Delivering an integrated carer support service

A draft model for the delivery of carer support services

Submission by the Carer Support and Respite Centre Inc.,
trading as *Carer Support*

770 South Road

GLANDORE   SA   5037

December 2016

TABLE OF CONTENTS

Executive Summary

Carer Support is a South Australian not-for-profit that has been operating since 1990 and provides services to more than 5,000 carers.

The primary goal of any carer service must be in ensuring equitable outcomes for carers when compared with their peers. This forms the basis of *Carer Support*'s submission.

We endorse the four objectives of the draft model, and recommend that consideration is given to three further objectives informing the model, specifically:

- Providing emergency respite during times of crisis;

- Long-term financial security and quality of life for carers as key to their wellbeing; and

- Access to employment, education and training outside of the caring role.

Regarding the model, *Carer Support* endorses the general distribution of activities nationally, regionally and locally, with some qualifications:

- That the focus on carer training should be extended to assisting carers to enter (or re-enter) employment, education or training;

- That there should be flexibility to enable carers to access the services they want in a way that works for them – for instance, counselling should be available face-to-face for carers who do not use or would not benefit from online services;

- That the regional hubs must be well resourced and provided with sufficient autonomy to operate in a manner that enables responses to be tailored to meet the needs of local carers; and

- That the exact mix of services that transition to the new model, once decided, is important in determining local delivery.

Carer Support believes that most sector agencies will already have established lists of relevant networks and working processes to ensure that these remain current. We suggest that the Results Based Accountability model used by many non-government organisations provides a possible mechanism for consulting and engaging carers in determining outcomes. Finally, *Carer Support* recommends that carer outcomes, as defined by carers during their 'carer journey' and beyond, should inform any quality framework.

About Carer Support

Carer Support and Respite Centre Incorporated, which trades as *Carer Support*, is an Adelaide based not-for-profit organisation that provides support to more than 5,000 carers each year and tens of thousands of carers since it was established over 25 years ago.

Funded continuously since June 1990 through the Australian and South Australian Governments, *Carer Support* has provided unpaid carers with personalised support, including:

- 1:1 contact at home or by phone;
- access to resources and information;
- in and out of home flexible respite;
- emergency respite 24/7;
- peer support groups; and
- subsidised outings and/or short breaks.

The aim of this service has always been to sustain the family at home and to build carers' resilience in the caring role under the banner of, *"You care for someone, we care for you".*

Since 2015, *Carer Support* has provided in-home assistance and support through the Commonwealth Home Support Program that targets anyone over the age of 65. Services include domestic assistance, social support group and for the individual, home maintenance and transport. *Carer Support* also provides Plan Management and Service Coordination services on a fee for service basis to participants and their families entering the NDIS.

Introduction

Carer Support acknowledges the Australian Government's commitment to carers and to the Carer Recognition Act 2010 in proposing this model.

As the Productivity Commission identified in its inquiry into Disability Care and Support, the transition into the National Disability Insurance Scheme (NDIS) is a critical juncture for carers and for the organisations that support them (Productivity Commission, 2011).

"Affording a carer the real opportunity to return to a life where financial security, employment, home and leisure opportunities equal those of other people their age, and where their role with the person they care for is restored to that of parent, partner, sibling or child, is the optimal result for all concerned."

Ms Mandy Toczek McPeake,
Executive Manager, Consumer Services *Carer Support*

As the NDIS progresses to full nationwide implementation, the *Delivering an integrated carer support service* concept paper comes at an important time.

Carer services organisations, like *Carer Support*, have built a solid foundation across the country over the last 25 years, based on national and international evidence that informs service delivery. However, there is a growing imperative to deliver services differently, reflecting the evolving needs of carers, new technological developments and the fiscal and policy priorities of the Australian Government.

Significant numbers of carers live the role of carer for many years before they identify as carers or access carer support services. During this time, there can be major impacts on the carer and their family, which in the experience of *Carer Support* in supporting thousands of carers includes:

- Poorer financial circumstances, particularly if the carer is unable to remain in the paid workforce;
- The loss of networks, including family, colleagues and friendship groups;
- Stigma attached to role definition and lack of status as a carer;
- A lack of meaningful and productive daytime occupation outside of the caring role; and
- health impacts, including physical strain injuries and mental health concerns like depression.

Collectively, these changes can increase anxiety and have a dramatic negative impact on carers' self-esteem. Evidence supports that peer support, informal and formal counselling

and breaks from the caring role are significant factors in improving carers' wellbeing and resilience.

The weekly median income of a primary carer was $520, which was 42% lower than for non-carers.

Australian Bureau of Statistics, 2016

However, the ultimate aim of any carer service must be in ensuring equitable outcomes for carers when compared with their peers. This forms the basis of this submission.

Carer Support welcomes the opportunity to comment on the body of the draft model as well as to respond to the four specific questions posed in the consultation document.

Objectives of the proposed service delivery model

Carer Support endorses the four key objectives of the model as outlined in the discussion paper, specifically to:

1. Encourage and normalise earlier uptake of services proven to help carers, in their caring journey.

2. Help more carers.

3. Deliver a service carers will value.

4. Provide a service carers find easy to access and use.

Further to this, _Carer Support_ believes that three additional objectives warrant inclusion:

5. Providing emergency respite during times of crisis.

    - Emergency respite prevents unnecessary admissions to care facilities for those with care needs.

    - Emergency respite reduces the demands made on services by carers and, accordingly, reduces their health burden on society.

6. Long-term financial security and quality of life for carers as key to their wellbeing.

    - A fundamental issue is the inequality that exists between carers and their peers – all services provided through the draft model should consider the long-term wellbeing of carers as a key objective.

7. Access to employment, education and training outside of the caring role.

    - Through virtue of their caring role, many carers have low levels of educational attainment and employment.

- Moreover, some carers have left fulfilling careers and professional activities to become carers.

- It is critical that current carers and those that are no longer caring receive additional assistance to engage or re-engage in employment, education and training to encourage financial self-sufficiency post caring.

Carer Support has identified a number of risks and opportunities emerging from the proposal. A summary of these is provided in Appendix 1.

Discussion Paper Question 1:

In relation to the program overview, do you believe that the objectives, outcomes and delivery principles are appropriate for the services required to be delivered under each program? Do you believe that the services proposed to be delivered at the national, regional and local level are targeted appropriately?

The National Program

Carer Support endorses the:

- use of a national central database and referral system;

- phone counselling service;

- website based information and education service; and

- online self-assessment tool.

Carer Support suggests that additional consideration is given to the following points:

- That management of the coaching and mentoring program be coordinated at a regional or local level, recognising the potential for more localised programs to reflect specific community need.

- That while training to assist carers in undertaking their caring role may be important to some carers, there is a benefit in expanding education and training to assist carers to gain skills and knowledge outside of their caring role. Accordingly, consideration should be given to offering educational assistance through this program – beyond simple referral to complementary services.

"I know of carers who had been in rewarding jobs that they had to leave to become carers. The grief that some people feel in abandoning their independence, status and income cannot be overlooked. It contributes greatly to depression in carers."

Carer

- While many carers can use online services, there is a significant minority for whom virtual support will not work, including those in rural communities and those without

internet access. Recognising that many of these individuals constitute the most marginalised group of carers, it is important that other avenues of service delivery are available, including face-to-face services.

The Regional Hubs

Carer Support believes that the success of the hub concept primarily depends on the number of hubs that operate across Australia and their geographical coverage.

Experience from Regional Assessment Service

The recent experience with the Regional Assessment Service (RAS) model in aged care is instructive. Anecdotally, many agencies and consumers perceive the RAS as a hindrance to accessing local services because of the lack of connection between distant hubs and proximate frontline services. *Carer Support* believes that a sense of distance from the provider may also have led to the poor uptake of the national Carer Gateway call centre.

Required support to make hubs work

Carer Support believes that the proposed dual function of hubs as providers of services to carers and as managers of grants and funding agreements requires specific supports to be successful. Our extensive experience with one such approach – the Southern Collaborative Project – which sees *Carer Support* administering funds to seven other agencies has provided a number of learnings. Of greatest relevance are issues relating to grant administration and the subcontracting of services, data collection and collation, monitoring of service standards and fund allocations.

Based on this experience, *Carer Support* believes the keys to the success of the hub model are:

- Clear role definition between the hubs and the national level and between the hubs and the local level services;

- Workforce planning, looking at both numbers and skill mix of staff including those who have in-depth experience in meeting carers needs; and

- Simple reporting lines and monitoring processes with data reporting from the hub.

Autonomy and flexibility in hub delivery

Carer Support believes that there is a benefit in allowing hub providers to operate autonomously in their identified regions, enabling the funded organisation to flexibly meet the needs of the local community.

Our recent experience in moving away from a central hub operation to establish three local Carer Centres for the region has had several key outcomes:

- It saved us money on lease and other site costs, which was redirected into carer services;
- It enhanced our reputation as a flexible and responsive one-stop-shop for carers at a local level; and
- It enabled the prioritisation of services to carers in identified high-risk carer cohorts.

"I speak from experience when I say that hanging on a phone (and some people do not have landlines any more) for an hour or so to speak with Centrelink is impossible when you are a carer. Most people caring for a loved one with dementia find telephone calls need to be short and to the point, otherwise their person becomes unmanageable."

Carer

Through this locally based model, feedback from carers has been that they feel a greater sense of ownership of *Carer Support* and a greater belonging to the organisation. Moreover, it has enabled the organisation to sustain extensive collaborative partnerships with its community peers and local businesses.

There is a risk that the hub model, as described in the discussion paper, will be difficult to access by some cohorts. In more than 25 years in operation, *Carer Support* has found that Aboriginal and Torres Strait Islander carers and those from culturally and linguistically diverse backgrounds access services based on trust, easy access and established individual relationships. Similar access issues can exist for LGBTI carers, those with a mental illness and those from low socioeconomic groups. *Carer Support* believes that

"Carers have among the lowest levels of wellbeing of any group of Australians."

-   Productivity Commission, 2011, p6.

alternative engagement and service models need to be available for these particular cohorts – particularly early in a carer's caring journey, including face-to-face contact.

Local Service Provision

The kinds of services proposed to be delivered through local carer support agencies are appropriately delivered at a local level and, as such, this aspect of the draft model is supported.

However, and as outlined on page 28 of the Draft Service Delivery Model, the Australian Government is yet to determine the exact mix of services that will form the new model. Determining the exact scope of services that are to transition to the model is critical in the form of local services that will best meet the needs of carers and *Carer Support* and other providers would be better positioned to comment on the service mix once this is finalised.

In principle considerations for local services are that they are easily accessible by all carers in ways that are meaningful to them. In our experience, the majority of carers are time poor and do not want to engage multiple services or agencies to access the services they require.

Discussion Paper Question 2:

A key factor in the effectiveness of regional hubs will rely upon their ability to understand the local service landscape and identify service gaps. If you were operating a regional hub, how would you undertake service mapping for your region? How would you ensure that you had captured a complete view of the available supports for carers in your region?

Carer Support believes that agencies engaged in local service provision already have established processes for service mapping.

In the case of our organisation, this involves developing a high-quality database that is updated through information from staff who establish and maintain community networks and links with other sectors. In our experience, these must include the NDIA, Centrelink, health, education, vocational, mental health and ageing services to enable quality data mapping and to ensure appropriate referrals can be made.

Discussion Paper Question 3:

It has been identified that outcomes measurement will be essential for a future model. Outcomes measurement involves identifying how effective services are in achieving a particular objective. This commonly takes the form of a questionnaire which helps to assess aspects [of] the carers role. However, there will be a careful balance in measuring outcomes, whilst not placing undue burden on a carer to answer multiple questionnaires, particularly where they may be accessing more than one service. What are some ways that outcomes could be measured and these issues addressed?

Carer Support believes that the Results Based Accountability (RBA) framework used by many non-government providers in South Australia and nationally provides a strong option to deliver this outcome.

RBA is based on the premise that organisations and programs can only be held accountable for the customers they serve. This helps organisations to identify the role they play in community-wide impact by identifying the specific customers who benefit from those services that the organisation provides.

For programs and organisations, the performance measures focus on whether customers are better off as a result of your services and on the quality and efficiency of these services. RBA asks three simple questions to get at the most important performance measures:

- How much did we do?
- How well did we do it?
- Is anyone better off?

The benefits of the RBA model are that it:

- Gets from talk to action quickly;

- Is a simple, commonsense process that everyone can understand;

- Helps groups to surface and challenge assumptions that can be barriers to innovation;

- Builds collaboration and consensus; and

- Uses data and transparency to ensure accountability for both the wellbeing of people and the performance of programs.

Carer Support suggests that this approach be adopted as part of the National Framework. This would necessarily include ongoing staff training, workshops, conferences and best practice sharing opportunities to embed the tool in practice, while undertaking national surveys of service users, sharing and comparing results amongst agencies.

Discussion Paper Question 4:

While this model will seek to help more carers, it will be important to ensure that quality services are being delivered. What would you view as the essential components of a future quality framework?

Carer Support believes that carers should be involved in all aspects of service design, development and evaluation – which should be embedded in the quality framework.

As outlined earlier in this submission, *Carer Support* believes that a carer journey must embrace both their caring role (with access to carer services) and their own personal development separate from the care recipient. We believe that this approach to the carer journey should underpin the quality framework.

Involving carers in service delivery – recruitment of a youth worker for Raw Energy

Candidates selected for interview were brought in together and underwent a speed meeting session with a group of our young carers who each wrote an opinion of each candidate. This was followed by a group shared activity, observed by the selection panel and then a private discussion between the selection panel and the young carers. This improved carer engagement with the Raw Energy program.

This recognises that the caring role will end for most carers, limiting long-term dependence on most services. Nonetheless, there remains some need to both recognise and support past carers (including former young carers) to enable them to move on and to return to or access study options, employment and financial independence.

References

Australian Bureau of Statistics. (2015). *4430.0 Disability, Ageing and Carers, Australia: Summary of Findings.* Canberra: Australian Bureau of Statistics.

Productivity Commission. (2011). *Disability Care and Support, Report 54.* Canberra: Productivity Commission.

Appendix 1: Opportunities and Risks in the Proposed Model

Opportunities & Risks

Opportunities

- More coherent overall national approach
- Nationally agreed best practice
- Less local fragmentation
- Better carer dataset
- Increased opportunity for carer co-design

Risks

- Inadequate resourcing: what level of efficiency savings is expected?
- Inflated outcome expectations: what increase in service levels is expected?
- Loss of expertise, carer satisfaction and quality, if hub tenders are open to non-carer organisations.
- If the transition happens too quickly this will disrupt existing services and supports, which will demoralise both workers and carers.
- Inadequate carer participation in co-design and transition to the new system will impact the quality of the end result.
- Inadequate staffing levels will impact on the quality of services and on the numbers of carers provided with a service.
- Loss of knowledge of the circumstances and concerns of a carer and risk of their having to constantly tell their story.