**DESIGNING THE NEW INTEGRATED CARER SUPPORT SERVICE**

**RESPONSE TO THE DRAFT SERVICE CONCEPT PAPER**

**FROM THE CRCC NATIONAL WORKING GROUP**

**MAY 2016**

1. **GENERAL COMMENT**

Feedback from carers has been that this Concept paper has been difficult to understand, so much so that individual carers reported that they gave up and only read the first few pages. Carers commented that the documents used a great deal of jargon for example, terms such as ‘carer-driven’, ‘drivers for reform’. Perhaps consideration could be given, in future consultations, to providing a plain statement executive summary.

Service providers, on the other hand, thought the paper concisely brings together existing research and information from consultations and sector input to provide the reader with a summary of the issues and design challenges.

1. **SERVICE CONCEPT OVERVIEW**

The Working Group endorses the guiding principles that form the basis for the design of the support service. The Group also endorses the elements of the proposed support system, as accurately reflecting the service mix required by carers

1. **DESIGN ELEMENTS**
   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?*

The Working Group is of the view that there should be multiple channels through which awareness raising takes place as reliance on one channel alone will not be successful. Our view is that a combination should include:

* National campaign to raise the awareness of the broader community, for example, the 2012 Care Aware campaign;
* Utilising existing national awareness weeks/months to promote carer services;
* Resourcing existing carer support organisations or state-wide networks that have an established presence in their local communities to utilise a community development approach to community education;
* Peers available to provide one-on-one access with newly identified carers and to provide information to service professionals, located in health networks and large community service providers, and with special needs groups
* Centrelink to link carers upon application for Carers payment or allowance
* Greater identification of carer needs through the health system, targeting GPs Hospitals, NDIS and or My Aged Care, ensuring a simple referral pathway
  1. **INFORMATION**

*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?*

We believe that information provision is most effective when carers are at that point in their caring role where they are receptive to receiving information. For this reason, one approach to information provision would be ineffective. While we see value in carer websites that enable carers to acquire information and do self-assessments, individualised information provision at the time other services are provided would be an effective use of limited resources. This information could be delivered through a number of avenues, eg, using existing agencies that provide support to carers and their families, peer support, a service/health provider/support group.

* 1. **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?*

As the Concept paper points out, Intake is designed to connect carers with services and supports. Intake should only be required in some circumstances and where direct services are required, for example, where a carer is accessing needs identification and planning, counselling, respite and financial support. Carers ought to be able to access information, education, mentoring and peer support without proceeding through an intake process.

While data is collected during the intake process that is not the only time data is collected. For example, information about client outcomes is collected post service delivery. It may be helpful for the Department to determine what type of data is required and consider a layered approach to data collection where intake is used to collect only basic demographic data.

Intake should be a process that enables the carer to tell their story once only and have this information recorded and accessed by relevant service providers with the consent of carers. Given the diversity of our community who have caring responsibilities it is important that there are a range of intake channels, from website, telephone to face to face services. Carers also need to be confident that the information provided at intake leads to equitable and transparent decision making. If the carer wants to go through the intake process they should be allowed to do so.

* 1. **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?*

Carer education can take a variety of forms and purposes. These include:

* Educating carers to enable them to better understand the condition of the care recipient and/or to skill them to respond to specific needs of the care recipient;
* Education that improves the capacity of the carer to self-manage;
* Education of young carers to enable them to participate effectively in society through meaningful employment; and
* Education of carers or those in transition from a caring role to re-enter the workforce.

There is capacity for the Carer Support Service System to integrate the provision of information, education and peer support by enabling peer support to be a vehicle for the provision of these services. This approach ensures that these service elements are provided within an individualised context and there is support and encouragement for the carer. Further, linking online education with peer support eg within a group setting, provides a vehicle for carers to connect with others and discuss online training within a mutually supportive environment. This would encourage completion of these programmes.

Another means of encouraging carer education is to link carers to nationally accredited training for which their caring experience could provide them with some recognition of prior learning as well as be linked to provision of Centrelink payments.

Education can also be linked to the multicomponent elements of mentoring and respite. Recognising that carers are time poor, linking respite with education can be a meaningful option as it recognises that for many carers, effective participation will require access to respite and possibly transport.

Information about educational opportunities that exist outside carer focussed supports could be made available through links on the Carer Gateway and information dissemination through peer support.

A significant challenge for any education provision will be the need to ensure that this education is accessible to carers in rural and remote communities, as well as being culturally appropriate to carers from ATSI or CALD communities. Linking education with information, peer support and awareness activities delivered through agencies valued and recognised by these communities would enhance carer participation.

* 1. **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?*

The experience of CRCCs across the nation is that peer support is integral to successfully delivered carer support programs. Peer support workers could be located in a multiple array of settings, for example, within special needs communities, within carer support agencies, within major public health networks and be utilised to provide or arrange information, education, mentoring and engaged in broader community awareness. Location in multiple settings are required as carers will access a range of services and their presence in these settings will ‘normalise’ carer experience and trigger carer engagement and participation in other support activities. We refer the Department to guidelines developed for the use of peer support workers within related programmes, such as mental health (see for example the Western Australian Association for Mental Health’s Peer Work Strategic Framework) as a useful resource.

To enable effective access, access to peer support should not require formal referrals but simply a chat or phone call or email. However, the Working group believes that access arrangements should differ between online and personal access. Where carers are seeking to participate in online forums/blogs or use other social media devices to engage with other carers as a form of peer support, then such social media sites should be moderated to prevent these sites from increasing a carer’s vulnerability and isolation.

For the benefit of peer support workers it would be valuable for them to be located in organisations/settings where they can receive the professional support that they require and have the supporting infrastructure that will enable them to design and conduct both group and individual peer support activities, as well as host information, education and awareness programmes. Within this context, carers transitioning out of a caring role would be valuable as peer support workers.

* 1. **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 discrete processes. Needs identification is a pre-requisite to effective planning but both processes can be conducted as separate activities. For example, when carers contact the CRCC seeking emergency respite, intake will carry out an initial needs identification process to ensure an appropriate response is provided. This surface level needs identification is also undertaken, for example, by MyAged Care staff before clients are referred to a regional assessment service for more in-depth assessment and service planning.

Goal based planning should be the basis for any planning with carers that seeks to identify outcomes that they (the carers) wish to achieve. This approach is integral to planning processes that focus on the carer and their needs, and should not be limited to carers in crisis with high needs, as at this point the focus is often on care recipient needs.

The option of self-assessment should be provided through an online tool and used to facilitate the carer’s thinking about their own needs before receiving formalised support through a carer support or a peer support worker. Use of this tool empowers carers and enables them to engage with workers about their needs in a more focussed and directed manner. However, our experience is that carers often under-report their own needs as their focus has been on the needs of the care recipient. For this reason, a self-assessment tool should be used as an entrée into the planning process rather than a substitute for planning.

An online tool could also be a useful for carers beginning their care journey to think about aspects of their caring role that they may not have thought about. In this context it could be a tool made available to carers through a network of agencies such as GPs, practice nurses, Centrelink officers, and community workers.

* 1. **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?*

The CRCC National Working Group acknowledge that government resources are limited and need to be used to produce meaningful outcomes in as effective and cost efficient manner as possible. For this reason, we are strongly of the view that access to service elements should be on the basis of needs identification and planning with carers. In other words the criterion for allocating supports is does this mix of services meet the carer’s needs and address the goals that they wish to achieve. The focus (and components) of the package should be on the outcomes to be achieved.

The Concept paper suggests the package will have three components. We would argue that the components need to be linked to carer’s identified needs, and that the entire service model be seen as a continuum of service that could be accessed by carers, as an integrated offering. We strongly urge government to look to creating local delivery points that provide access to the entire range of supports. This can be achieved efficiently through shared resourcing between support agencies, use of online tools and delivery systems, and linking carer support with mainstream activity/specialised community networks.

It also needs to be recognised that there are communities where the option of planned preventative measures is highly problematic, given the absence of adequate and appropriate infrastructure or services within that community, for example, within a remote rural community, within an ATSI community or a community of recently arrived immigrants or refugees. In these situations, carers are not always in a position where they can access quality services regularly or consistently. Thus a challenge for any service design is to build in the capacity to be flexible to respond to local needs and circumstances.

* 1. **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?*

This service should be called “Direct Cash payment’ so as not to confuse the content with financial support provided through the Commonwealth’s social security net. The Australian experience through the Consumer Directed Respite Care programme is acknowledged and the findings from the pilot should inform further developments. (We should point out that the funds provided by the program during the evaluation were for the full year, and not six months as suggested in the Concept paper).

The option of direct cash payments should be linked to the outcomes of goal directed planning and whether this option would enable the carer to achieve the outcomes that they have identified.

Direct cash payments or the provision of brokerage funds needs to be flexible to accommodate a number of circumstances, for example:

* the age of the carer, for example, would young carers have access to this option or would they be supported through a carer mentoring program to access a dedicated set of brokerage funds?;
* the available infrastructure and services available within a community, for example, will access to brokerage or direct cash payments enable isolated carers access services more effectively or can these funds be sued to create alternative models of carer support?;
* the development of innovative funding options, such as a debit card, that could minimise the administrative burden of record keeping.

It may be necessary that a range of options are made available to cater for this diversity of circumstances.

Critical to the success of this service element is the capacity of carers to self-manage. Carers will vary in the degree to which they will be comfortable in self-managing their supports and will need to be supported through this process.

* 1. **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?*

Feedback from carers is that the term ‘carer mentoring and coaching’ is meaningless to them. For some carers this work is seen to be an element of the support that could be provided by a peer worker. For others it was linked to the provision of case management support.

Any coaching or mentoring programme is only effective if it is delivered at a time and pace that the mentee is ready to receive and engage with this process. For this reason the provision of carer mentoring should be an outcome of the needs identification and planning process, and linked to the achievement of a carer’s goals and desired outcomes.

There will be some circumstances when carers are not emotionally or physically well enough to benefit from coaching and another form of support may be more appropriate.  For this reason, mandating this activity would be unproductive. Participation in mentoring should be at the carer’s choosing and through mechanism that work for the person.

A nationally devised programme while well-meaning will not succeed. Instead, peer and carer support workers should be skilled to offer coaching to carers and this activity be provided both via formal training activities and through informal one-on-one or group activities.

Note:  it would be beneficial if the coaching program were to include how to empower the client to maximise their strengths and do activities for themselves.  Carers at times need the skills in knowing how to encourage the client with this and this may alleviate some carer responsibilities.

If mentors were to determine whether the carer has the capacity to participate this would need to be based on the completion of a nationally standardised tool to ensure consistency.

* 1. **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?*

The Concept paper acknowledges that the needs of carers is being lost in the care recipient focussed programmes. The sector reforms in ageing disability and mental health are all focussed on the needs of the care recipient and enhancing their wellbeing, independence and capacity. There is no recognition that carers themselves as consumers of services in their own right.

Throughout these programmes, there is discussion about the ‘respite effect’ that the carer receives through the provision of services to the care recipient. This is a misunderstanding of the nature of ‘respite’. The outcome for the carer in these circumstances is that they have time to do all the other activities of daily living such a pay bills, clean the house. The provision of services to the care recipient does not address the overall health and wellbeing of the carer nor does it enable the carer to have a life outside of their caring role. For carers, the outcome of these services is maintenance of care for the care recipient that the carer cannot provide.

For carers, respite is an alternative support option which sustains the continuity of care for the care recipient while providing the carer with the opportunity to pursue activities that sustains their health and wellbeing and builds their capacity and resilience.

Starting from the premise that there will need to be a direct pathway for emergency respite support which is not immediately paired with a multicomponent intervention, our experience with consumer directed respite is that planned respite works effectively in enabling the carer to develop a coherent plan for support, that includes a range of supports in place with respite being just one of those components.

The greatest danger is for carers to focus solely on the needs of the care recipient rather than themselves. This shift in mindset can take some time as carers’ focus has historically been on the wellbeing and welfare of the care recipient. Ensuring the carer has support in planning and booking respite, some of which will occur in the home, is critical to preventing carer’s from underutilising the potential of this service.

For these reasons, it is important that planned respite is an outcome of the needs identification and planning processes. This assessment needs to be prompt and timely and needs to cover emotional, physical, impact on wellbeing and financial effects of caring.  Working carers should be supported to continue in the workforce.  The aim should be to provide carers with a balance of work/volunteer, social and caring responsibilities.

Carers need to be given the choice of the level of support they require from a support agency, as not all carers will want to manage their support plans. For some carers this would be perceived as an additional and unwelcomed burden. Where carers are managing packages on behalf of the care recipient, consideration should be given to some alignment between the care recipient and carer packages.

* 1. **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?*

Counselling types should be tailored to the individual needs of the carer, as there is no single model of service that will be most effective across all carers and in all contexts. Service delivery will also be dependent upon the context, for example, in remote communities or ATSI/CALD communities. A suite of options should therefore be available eg, online support groups/forum, telephone counselling, one on one or group.  The carer mentoring role should hopefully reduce the need for counselling in some carers and should mean an appropriate and timely referral for counselling for some carers.

Counselling needs to be considered across the carer’s lifespan including young carers. It must also be recognised that the caring role impacts beyond the immediate carer, for example, relationship counselling for co carers need to be considered, along with support for other family/community members who may contribute to the caring role, for example in ATSI or CALD communities. The needs of carers in transition where the care recipient has moved into permanent care or has died, should also be recognised.

* 1. **SUPPORTING ALL CARERS**

CRCCs throughout Australia recognise that the contexts within which carer support is delivered are diverse. For these reasons a critical element of the proposed service design will be the flexibility built into its implementation and structure to respond to Australia’s diversity.

The carer support needs of carers living in rural and remote communities are often impacted by the availability, quality and size of social capital and community infrastructure in the local community. Residential respite options, for example, may require transport across considerable distances to access. Twenty-four hour/7 day a week services, such as in home respite, may not exist.

Supporting carers within indigenous communities is often a complex process, requiring an investment in time to build trust between community members, indigenous agencies and carer support provider. To quote one CRCC:

for our Centre we have a large Indigenous population, however only a small number of carers accessing respite programs – we have quite a few Aboriginal Specific organisations, which I think are meeting the current needs of Indigenous Carers in Broken Hill – though, in saying this, we occasionally have referrals from these organisations, so they know who we are, and how to get in contact with us.

We have built trust with a number of Indigenous families, initially the requests for care and services came through the referring organisation; however, over time we have seen quite a change where the carer will directly contact the Centre for respite, which is awesome – it has taken a long time to build this trust.

Similar issues can occur when working with CALD communities. The Concept paper recognises the challenges facing CALD communities. “Older CALD Australians experience considerable disadvantage as they age because of language barriers, lack of awareness of available services, a mistrust of government institutions, limited access to the internet, and lack of both skills in, and access to, information technology “ [[1]](#footnote-1). Consequently, one of the challenges of a national strategy will be how best to support communities not only to create and to access culturally appropriate services but also to engage in a culturally appropriate manner in discussion about the ‘caring role’ and the place of ‘carer support’.

Attention also needs to be paid to two other carer groups within the community, namely, working carers and carers in transition, that is, carers ceasing their caring role due to the death of the care recipient or the transfer of the care recipient into some form of residential care. Both groups have unique needs that require attention.

1. Federation of Ethnic Communities Council of Australia, 2015, FECCA’S 2020 Vision For Older CALD Australians [↑](#footnote-ref-1)