## Response to “Designing the new integrated carer support service” draft Service Concept document May 2016

OVERVIEW

This document provides BaptistCare –NSW & ACT feedback, as requested within the consultation phase of the DSS “Designing the new integrated carer support service – draft Service Concept” document. Our response to the document is based on our experiences and learnings from providing support services to carers of people living with dementia over many years.

A. STATEMENT OF NEED

* It is also our experience that many people who are carers may not identify themselves as such, and not only remain hidden (p.7 of 72), but when found, are sometimes offended by the term ‘carer’ or still reluctant to access services to which they are entitled, and in need of, then in hindsight comment that they wish they had accessed help earlier. When you visit carers and you start asking questions about how they are going as opposed to their care recipient they are surprised that someone is interested in them. They don’t seem to have any trouble accepting help when it is delivered in a way that is respectful towards them and acknowledges the great job they do; even if they don’t feel they are doing a great job! It may be helpful for marketing this new integrated support service to highlight this.
* Given so much goes through a portal now, couldn’t carers be identified through this at initial point of referral? That way when they are calling to enquire about their care recipient and services for them (which they are better at doing, as it’s not for them) they could be entered into ‘the system’ and services specific to carers can be flagged for them?
* Carers don’t know what services exist so don’t access them
* Carers report to us that the main source for information for them is their GP, and therefore it is important to target GPs awareness of the system and involvement in its development
* It is also our experience that the shift from receiving care in a residential facility to receiving care in a community setting has increased reliance on informal care provided by unpaid caregivers and that current levels of support are insufficient for many carers. One carer’s comment was “I am anxious about our future, our ability to manage financially and about my world shrinking in the way I have seen other carer’s world shrinking as their person’s care needs increase”.
* The statement of need does not adequately acknowledge the significance of behavioural and psychological symptoms of dementia on the caring relationship and the added burden on carers. The Australian Government’s Australian Institute of Family Studies Research Report No.16 (2008) reviewed the literature on the mental and physical health of family members caring for a person with a disability and found that behavioural problems associated with a disability had the strongest association with carers’ depression. Cognitive impairment was also strongly associated with carer depression. Pinquart and Sorenson (2003) found that caring for a person with dementia was particularly challenging, with carers of people with dementia reporting the highest levels of stress and greatest impairment in psychological wellbeing. Vitaliano, Zhang and Scanlan (2003) indicated that carers of a family member with dementia had 23% higher levels of stress hormones and 15% lower levels of antibody responses than did non-carers.
* Would it be possible to align carer assessments and eligibility to care recipient assessment and entitlement? For example, CHSP client’s carers could be identified on care recipient intake, and directed to the National Carer Gateway and emergency care plans. Once a care recipient is eligible for package level of care, could the Carer also be eligible for a consumer directed carer package, at the equivalent level? Currently, many clients are assessed as eligible for Level 3 or level 4 packages yet these packages are unavailable. This results in care recipients with high care needs (who are not always suitable for centre based respite due to their high care or complex care needs or particular BPSD) having less access to suitable services and ever increasing demands placed on family caregivers.
* An integrated carer support system can only really be integrated when care recipient services are adequate to respond to their needs – many high care assessed clients only able to access lower level aged care packages or CHSP services
* Carers can have a perception that it is a waste of resources for them to access help - they would rather the resources go to the care recipient and many don’t want to think about it yet
* Self-funded retiree carers express concerns re high assets and low cash flow, and therefore many concerns over costs
* Carers report to us their desire to have a known and trusted contact person to avoid having to retell their story to new people all the time
* The guiding principles should assist in providing a way for projects to weigh progress and should assist in responding to carers identified needs.

B. THE DRAFT SERVICE CONCEPT

* Would be helpful to include quality indicators for information such as relevant, current, consistent, timely and accurate. We have heard from several family carers frustration and annoyance at responses they have received when using My Aged Care phone assistance – they report being transferred from one place to another because they have not known a ‘correct term’ or word to use when asking for help. Some have also been advised to call again another time because the answer they get will be different. Whilst all new systems will have teething issues, for a carers of a person with behavioural and psychological symptoms of dementia, finding a convenient time to make a call in the first place can be challenging – when these calls becomes an additional source of stress, it is not helpful.
* Some of the issues that carers report to us are around accessing services, once they have been made aware they exist. It seems there is no easy way to contact providers of services, and it is as if you need to know the answer to your question in order to get the right information. If you ask a provider (or MAC) a question in the wrong way you may get told something that is not correct, e.g. told that a service you are looking for doesn’t exist, even though your friend accesses this. If you call back another time and ask the same question in the same way you get a different response (this has actually happened).
* Would it be possible to have a National multi-component intervention for carers, aligned with care recipient assessed needs? For example, a care recipient in receipt of single, services such as CHSP could identify the carers at intake and refer to information and emergency care planning services. Once the care recipients needs increase (to packaged care), the Carer may be identified as eligible for a Consumer Directed Carer Package (perhaps aligned top levels 1-4 also), still with emergency respite services accessible in addition?
* Service Concept Overview (p22 of 72) – may be helpful to list by delivering these services following process – e.g. awareness, intake, then needs identification and planning with services to meet identified needs coming off them such as information, education, peer support, counselling, financial assistance, respite
* Add linkages to intake service, as some carers will need assistance to arrange the contact
* Consider offering the multi-component support package nationally under a Consumer Directed Carer package model
* What happens at crisis points? Already services are not adequate to provide supports required to many carers.
* P25 of 72 – information on topics important for carers of people with dementia as well as palliative care
* Consider carer link workers who are familiar with available services and can be an opt in opt out familiar contact for carers throughout their caring role
* Consider developing National online or other educational resources around completing emergency care plans and make Nationally consistent system and supporting documents that are readily accessible
* A goal planning approach is important to the assessment Stage of the process – otherwise how can you focus resources and evaluate the effectiveness of strategies/ supports in meeting needs? (p32 of 72)
* Please ensure that people conducting assessments are well trained and knowledgeable about the needs of carers and have access to information about conditions experienced by care recipients – the NDIS experience for people living with Younger Onset Dementia has had challenges.
* Coaching programs are most effective for a carer where skill development is required or where a carer’s knowledge, confidence or stress/ emotional state are negatively impacting their lives, or where a carer seeks coaching style support. Timing of the coaching may be determined in consultation with the carer (e.g. fortnightly, monthly, weekly or as requested – e.g. carers could purchase a defined number of sessions and select the content they required)
* Respite concerns from a service providers perspective, which impact on availability and satisfaction for service users, include:
  + Low care assessment with no need to reassess – so not financially viable for residential service providers,
  + last minute residential respite booking cancellations by clients, resulting in lost income,
  + lack of appropriate service model for those high care residents still at home (e.g. centre based respite for low care clients but now many high care clients at home, necessitating more frequent carer respite and less availability),
  + Uncertainty of ongoing funding for cottage style and centre based respite services.
  + Lack of transition support groups or ‘readiness for residential care’ style workshops

Fully agree with the drivers for change as described. However, there may be potential for budget blowout – with current funding not adequately meeting existing demand, and with 82% of carers not identifying as carers (p15 of 72), how will a carer service be adequately funded? Will it be like the dementia supplement offered to RAC and then withdrawn due to unexpected exceeded demand? What systems will be applied to ensure that funding reaches those most in need and only for the length of time of need?

Thanks you for the opportunity to comment on this important document. Please contact Marleina Fahey on [mfahey@baptistcare.org.au](mailto:mfahey@baptistcare.org.au) if you require further information or clarification.