DESIGNING THE NEW INTEGRATED CARER SUPPORT SERVICE

RESPONSE TO THE DRAFT SERVICE CONCEPT PAPER

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1. **GENERAL COMMENT**

- This paper summarizes information and current thinking about what works, what is proposed and questions for further consideration. It is a useful discussion paper.
- It would be good if future carers consultations could:
    - Feature an executive summary in plain English designed for a wider readership – several active carers gave up reading the discussion paper;
    - Use more inclusive processes than a written submission (e.g. online surveys/phone in's) so that people who are unlikely to read the full discussion paper can still participate in the consultation process.
- Providing flexible, customized support to carers will increase its effectiveness and the duration of in home care.
- The weakest element of the concept paper is Respite; where there appears to be a misunderstanding of the role that home care by a provider plays in the life of a carer. The care provider's role is role is greatly appreciated, however, these practical assistance visits can result in unintended burden on a carer, and this is under estimated in the concept paper. For example:
    - providing care to the care recipient does not amount to respite - at best it provides a brief moment to catch up on all the daily living essentials - paying bills, catch-up cleaning, catching a cat nap to relieve sleep deprivation, setting medical appointments or having a haircut.
    - loss of privacy - as timing is usually set to match the provider and care recipients needs with little consideration of the needs of the carer (as they are not the client) and their life is exposed to the staff coming to the home.
    - exposure to judgement or lack of professionalism on privacy issues – I have had misinformed comments 'reported' to me on several occasions by friends who have had contact with a carer in another setting.
- Care can be a 24/7 process. The need for respite programs to include respite care breaks for rejuvenation for the carer, but also holidays and 'sick leave' is essential.
- As respite places in aged care are scarce, especially high care places, the introduction of increased service flexibility in home and residential aged care (e.g. more hours; more beds dedicated to respite) would be timely. It's likely to increase the success and duration of home care.

2. SERVICE CONCEPT OVERVIEW

- I generally agree with the elements of the proposed support system.

3. DESIGN ELEMENTS

3.1 AWARENESS

What would be the most effective and efficient means of raising awareness for individual carers early in their caring journey? Should more resources be directed towards raising awareness about young carers (and carers in general) in the healthcare sector, rather than in schools?

Taking many different approaches to raise awareness of support for carers will be important. I don't think that it should be restricted to the health system or schools or by only using one mode of communication (e.g. letter drops). General community awareness is required. Strategies could include:

- A national campaign to set the ball rolling – and not advertising the portal – I don't think it works as a first point of contact.
- Providing grants or other funding to promote local community education strategies on message
- Develop a system of carer champions, especially in regional areas to provide information to local GPs, community groups etc
- Support Centrelink workers to make sure all carers are aware of local carer support networks.

3.2 INFORMATION

While information is available through carer organisations today, as well as the Carer Gateway, would individualized recommendations be of benefit when carers are undertaking or receiving other services?

- I was completely unaware of the range of payments and support services at the time I became a carer for my mother. I was aware of an organization that actively supported families of the progressive condition that she had, but there did not seem to be any links to other forms of carer support. Consequently I don't think that one approach to information provision works.   It would have been great if I could find carer websites online that help me make my own assessment, link to service providers and find out

what I need to know now, then check back in as my needs change. I would also like to be able to speak to someone about the best fit for me, so a telephone service that understands my region would also be very useful. The local Red Cross funded service has played a critical role in this way.

o   If other services are engaged in providing information, then let's make the information simple – e.g. GPs able to provide local phone contact or website information to someone that can help the new carer get their head around the system.

3.3   INTAKE

Are there ways to make intake a more beneficial process for carers? To ensure that intake is of direct benefit to carers should intake be limited to those times it is necessary and when should intake be a mandatory process?

o   It is suggested that the mandatory information for a service is collected (i.e. counseling; in-home respite) at the point of service. It should and relate only to the service provided and remain non-identified for data collection purposes.

o   If there is a national need for data for policy purposes, create engagement strategies that enable a broad range of carers to participate as and when required.

o   Carers are busy and need information and referrals accurately and promptly from trusted sources.   Feeling that multiple strangers have access to information at a point when you may be vulnerable isn't useful.

Note: It is my view that intake data is not required for information, online education (unless it is nationally accredited) or referral to local services. I don't believe the current approach to generic telephone services is useful. I spent 45 waiting minutes one morning trying to find the people who actually assess the Financial Assessment for Residential Care so I could ask them a question. I started at the MyGov link to Aged Care webpage, and finally found a number – and was then referred to a series of 4 different numbers (some national/some state). I had a simple and generic question (i.e. what is the number for the people who actually assess a person's financial assessment for residential care purposes). If an intake system was in place I would have had to complete 'intake' information or passwords for a generic database to get the wrong information 3 times!

3.4 EDUCATION

How can we encourage carers to access education support? If education were to be offered online, how can we encourage carers to participate and complete an education programme? How can the future Integrated Carer Support Service help carers to be aware of, and access education which may be relevant to them outside of these carer focused supports?

- Use links to existing contact points more effectively - My mother has Parkinson's. Education about her condition has occurred over 20 years for us. I think it is problematic to believe a Carer Support Service System has the capacity to be all things for all people. Linkages from the WebPages of chronic condition organizations (e.g. Parkinson's; MND etc) to relevant training opportunities could be useful.

- Allow carers experience and formal education to count towards nationally accredited training.

- Use training modules that are easy to use online, and promote them in e-libraries and Telecentres.

- 1:1 peer support and mentoring can be very useful to help sort out education options.

- Ensuring that training is sensitive to ATSI, CALD and all forms of family relationship would be useful.

- Education needs to be optional and not linked to payments or other services.

3.5 PEER SUPPORT

What are some of the tools or supports which could assist in delivering peer support to a broader base of carers in a cost effective manner? How can a peer support model be designed which encourage carers to participate and remain engaged?

Should peer support be a service able to be accessed without pre-conditions or structure processes?

- I have not thought about this extensively.

- o What would have been supportive for me is a better community understanding of the choice to care for my mother at home.
- o What has been useful is having a chat with a professional care service worker who has been able to act on my behalf in an emergency, but also help me plan respite and engagement in the workforce etc.
- o What has been useful is the ongoing support to my mother by my mother's friends as it provides respite that is meaningful to my mother and keeps her connected to her life.

3.6 NEEDS IDENTIFICATION & PLANNING

To what extent do you think goal based planning should be used at the assessment stage of the process? Given that a carer may not necessarily receive financial allocation of some form, would a goal based planning approach be worthwhile? To what extent should self-assessment form part of the future model?

- Needs identification and planning are two different stages and I think that they are separate activities.

- Needs identification requires cool, clear thinking, and self reflective processes alongside a strong knowledge of what is available to support caring.

- Planning is then about matching available supports or self-driven activities. It would be useful to complete with a coach or mentor.

3.7 MULTICOMPONENT PACKAGE

Multi-component support seeks to amplify the effects of the supports by combining them. Given that this model is seeking to apply preventative thinking, how can we ensure these supports are allocated to those carers who will benefit the most from them? What should be the criteria by which this is determined?

- o Does this question suggest that some carers won't benefit from a multicomponent package or suggest that more funds need to go to those with fewer resources? In my view, the latter is preferable and relate to both family capacity and financial situation.
- o Self-directed carer packages are extraordinarily valuable tool to support carers. I have received an additional budget that has meant that I have been able to plan respite, provide support to my mother that would not otherwise

be available to her; improve my overall health and well being; and been able to call on resources in an emergency.

o In short, I believe that such packages need to be goal oriented, self-directed and be highly flexible, including the capacity to transfer funds from one area of expenditure to another in a planned way or to accommodate unforeseen events.

o It is useful to have a skilled support worker/mentor able to help set goals and activities.

o Flexibility is most important in remote and regional areas.

3.8 FINANCIAL SUPPORT

How can we help carers to use these funds appropriately without large administrative burdens on carers or providers who may be assisting them?

o A twelve month budget allocation for an individual carer would be the most useful.

o Funds need to be flexible to allow for variations in circumstances.

o I like the brokerage service model as it provides both mentoring, administrative support and ensures funds are an investment in the carer.

o In some instances, it may be that a debit card is provided to the carer to spend at their discretion, so once again flexibility is required.

3.9 CARER MENTORING

When would a coaching programme be most effective for a carer? Given this is intended to be part of a multi-component support model, should this be a mandatory part of the service? Or should mentors should be able to determine whether the carer has the capacity to forgo coaching until another time?

• Creating a uniform approach to the skills development of a carer is problematic. I don't think a coaching program can be generic. I have found the case worker approach attached to the Carer Directed Respite program was an excellent mix because it remained highly relevant as my needs and issues developed. Further, I then had the resources to address those issues. This has been crucial and has extended my mother's care at home.

• I wonder if carers understand the difference between coaching, mentoring, and brokerage and support. In some instances I've observed that what has been called mentoring is really 'befriending' at best.

3.10 RESPITE SUPPORT

A number of carer organisations have reported anecdotally that more flexible responses such as brokered respite have resulted in longer term outcomes. It is for this reason that this service is proposed to be coupled with financial support, as a form of consumer directed respite and coaching. Will moving to more of a consumer directed model, where funding is attributed to an individual carer result in unintended effects? What might these be and how can they be mitigated?

- o I think that the discussion paper confuses the needs of carers and the care recipient some times. I believe that carers themselves need to be consumers in their own right. I don't think that having someone come into the home and provide cleaning, or a personal care service is respite.
- o Respite is about a complete break and look after their health, wellbeing, economic and social needs at that time. Respite care is also about the safe care for the care recipient while they are usefully occupied elsewhere. It's important to recharge the batteries some times.
- o Three kinds of respite are required – all of it to match the carer's situation - :
  - ▪ Emergency respite – when something unforeseen happens to the carer
  - ▪ Planned short break respite – to ensure carers have downtime to rejuvenate (e.g. series of overnight and 2 week breaks on a timed schedule)
  - ▪ Holidays – that is separate from planned short break respite.

3.11 COUNSELLING

Much of the evidence relating to effective counselling programmes for carers is focused on CBT. What other counselling programmes and techniques would be beneficial in reducing carer burden? Could these be delivered to a broader group of carers through telephone or online channels?

Counselling is very useful to carers as there is so much to work through as your relationships with the care recipient changes. However, I think the model of counseling needs to rest with what works for the carer – some will like group support, others telephone support, others 1:1 talking sessions. The options available need to account for location, cultural background. It would also be useful during times of transition ….becoming a carer or ceasing to be a carer.

3.12 SUPPORTING ALL CARERS

It is important that the services recognize the situation of the individuals caring:

- Age of carer
- Relationship to care recipient
- Working or not working
- Geographic location
- Languages spoken at home/religious or cultural differences

Ultimately one size won't fit all, and it needs to be flexible and consumer directed, but with access to quality support and information as needs change.