum. In regard to my personal experience, for the last four years I have been the convenor of the Canberra Mental Health Forum. For the last two years I have been the ACT carer representative on the National Mental Health Consumer and Carer Forum, which is a combined national voice for mental health, consumers and carers. I have also advocated for an improved coronial system in the ACT for the past seven years, and was a founding member of the Coronial Reform Group in the territory, and now a community advocate for the Alliance for Coronial Reform.

I am also a person with lived experience as a carer for a family member with a mental illness. I cared for my son, who died in 2010. Because of this background my comments mostly relate to carers of those living with mental illness. However, there is a very significant overlap with the concerns of carers of people with other disabilities. There is a large body of research spanning many decades which supports a clear link between a mental health diagnosis and poor physical health.

I am keen to speak to the committee because I want to emphasise how important it is for the ACT to have a strong carers recognition act. Firstly, I am aware that the ACT

is the only jurisdiction in Australia which does not have this type of legislation, so the legislation seems well overdue. Secondly, the numbers of people who require care are increasing across the country. We all know Australia has an ageing population. The rate of disability is increasing, including those with mental health, and the rate of drug use in our community is also increasing. Therefore, it is essential that we support our carers well, or they themselves will need care in the future. Carers Australia informs us that the estimated annual replacement value of all unpaid care in Australia is \$77.9 billion, which is an increase of 29 per cent since similar research was conducted in 2015.

Thirdly, legislation is required because carers in the ACT have great difficulty in having both their individual and collective voices and opinions heard. Over the years that I have worked in this sector, 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.

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. The Canberra Hospital failed its accreditation in 2018 and the *Not Met* report highlighted that there were 235 uncompleted discharge summaries from 2017 and that over 200 were more than 900 days overdue since discharge. 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, 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. Who do I call if things start to deteriorate? If I need to be supervising medications, what are the medications and what are their side effects? And perhaps even more importantly, has this family member been assessed as a suicide risk at any time during the last month? I could provide you with specific examples of where this has not occurred. The last time I looked, the readmission rates back into the Adult Mental Health Unit were the highest in the country, or certainly very high.

Last year's Productivity Commission report into mental health tells us that all mental health services should be required to consider family and carer needs and their role in contributing to the recovery of individuals with mental illness. The report also repeatedly refers to carers as key participants and concludes that there is scope to improve how families and carers are included by mental health services. Carers are often the one consistent factor in the life of someone who has persistent and severe mental illness. Doctors, case managers and support workers move on with frightening regularity, so carers are often the only people who have the full picture and who, for the most part, are going to hang in there despite what might come next.

I was always surprised that my family's suggestions and opinions were so regularly and lightly dismissed. A them-and-us culture is alive and well, with "them" being the

professionals who know everything and “us” the ones who know nothing. It was then, and remains, perplexing to me that our family’s willingness, insights and hard work should not have been valued, especially when the system itself is so stressed and under-resourced.

At this point I would like to say that I am well aware of the complex issues surrounding privacy and confidentiality. 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.

As carers, we walk this tightrope on a day-to-day basis. We know about advanced care plans and being nominated people. In my experience and the experiences of others, privacy and confidentiality becomes a convenient cover for all workers to tell carers nothing. There is a lack of depth of understanding of the legislation, and this lack of knowledge can put both consumers and carers in danger. The parents of Kaitlin McGill were perhaps unknowingly voicing the concerns of many families when they told the ACT Coroner’s Court last year, after Kaitlin’s untimely death, that if they had been provided with better information, Kaitlin most likely would not have died.

Not only do carers have difficulty having their individual voices heard, but they also have difficulty having their collective voices heard. The bill could be strengthened in this regard. In the ACT there is no specific entity just representing carers, and whilst I value and admire the work of Carers ACT, their remit is huge and the organisation is conflicted in that it is both a carer support agency and a service provider. This situation is unique in Australia. Too often, places on key advisory and policymaking committees that are allocated to carers representatives are filled by paid staff members. When this has been questioned the comments that I hear are that carers are usually too emotional or that they would not understand the complexities that committees discuss, or that carers are not available or are unwilling to do this work. This situation does not exist in other jurisdictions, so it seems very unlikely to me that it applies here either.

At a more bureaucratic level, mental health carers also miss out on having their voices heard in planning and policymaking. ACT Mental Health informed me, in an email I received in March this year, that our formal consultation processes will only be through the Mental Health Consumer Network, Carers ACT and HCCA—the Health Care Consumers’ Association—which are all agencies receiving government funding. This legislation, I hope, will place the onus on service providers in this sector to take their responsibilities to engage with grassroots mental health carers more diligently. I am well aware of the continuing staffing shortages in the mental health sector; however, carers are often the ones who signal when early intervention would help, and timely action at that stage would prevent family members becoming unwell, reduce attendances at emergency departments and lengthy and expensive admissions to mental health units.

I request that the definition of “carer” in this bill be widened to include bereaved carers. The rates across Australia are increasing. According to the latest ABS figures,

in 2019 there were 3,318 deaths by suicide in Australia, and 53 of those were in the ACT—much higher than the road toll. This is a very significant increase on local previous figures and the figure is most likely even higher as a result of COVID. Unfortunately, a very high percentage of those deaths are young people and, as they are untimely deaths, they will be investigated in the Coroner’s Court. In the ACT, the coronial process could take three to eight years. During this period, bereaved carers once again struggle to have their voices heard. They struggle before someone dies to ensure adequate care is provided, and, believe me, it is a continuing struggle during that terrible time after someone has died. During those years of the coronial proceedings, carers are the voice of their deceased relative. The agencies dealing with bereaved carers at that time therefore need to be included in this bill. Currently, there is little tracking of the bereaved carer experience, data collection or reporting, and little awareness of principles such as care relationship principles mentioned in the bill.

I would like to state that I support the issues made by Canberra Mental Health Forum, particularly the necessity to better define the agencies to whom the bill applies and, importantly, to specifically name ACT Health facilities as examples. The wording “carer” and “carer support agency” is vague and confusing, not only to people working in the sector but to carers as well.

In conclusion, I would like to commend all those who have worked on this bill to put it on the agenda. I am hopeful that it will make a significant difference to those hardworking and largely unsung heroes in our community. Thank you.

THE CHAIR: Thank you, Ms Childs and Ms Williams. We will start with questions if that is okay, and I will kick us off. I am interested in your opinion on how we should best provide support for carers of people with episodic conditions in particular. I know it is quite broad, but I am happy for either one of you to take that.

Ms Williams: Well, we could talk about that for quite a long time, but I think the most important thing, really, is to listen to their voices. As I said, the carers are often the only people with the full story. Making sure their voices are heard; including them as part of that planning process so that if someone is being discharged from a facility, and that some planning is being done, then that planning is being done in consultation with carers, where the person wants those carers or family members to be involved—and we know that that is complex and that it changes.

Dr Childs: Within this documentation, there is a reference to a model of a triangle of care, where there is a health provider, the person receiving care and the carer. If that sort of relationship is established early on, then that can be instated when there is some episodic illness, and that can be addressed.

THE CHAIR: I think it is fair to say that the things that you have said would be true for carers of those people with physical challenges. I am curious if there are any specific challenges that should be considered which are unique to those carers who are caring for somebody who may be vulnerable to episodic conditions. I would be more than happy for you to take it on notice if you would like to.

Dr Childs: Yes, we can consider that. Where people have an advanced care direction in place, that is certainly helpful—when people are more well, when they have

thought through some of these issues and what additional supports might be required and if there are key triggers that should be addressed—so where we can encourage people to put some of those advanced key planning directions in place would be very helpful.

Ms Williams: The other point is that the intensity of that caring role is huge. So I think that having provision for respite care is very important, and making sure that there are suitable options. If somebody does not wish—or is prevented for some reason—for their family member to be living in their home, there needs to be enough support places, accommodation places. I think, Alison, you talked about choices. So it is about having choices rather than coming back to the family home as the only choice, which often is the case.

THE CHAIR: Thank you. Any supplementary questions, Mr Milligan?

MR MILLIGAN: Time is tight. I am not sure if we have time for any supplementary questions here.

THE CHAIR: With the permission of the room, I am happy to give everyone on the panel at least one question.

MR PETTERSSON: Let us do quick substantive questions.

MR MILLIGAN: Okay. Just in relation to discharge planning, I take it that that is from the hospital—when someone who is going through mental health issues and they are discharged. Typically, I would assume, a mental health plan is put together for that patient. Are you suggesting that that mental health plan should be provided with greater recognition of the carers so that they can provide greater support for people that are being discharged?

Ms Williams: The discharge plans are not always put together—the documents do not exist. But where that carer or the family member is a nominated person—so there is permission from the patient to provide that information—then carers need to be informed of that. That, in my experience, often is not the case.

MR MILLIGAN: In your experience, are these documents not normally prepared by ACT Health?

Ms Williams: I go back to the *Not Met* report that I referred to. I have certainly spoken to a carer this week who did not cite a discharge plan, and no planning on discharge was discussed with that person, despite the patient being very willing and wanting their family to be involved. So they are not prepared. They are sometimes emailed to a GP, but not everybody with a mental health problem will have a GP. So the whole system really needs looking at. If we could mention discharge planning specifically in that, I think it would strengthen the rights that carers have.

MR MILLIGAN: I guess it just depends on whether that would fit within the purpose of this bill. Obviously, this bill is about providing the principles and the foundations for carers, but whether that would fall within this bill or whether that would be a completely separate amendment down the track—

Dr Childs: I think it could be included in the systemic planning, because there are certainly references to planning transitions and other issues. So if that was broadened slightly, I think that would certainly support it within the scope of this bill. And it is not just the hospital system, it is broader in other support areas.

MR MILLIGAN: Yes.

THE CHAIR: Being cognisant of the time, I just might let Mr Pettersson ask his substantive question.

MR PETTERSSON: Thank you. You mentioned briefly in your opening statements the recognition and role of carers groups. I was wondering if you could expand on where we need to recognise and involve carers groups, where we are not currently doing that.

Dr Childs: I think the wording of the bill, in one of the sections, made reference to an “entity” rather than “entities” or plurals—so multicultural groups, foster groups, kinship groups or, for example, our group as an independent Canberra Mental Health Forum, even though it is not prescribed through, for example, Canberra Health Services. I think that would be of great benefit. There are a range of groups.

MR PETTERSSON: Wonderful.

THE CHAIR: On behalf of the committee, I would like to thank you both for your presentations today. Ms Childs and Ms Williams, I appreciate that.

Dr Childs: Thank you for your time.

Short suspension.

KELLY, MS LISA, Chief Executive Officer, Carers ACT

THE CHAIR: Ms Kelly, when you are ready, could you acknowledge the pink privilege statement.

Ms Kelly: I acknowledge the privilege statement and I acknowledge the Ngunnawal people of the land on which we meet today.

THE CHAIR: Thank you, Ms Kelly. Do you have an opening statement?

Ms Kelly: In the interest of time I am going to keep it very short and say that there are few moments in life and in career as poignant for me as the moment we are in today. For 20-odd years I have been working for and with carers. I was a young carer. To sit here today in front of you to support an act that finally recognises and acknowledges the work of carers is beyond the expectations of what I would achieve in my lifetime. So I thank the private member, Ms Orr, for doing the work to bring us here, but I also acknowledge my predecessors and the people who have been fighting for this for very, very many years. I will take questions; I think I have made enough statements about why we need this act.

THE CHAIR: Thank you, Ms Kelly. I suggest you spend more time in the Assembly and teach all members an act of brevity; that would be very useful! My question is: what support do you feel service organisations need right now to help them report the number of carers within the carer workforce that are paid and unpaid? I know that is one of the obligations of the bill. What would government need to do to make that easier?

Ms Kelly: I am going to split that down into three different agency groups in terms of, therefore, what is needed. I believe that all agencies that work alongside, or with, or for carers should be reporting. For those agencies who are secondary or tertiary agencies—I think that is how they are classified in the bill—a template and some guidance on how to report is simply all that is required. 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 them.

MR MILLIGAN: You suggested in your submission that the bill does not go far enough in terms of support for carers' needs. I am just wondering if you could elaborate a little bit more on that. If you were able to amend that bill, how would you do so? Taking into consideration the barriers that the carers go through, what could be done to strengthen that spot?

Ms Kelly: Asking me what we need to support carers is like asking how big the world is, in lots of ways. I think that the biggest issues around support for carers at this point in time is around being able to provide respite funding—to provide capacity for carers to

take legitimate breaks that enable them to participate within policy, within forum, within public commentary as well. I do think that carers are passionate about supporting and changing the world, but I think that their capacity to give time to that can sometimes be more limited. If we want carers to have a public voice, and we want them to participate actively in public policy, then we need to provide support for that to happen. We need to provide respite support. It needs to be non-tokenistic support. I was at a committee, for example, yesterday, that has a \$50 gift voucher, and I go, “Really?” I get paid more than \$50 an hour to sit there. So, it is about how we provide a legitimacy to the voice, about how we provide a capacity for carers to be supported, educated and encouraged.

MR MILLIGAN: So, in effect, for that agency to provide an opportunity for the employees or the carers to participate in forum policy discussions on how to improve their own workplace but also obviously improve the service that they are providing to the people seeking that care?

Ms Kelly: Can I just ask a clarifying question, when you talk about employees and you talk about workplaces—

MR MILLIGAN: The carers, yes.

Ms Kelly: The term “carer” is often used to refer to paid support workers. That is a real problem, because we are not talking about paid support workers. We are talking about family members and we are talking about friends, who are not paid. They are fulfilling the role that should be filled by paid workers, largely. They are doing it through love and care and family. We are not talking about paid support works. So I just want to make sure that there is a distinction there.

MR MILLIGAN: Yes. It seems to me that this bill is mainly focused on those paid support workers through the agencies—

Ms Kelly: No. The definition of “carer” in the act is an unpaid family or friend. If that is the reading that is happening in the act, then I would be taking back my recommendation that we should support the act, and say that we need to do another round of editing to the act to make it much clearer that this is not an act for paid support workers. This is not an act to say the person who works at the nursing home should have greater support. That is not what I sit here for today. I am not taking away from that group of people, but that is not the 50,000-plus people that Carers ACT represents today. We are talking about people in families. We are talking about friends. We are talking about neighbours, aunties, uncles.

THE CHAIR: Okay.

Ms Kelly: Yes. I am happy to take the question again, but I just wanted to really clarify that.

MR MILLIGAN: Yes, that is okay.

MR PETTERSSON: In your submission, you recommend that there are no changes to the reporting requirements. I was wondering if you could expand on why that is.

Ms Kelly: I am concerned that the reporting requirements will be taken from the bill. I am aware that in every other bill, in every other jurisdiction in Australia, there are no reporting requirements, there are no conditions under which we judge whether or not people have fulfilled the requirements. 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 it.

MR PETTERSSON: And if you were to increase the reporting requirements, how would you do that?

Ms Kelly: I would go back to including that all agencies—whether they are public funded, privately funded, NDIS funded or My Aged Care funded—if they work and engage with carers or people who receive care should be reporting on an annual basis, at a minimum, how they have upheld the principles of carers. I see that as a very simple entry in an annual report or on a website.

MR PETTERSSON: Thank you.

THE CHAIR: Do you have a supplementary question, Mr Milligan?

MR MILLIGAN: I think that is already part of the bill, isn't it, that they provide that report in the annual—

Ms Kelly: It is compulsory for public agencies; it is only recommended for other agencies.

MR MILLIGAN: Right.

Ms Kelly: If I had my way—because the world should be according to Lisa, if we are being truthful!—then that reporting would apply to everybody and the requirement for the reporting would apply to everybody.

THE CHAIR: Thank you so much, Ms Kelly.

Ms Kelly: Perfect, thank you.

THE CHAIR: On behalf of the committee, thank you very much for your evidence or your testimony. I am not quite sure the right word, but I appreciate it, nonetheless.

Ms Kelly: Fabulous; thank you for the opportunity.

Short suspension.

O'BRIEN, MS LAUREN, Systemic Advocacy Team Leader, ACT Disability Aged and Carer Advocacy Service

THE CHAIR: Please acknowledge the pink privilege statement.

Ms O'Brien: I acknowledge the privilege statement.

THE CHAIR: Great, thank you so much.

Ms O'Brien: I would also like to follow Lisa's example and acknowledge the traditional custodians of the land on which we meet today, the Ngunnawal people.

THE CHAIR: Thank you so much, Ms O'Brien. Do you have an opening statement for the committee?

Ms O'Brien: In the interest of time, I think I will also follow Lisa's example and seek to keep it fairly brief. ADACAS is a human rights-focused independent advocacy agency. We welcomed this bill. We are very excited that this bill is being put forward. We thank and acknowledge Ms Orr and Lisa at Carers ACT and all the work that has brought it to this point. Rather than go into some of the other things, I will just open straightaway for questions, if that is okay.

THE CHAIR: I appreciate that, Ms O'Brien; thank you very much. I would like to ask you how we can co-design carer policies for people who are carers and themselves have a disability. I am always interested in exploring the codesign and I want to learn a bit more detail from people who know what they are talking about, so, if you would not mind, could you elaborate on that a bit.

Ms O'Brien: Yes, sure. 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.

I know that one of the suggestions that ADACAS put forward in relation to the consultation on the way that the Carers Recognition Act is currently established is that there be perhaps some funded work by Carers ACT around some co-design on how organisations in the community could better work with and respond to carer needs and what is important to carers—as a way to seek to balance that input at a systemic level and the policy input with the demands that can be placed on carers if the suggestion is that every time a carer is in contact with an agency that they are being asked policy questions. It is important that the opportunity is there, but sometimes the timing might not be right for people if they are in contact with, say, an agency, because there is a situation that is stressful.

MR MILLIGAN: 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?

Ms O'Brien: Okay. The carers' rights in terms of what is needed to support them in their own caring role can be quite different to what is needed in terms of supporting the care relationship and enabling the care relationship to have the support that is needed. The principles that are outlined at the present time are focused strongly, as they should be, around the rights of carers in terms of what carers need in their individual capacity, but there is also a dynamic and an interaction that happens between the carer and the person receiving care. How that relationship is supported as well, is something that the act is conscious of.

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. I guess we were conscious in what we were putting forward that it is important that this bill respects the right of carers and respects the care relationship, but also that it does not necessarily privilege—in situations where it should not, because in some situations it should—one voice over another.

MR MILLIGAN: Okay.

MR PETTERSSON: Thank you. In your submission you make reference to consultation sometimes being a bit burdensome. How do we, as a whole, make sure we get that balance right—that consultation is appropriate but not too much?

Ms O'Brien: Yes. One of the key things I would say would be to ensure that the agencies that are being asked for consultation, or who are consulted, are adequately funded. Carers ACT does a lot of work through the Carers Strategy, and it is really important that they are funded to a level where they have the staff available for people to consult with them. In terms of the individual carers, there are some policy steps that would be possible. If you have an organisation that is working with care recipients and also carers, if there is some work that has been done in the policy space—codesigned and coproduced with carers around what best practice would look like and how agencies can seek to incorporate those principles into their own service organisation—that would be a good starting point so that organisations are working directly with carers in a way that works for the carers that they are working with.

At ADACAS, for example, we are often working with people at a time when something very stressful is happening. Generally, people are seeking advocacy because there are barriers that they are experiencing. At that time some people may go, “Yes, absolutely, I have some time and mind space to engage with the broader systemic questions,” but others may go, “Look, not at this moment; ask me in six months' time,” or, “Actually, can you just talk to Carers ACT or one of the other organisations and see what advice they provide.” So, I think there is balance needed in that sort of space.

MR PETTERSSON: Hopefully we will find it one day.

Ms O'Brien: Yes.

THE CHAIR: Thank you, Ms O'Brien. On behalf of the committee, thank you very much for appearing before us today.

Ms O'Brien: Thank you.

THE CHAIR: Ms O'Brien and Ms Kelly, you shortened your opening statements in the interests of time. You can see that we are now back on time, so I suggest that if you have comments which you were intending to make in your opening statements but were unable to, please feel free to get them through to the committee secretary. We will receive them as exhibits and be sure to go through them.

ORR, MS SUZANNE, Member of the Legislative Assembly

THE CHAIR: It seems almost a bit redundant, given your role in this place, but could you state your full name and the capacity in which you appear, and acknowledge the pink privilege statement.

Ms Orr: I am Suzanne Orr, member for Yerrabi. I am appearing today as the private member who has moved the bill. I acknowledge the privilege statement and also, for Aboriginal and Torres Strait Islander people, the Ngunnawal lands that we are meeting on. I would also like to say I have an asthma cough at the moment. If I cough, it is not COVID; I have been tested.

THE CHAIR: Good to know. You have had the swab. Perfect.

Ms Orr: Yes. I have horrified a lot of people by coughing in their presence.

THE CHAIR: Would you like to start with an opening statement?

Ms Orr: No. I am happy just to jump into questions, in the interests of time.

THE CHAIR: Perfect. I was wondering if you would mind elaborating on what you see as the role of the wellbeing indicators in recognising carers.

Ms Orr: Okay. That is a really good question. It is not something I necessarily put a huge amount of thought into in developing the bill. We have looked at other states and territories in putting together this particular bill. What I know of the wellbeing indicators, though, is that they will be looking across the whole of the community, so I would encourage the good people in CMTEDD who are developing those indicators to have a look at the bill to see how they could use those indicators perhaps to shine a light on carers, because that is a good longitudinal data set in the making, which could be quite good in informing how we support carers in our community.

MR MILLIGAN: I am just looking at your guidelines and principles. How are you going to monitor whether they have been adopted and implemented well?

Ms Orr: This goes, I guess, to the enforceability of the principles.

MR MILLIGAN: Yes.

Ms Orr: The principles are there. The enforcement comes through the reporting. This bill is a little bit different—as has been alluded to, I think, by Ms Kelly in her remarks—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 enforcement.

It was also something that came through very strongly in the submissions that I received. We had a number of submissions. I did forums with ACTCOSS and Carers ACT. I wrote to organisations, including ADACAS and AFI, asking for information and feedback on the bill. What we heard throughout a lot of that, particularly from

carers—and a lot of individual carers did make submissions—was that if it did not have some level of accountability and transparency, it would not drive the systemic change that they wanted to see. So, it was really important that it was included.

On the other hand, 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.” There was also a view that it needed to be consistent reporting, so people were not just writing whatever they wanted and you never got a good picture as to how the principles were being put in place. So the regulation that is there is based on a Victorian regulation that the health department put out in their Carers Recognition Act. We did not feel the need to reinvent the wheel when there was something already in place which, by all accounts, was working.

The regulation is there to provide consistent reporting feedback—clarity for organisations so that they know clearly what their obligations are, and they have to make it publicly available, whether that is in the annual report or on a website, so that it is there. That is the accountability. If they are not doing anything, it is going to be pretty clear because it is going to be out there in the public forum that they are not doing anything, and they can be called out by carers on that.

MR MILLIGAN: So, in effect, they publish their report using the template that is provided, following the regulations as well. My question is, who is looking at that? Is it government looking at every one of those reports and making sure that they are meeting the guidelines and principles?

Ms Orr: Yes. I think what you are alluding to is what the penalties are if you do not.

MR MILLIGAN: Well, who is reading those annual reports?

Ms Orr: Yes. 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. Carers have told me that they would be looking at them and it would give them an opportunity to put some weight behind what they are doing. 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. So there are ways there to work it up. Mr Milligan, I think there is a question there for the committee to consider—and this is certainly something that I have heard very contrasting views on—as to how strong you make the reporting requirements, how strong you make the compliance and how you check it. We have gone with the lightest touch we can, based on the feedback we have got from organisations. From your own line of questions, perhaps there is a willingness for it to be a bit stronger. There are people out there who have the view that it should be stronger.

The point I got to in the first instance was—in considering that it has expanded those reporting obligations to a much broader field than we would have in other jurisdictions—I felt that that was probably enough of a step change. Through the review period, if it were not providing what some people feel it will not provide, we

would need to build that 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. But I am very open to the committee having a look and making recommendations, if they feel there is a better balance.

MR MILLIGAN: Thank you.

MR PETTERSSON: I was hoping you could tell the committee why you are bringing forward this bill?

Ms Orr: Yes. I provided my introduction speech to the committee, and that goes into a lot of my personal reasons, growing up in a family that did provide care. I think my words in the speech went something along the lines of, “My whole life has been an education in why this bill is important.” Certainly, in talking to my parents over the 20-plus years that they have been carers, they have said that they have not seen a lot change. My experience in talking to carers since I have been in this place is that there is still a lot of work to do there. The thing you hear from most carers is that they just feel invisible, and that they just want to be recognised and valued for the input that they have. So, in bringing forward the bill, my great hope is that it finally draws that line in the sand and puts it in law: carers exist and they cannot be ignored.

MR MILLIGAN: It mentions there that carers are not necessarily respected. Who are they not respect by? Where is that coming from?

Ms Orr: That is a really good question. I think I could get you a series of carers who could probably answer that very clearly for you, Mr Milligan. I am talking on behalf of carers here now because you put this question, but it actually goes to a person other than me, so I will give you my take on what I have been told.

MR MILLIGAN: Yes.

Ms Orr: Carers, in the feedback they have provided to me, say that they are quite often put to the side, almost. The conversation that happens is about the carer just being there to do, but they are not there to inform the process that comes from what they are doing. It is about how you give voice to all sides. I think this is partly what Lauren was going to in the discussion she was having: how do you make sure all voices from the care relationship are brought into how the care relationship operates? The key to this bill is bringing that in, so that carers are no longer just told, “This is the care we need you to provide,” but they actually have a chance also to shape that, based on the knowledge and the experience that they bring to the relationship.

Can I just add some things for the committee’s consideration?

THE CHAIR: Please.

Ms Orr: I just want to pick up on what Ms O’Brien was saying about the change there from the consultation draft, which I can provide a copy of to the committee. I will have to send that through. We did have another section, which was on the carer relationship principles, the treatment of people receiving care and the treatment of people in the care relationship. I believe some of the comments that Ms O’Brien was

making alluded to that section. That has been one of the harder parts of the bill to work through. There were a number of stakeholders who felt that people receiving care were well catered for in other parts of legislation and did not want it to be confused by adding in another bit of legislation. So we left it very simple to point to those other bits. But I draw the committee's attention to that. It is something committee members might want to turn their minds to, especially based on Ms O'Brien's testimony. If there is something that could be a better balance, I am open to that.

The other thing I wanted to respond to was the "care" and "carer agency" definition. This is a particularly hard one and it is something we have worked on quite a lot with the drafters. It is not clear in any of the bills. Unfortunately, there was not a perfect definition we could pick up and copy; otherwise, we would have done that. But we have taken the experience of other jurisdictions, what they have learnt, and feedback from Carers ACT and other organisations through the consultation process, and really worked on that definition.

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. What I have been thinking about, though—and I said this in my introduction speech as well—is that there is probably a body of work that goes to 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. They will change, and our understanding of the care relationship will change. 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 included. I just put that out there, too, because I know that came up in the other testimonies.

THE CHAIR: Thank you, Ms Orr. That concludes this. I would like to thank you very much for presenting before the committee today. Once again, in summary, I thank all of our other submitters—Dr Childs, Ms Williams, Ms Kelly and Ms O'Brien. If witnesses undertook today to provide any further information, or they took questions on notice during the course of the hearing, whilst the committee has not set a deadline for the receipt of those responses, answers to those questions would be appreciated within two weeks of the date of this hearing. When available, a proof transcript will be forward to witnesses to provide an opportunity to check the transcript and suggest any corrections. I now close the hearing.

The committee adjourned at 3.57 pm.