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## **Submission:**

### **Integrated Carer Support Model**

**May 2016**

#### **Background:**

Carer Support is a 100% Government funded organisation that has successfully supported tens of thousands of Carers, the person they care for and their families, for over 25 years.

In providing feedback on the proposed Plan for a new Integrated Carer Support model, some initial foundation comments are needed.

- The Carer Recognition Act 2010 must underpin what is delivered and by whom.
- Carers require support in their own right outside of what is required to sustain them in their caring role.
- Carers have a right to a life and lifestyle choices outside of their caring role.
- Dedicated carer services cannot and will not be available or delivered through a care recipient focused program. If carer funding goes, so do the carer services.
- Respite is a carer term not a care recipient term and it relates to the outcomes for the carer. Both the carer and the care recipient benefit, however, because they are linked by outcome.
- The diversity of carer need requires a dedicated carer service to be able to respond.
- Carers are of all ages and cultural backgrounds. They care for people of all ages and cultural backgrounds. The 'one size fits all' approach simply will not work. Obviously, how a carer aged 15 is supported and the nature of the supports they need will be dramatically different from those of a carer aged 75.

## SUBMISSION:

### 1. In the concept paper the following comment is highlighted:

#### **Statement**

*Therefore, the Committee is concerned by evidence which indicates that the current levels of support are insufficient to give carers the assistance they need to care, or enable them to make genuine choices in relation to their involvement. This is even more concerning in view of the expected increase in demand for care and predicted shortfall in the supply of people to provide that care."*

*From the 2009 'Who Cares...?' (House of Representatives, 2009).*

#### **Response**

This statement is accurate and meaningful. It is critical to accept that carers need to be recognised in their own right as consumers of services and not only bound by the care they provide to the person being cared for. Choice for carers is a fundamental right. This new integrated carer service must have this principle at the forefront of WHY it is being developed.

2. The diversity of carers and the individuality of their situations require a model that is flexible, carer focussed, resourced appropriately, and local and accessible.

3. The Carer Gateway must be able to link carers to dedicated carer support services.

#### 4. **Statement**

*As planned respite is funded under the main service systems targeted for care recipients (e.g. CHSP), carers face increasing difficulty in seeking this type of support, particularly where they are caring for more than one person.*

#### **Response**

Carer Support totally agrees with this statement and therefore, as it is a reality, the question has to be asked, WHY IS THE TRANSITION OF CARER FUNDING CONTINUING TO HAPPEN?

5. Respite as one component of the multifaceted approach is supported, as Respite is widely accepted as being one component of effective carer support. Please refer to the attached paper on Respite. This is the organisation's understanding of and commitment to what Respite is and who it is for.

#### 6. **Statement**

*Identifying supports known to improve carer outcomes is challenging. Identifying interventions known to improve carer outcomes presents two dilemmas: 1. A review of the research shows there is a lack of consensus as to those supports which are most effective at improving carer outcomes; and 2. Carer preferences can often conflict with current evidence on what supports tend to have stronger effects. For*

*example, evidence suggests more frequent interactions whereas carers often express a preference for less frequent interactions (Joling, et al., 2013).*

**Response**

It is our experience over 25 years that this outcome occurs due to the diversity of carer circumstances and the need to have a flexible model of support which can respond on an individual basis. A menu driven service framework will not work. Carer choice is fundamental and unique to that carer. It is therefore completely understandable as to why the above 'dilemmas' have been identified and why flexible service responses are essential.

**7. Statement**

*Given that an objective of the future model will be to assist as many carers as possible, it will be necessary to identify those carers who will require a higher level of support so as to target Government assistance for those most in need.*

**Response**

If funding for carers is transitioned to care recipient focused programs, and there are no formal assessment processes to identify carer need anywhere within these programs, who will assess which carers are most in need and how will this be determined? Further, as not all carers will be linked to programs such as NDIS or CHSP, who will assess these carers if not dedicated carer support agencies? And why would carers' need-assessments be performed by more than one agency?

**8. Guiding Principles as stated in the paper:**

**Response**

The Guiding Principles are excellent and Carer Support totally supports them.

**9. Carer mentoring:**

**Response**

Our experience with a similar model is with the CDRC Respite Pilot, in which our organisation was involved. Please refer to the attached paper from a carer who was a part of this trial. This carer's perspective in terms of an outcome for them is exactly what is needed for this part of the new model.

**10. Statement**

*Providing Integrated Support.*

*Assistance for the person they care for. This includes links with:*

- My Aged Care*
- National Disability and Insurance Agency*
- State based disability services*
- Department of Veterans Affairs*

*The design of the service will need to include relationships with these organisations to support carers in navigating the system.*

**Response**

There is a significant difference between linking with these agencies/programs and carer funding being encompassed within them. Funding for carers in their own right needs to underpin this new model.

**11. Statement**

*Support when caring changes or ends.*

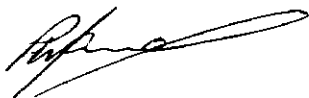
**Response**

Past carers and the impact of caring over many years have always been known but they have never been formally addressed or funded. In the new model being developed, these carers and the impact caring has had on them must be recognised and resources provided to assist and support these carers to transition to a life without a caring role. This also then raises the issue of where and how these carers will be supported, as they will not sit within any care recipient focused program.

**12. The design progression and the process from here:**

**Response**

Current carer funded programs are continuing to transition to care recipient focused programs. The work of everyone in developing this new model is excellent. Further, it is acknowledged that funding and implementation of the model are not yet being discussed. However, the question arises: if this new model is proposed to the government and is not accepted, or it is accepted but funding is limited and existing funds have transitioned, what happens then for those carers already accessing support, let alone the potential many thousands more carers wanting to access support? Where will this leave current programs and funding? What will exist for carers to access? While this scenario is yet to be reviewed, consideration must be given now to the probability of this outcome.



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