Designing the new Integrated Carer Support Service

Response to the draft service concept paper – 16 June 2016

FamilyCare broadly supports the guiding principles and proposed support elements outlined in the Integrated Carer Support Service Concept paper. FamilyCare submits the following feedback for consideration in the further development and design of the Integrated Carer Support Service.

<u>**Awareness**</u>

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?

FamilyCare supports efforts to increase awareness of carers and who they are. There should also be efforts made to increase community responsiveness to the role that carers play and its significance for the people receiving care and the broader community. We believe there is value in considering this exercise as comparable to a public health messaging campaign, with particular focus on:

- Universal services that carers will interact with, including GPs, hospitals, health services, My Aged Care, schools, neighbourhood houses, local government etc.
- Enhancing the prominence of current awareness (national) weeks/months/campaigns.
- Continuing to develop the use of social media.
- Ensuring that information about the caring role and the impact it has on health and wellbeing is embedded in relevant tertiary courses, as well as ongoing education for health professionals.

<u>**Information**</u>

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

Information should be available at all points of contact. It is however most effective when carers are both in need of the information and receptive to it. Often carers may need to hear particular information a number of times before they are in a position to take it in. In this way, repeated simple messages are important and information should be accessible across the journey of the caring role and as needs change.

Information should be delivered through a variety of methods including peer support, support groups and service/health providers. General information such as

supports available, access to services, costs, contact numbers, online resources and so on, could be managed well through the Carer Gateway. More detailed information regarding health conditions and their implications, impact of caring on wellbeing, loss and grief and locally available services, are in our experience best provided as part of the individual support offered to carers at a local level, to ensure it is tailored to the specific needs of the carer.

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?

Primarily, Intake is a process to link carers to support and services. If undertaken in a thoughtful, sensitive and detailed way, a good intake process should reduce the need for carers to tell their story repeatedly. Achieving that outcome will require more effective methods of data sharing across services and sectors. Further, a system linking carer and care recipient records would be beneficial, recognising that the key will be obtaining appropriate permissions at the outset to facilitate effective access and sharing.

The information collected at intake also provides important demographic data for DSS, regarding the people accessing services, and what types of service they are accessing. In order for government to get an accurate view and to continually improve services and outcomes, all carers accessing supports through the Integrated Carer Support Service should be counted at intake and de-identified data aggregated across the service system.

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 focussed supports?

Education provision should be targeted to carer needs and linked with respite support – to make participation more achievable and less stressful.

There is value in providing online educational opportunities to carers, however access should be offered in a variety of locations including settings like community houses, libraries and neighbourhood hubs' where online options can be enhanced by personal contact. If education is only offered online, those without access to reliable internet, who do not own computers, or have low literacy may be disadvantaged and may fail to benefit from vital information. Over reliance on web-based options may also increase social isolation.

Often education delivered to carers is 'psycho-education', and part of the benefit is being in a group with others. Certain topics can also trigger emotional distress for participants and appropriate physical options increase the potential for other support needs to be identified and achieve timely response.

The option to link with accredited education or competency frameworks also warrants exploration. This could assist in supporting carers to work toward a qualification that can be used after their caring role ceases. Further, a system which recognises the skills that the carer possesses would be useful.

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?

FamilyCare recommends the exploration of multiple methods of peer support, not a one size fits all approach. Options range from social media, and web based support to traditional carer support groups. In regional and rural communities people value personal contact highly. It is also imperative that facilitators of peer support have appropriate resources and support. As is often the case in regional areas, ignoring the reality of travel times and costs, reduces the likelihood of service options being available and participation.

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?

Self assessment may be a good approach to empower carers and encourage them to start thinking about their needs. We acknowledge it as a potentially significant component of a broader assessment. In FamilyCare's experience however self-assessment should be followed by further exploration through a carer support professional. Relying on self-assessment alone produces a limited picture - as carers will often downplay their role and their needs. Support may not be sought until a situation has escalated and the carer as well as the care recipient are at risk.

Goal based planning is critical to ensure carers are focused, address needs, make good use of resources and to facilitate measurement of outcomes. Goal based planning, focused on the carer's need will help to identify outcomes that the carers wish to achieve and not just the needs of the care recipient, which can often be the case, particularly when carers are in crisis with high needs.

There should be provision for assistance for carers who are in most need. Needs fluctuate, and at times can quickly become a crisis. When that occurs, a higher level of support than normal is required, promptly and efficiently.

Multicomponent Intervention

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?

A genuinely carer driven system should be able to deliver any of the service types / interventions either singularly or in any combination – in response to the carer needs identified. This should not be limited only to financial support, carer mentoring and respite support. Each one of these service types should also be able to available as a stand-alone. Support services that provide the entire range of interventions to carers would ensure that when carers need access the appropriate support could be provided - as basic, or as complex as required. Generally, supports and allocations should be determined at the time of assessment – recognising, as already noted, that needs fluctuate and in particular that access to emergency respite is available as required.

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?

There should be provision for financial assistance for carers most in need. At times of crisis, financial support will be required promptly and efficiently.

A range of different options for financial support or brokerage should to be made available. Through a CDC approach, the option of a carer's card with pre-loaded funds could be explored – but should be linked to outcomes of a goal based plan.

Carers should have choice over how much of their finances they are comfortable in self managing. Many carers may find this an additional pressure. Additional supports should include specialist services like financial counselling. Centrelink's Financial Information Service is a vital support option but should be expanded and preferably community based.

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 be able to determine whether the carer has the capacity to forgo coaching until another time?

The proposed model of Carer Mentoring outlined in the concept paper appears to be well aligned with the Victorian Carer Support Worker model – which includes assessment, support, linking to respite, individualised education, skills building, and referral to other carer and mainstream services. If adopted we would recommend it be available in combination with other services and as a stand-alone option.

We would support access to a mentor being available at any time in the caring journey - and based on needs as they change and as the caring role changes. All Carers could benefit from a mentor relationship, providing a variety of personal support and advice over a longer period of time. In particular the role could have great value at times of significant transition or change. The transitions might include diagnosis, transition to permanent care, significant family changes and so on.

The terminology used and in particular the term mentor should be explored further. This term implies expertise. This may not be received well by carers - who are in fact the experts in their own lives / situations.

We also do not support mandatory application. Carers should be free to choose what services they access when.

Respite Support Service

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?

CDC can work effectively for carers to develop a plan of support that allows flexibility as required. Carers however may need additional support for implementation of a comparable approach. As mentioned earlier in this submission, some carers may not be able to manage their own finances, or may already be under significant stress. Having to direct all elements of planning and support may cause additional pressure.

Assessment and planning processes need to address emotional wellbeing aspects of caring as well physical. The provision of services to the care recipient, whilst often referred to as providing 'respite effect', allows carers to attend to everyday activities like cleaning the house, and running errands. It does not address the health and wellbeing of the carer or necessarily enable them to engage in other life activities outside of the caring role.

Carers require access to supports that enable them to engage in activities that sustain their health and wellbeing in addition to respite support - both planned and emergency. Respite should not be merely used to top up an inadequate care recipient package / service system.

Counselling

Much of the evidence relating to effective counselling programmes for carers is focussed 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?

A variety of emotional support options should be available to carers including one on one, online, group, telephone and such support should be tailored to the individual needs of the carer. Most importantly it needs to be easily accessed. Counselling should be available throughout the caring journey.

There can be stigma and negative perceptions associated with counselling. A change in the name, such as emotional support, or increased promotion and a normalisation of counselling may assist to overcome that stigma.

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