**Feedback to Integrated Carer Support Service**

**Joint response by**

**UnitingCare Wesley Bowden**

**and**

**Northern Carers Network**

**South Australia**

**Overview**

UnitingCare Wesley Bowden and Northern Carers Network have worked together to provide a range of support services including respite to carers living in the Northern, Western and Central areas of metropolitan South Australia for almost 40 years. We believe our experience in meeting the unique and diverse needs of carers provides us with the experience needed to inform the design of the integrated carer support service model.

In responding to the draft, we have considered key points from the eight service types in the draft proposal and made relevant comments for consideration:

**Awareness**

*Find carers, particularly those most often overlooked, through outreach, partnerships and co-located services and encourage their use of available interventions*

* We welcome a national marketing approach to raise awareness of carer alongside a comprehensive and effective campaign to help people acting in a caring role to self-identify. This would be especially targeted at “hidden carers” such as those from a CALD background, people from an Aboriginal or Torres Strait Islander background or young people who may not identify as being a carer.
* This campaign should use multiple media formats including face to face connections with communities to outline possible services and supports available to carers. It should also provide carers with a clear pathway in to a central location, identify how the process works and what carers are likely to expect following their registration. This should include the types of support available to them and how to access that support
  + Much of this support should be done informally and based on community development principles. It allows for Carers to tell their story (narrative) in a warm and friendly environment known to them, as opposed to a clinical environment. Research indicates that carers become empowered through the provision of information, advice, non-therapeutic counselling and overcome social isolation through carer/peer support groups lead by skilled staff.
* There always has been, and will continue to remain a need for local level service access and community awareness/community development activities. It is not clear how these may be funded, however we propose community engagement/development funds are considered in preparing carers for transition into a new national system. We see this as being similar to the education campaign which has occurred prior to the rollout of the NDIS.
* Awareness campaigns also need to target key groups who are likely to come across carers, including potentially hidden carers in their daily activities. This includes NDIS planners and local area coordinators, state mental health services, aged care services, educational facilities and the health system including GP’s.
  + We also recommend that a broader awareness campaign targeted at workplaces should be considered to draw awareness of the experience of working carers.
* Awareness of young carers needs to be raised in the community care; health and education sectors with a focus on targeting schools with details provided about local carer support services.
* The proposed model does not actively note young carers as part of this service concept. Young carers may be caring for an older parent/grandparent. The care recipient may be funded by NDIS or Aged Care. The model potentially will increase the number of hidden young carers.
  + It is imperative that young carers be recognised in this model as a separate group who are at high risk of developing significant lifelong issues relating to their mental and physical wellbeing. This is particularly pertinent as current funding to support young carers has been marked for transition to the NDIS, which will provide limited support opportunities to carers.

**Information**

*Provide carer focused information about their situation and availability of carers services. Assist carers to identify appropriate next steps*

* It is imperative that carer services are identified and delivered as a suite of services **independent** of services to the person they care for. Carers have rights of choice regarding how they live their life separate to their caring role. Carers require a service of support in their own right, outside of what is needed to sustain the care relationship.
* As stated in the *Carer Recognition Act 2010*, carers should be acknowledged as individuals with their own needs within and beyond the caring role. Carers require a service of support in their own right, outside of what is needed to sustain the care relationship
* Carers need to be informed on how the packages of support might work for them. How the new system of services for Carers is run alongside the packages for their person. Prior to the rollout carers need to know how the education component might work, what the differences are between the types of services they were receiving prior to the introduction of the integrated carer support program and how to obtain maximum benefit from their package.
* In order to facilitate a smooth transition of existing services, there needs to be a period of transition between the release of this package and the full rollout. Carers need to gain access to information on:
  + how the new packages of support can be accessed,
  + how they can complement the package of support the person they care for receives,
  + how the education component might work,
  + the differences between the types of services they were receiving prior to the introduction of the integrated carer support program
  + how to obtain maximum benefit from their package according to their individual circumstances
* We recommend that the Carer Gateway will be further developed as a central repository for:
  + information regarding the caring role including links for accessing support,
  + additional education tools on disability, ageing and mental health conditions
  + various carer wellbeing resources such as manual handling, stress management techniques and self-care

**Intake**

*Conduct carer intake, by capturing a set of information to assist in connecting a carer to locally delivered services*

* We support the view that intake is intended to capture basic and demographic information and to capture a snapshot of the carer’s circumstances. Needs assessment is time consuming and may be a barrier to access where detailed information is requested for simple referral, or information on services.
* Clear, transparent, nationally consistent criteria needs to be established to prioritise the needs of carers.
* It is also important to have a range of modalities available for registering. Many carers prefer to register online for services whilst some may require telephone assistance. We would suggest that the new service builds in self-assessment tools.
* Recommend a central intake process which purely ascertains **eligibility** and manages **registration** and **establishes a funding/package** ‘tier’ value. Warm referrals then made to **local agencies** who would commence **needs assessments** and **support/goal planning** alongside the carer.
* To ensure a nationally consistent approach the carer gateway could have an overarching administrative component and client management portal like MyAgedCare. This would minimise the need for carers to tell their story over and over again if they move geographical regions. It would also centrally identify people who are accessing emergency services frequently (*indicating that they require higher levels of support*) and trigger a review response.
  + Adopting a “no wrong door approach” for assessment/ intake to support carers who will only share details with a trusted service.
  + We assumed that this function would be managed by the Carer Gateway once fully operational
* We propose that funding packages are tiered according to circumstances and need to be considerate of carers caring for multiple people – as well as those who may have incurred carer fatigue due to a lifetime of caring with limited or no support.

The following provides an example:

* Tier 1: Comprehensive funding along the lines of Consumer Directed Respite type funding which would require coordination and plan management. Activities would be purchased at carers discretion.
* Tier 2: Lower level funding with activities purchased at the discretion of the carer which can be self-managed or some coordination of support provided from skilled staff.
* Tier 3: Flexible service offerings such as planned respite which can be self-managed.
* Tier 4: Block funded carer support activities such as those provided through a non-therapeutic, early intervention and prevention, community development model.
* The evolving and fluctuating needs of carers will require them to move in and out of services as their circumstances change throughout the caring journey. As such, we suggest the preservation of some discretionary funds which would be accessible alongside these core activities to be accessed as ‘one off’ services or as circumstances change unpredictably. For example where the carer becomes unwell and needs to purchase some additional coordination or emergency respite to cover a hospital stay support.
* In addition, carers not needing high levels of support or in receipt of a package should also have access to isolated occurrences of support, including occasional respite and education and social activities
* Those carers who require additional support due to age, cultural background, numeracy and literacy challenges and translation support will also need additional ‘service access’ funding to support them to engage with the model.
* **Emergency respite absolutely needs to remain available outside of packages** to ensure critical needs are met in a timely manner.
  + The emergency component of carer support is essential, however the definition of emergency respite needs to be tightened for providers and participants. For example an invitation to a wedding or dinner might be perceived as urgent (*last minute*) but this type of service should come from a person’s planned respite package. Emergency respite should remain the domain of medical intervention such as the carer or another family member being admitted to hospital/ requiring urgent medical intervention or at the point of relinquishing care.
* Intake absolutely must be responsive, efficient, reactive and neither cumbersome nor prohibitive to access
* Must provide ease of access for carers from all special needs groups including CALD, ATSI and young carers

**Education**

*Education and training programmes aimed at increasing a carers knowledge, educating them about the resources available and teaching skills (ie: problem solving, lifting techniques)*

* This is a positive approach and building capacity and resiliency utilising evidence based programs and intervention is welcomed. There is a need to acknowledge specific needs of carers for example the carer of a child with a disability has very different needs, issues and concerns than that the a wife caring for a partner with dementia.
* Quality frameworks that overarch the new system must ensure there is diversity in choice available to education programs to best meet the needs of the carer as decided by themselves.
* The educational benefits experienced by carers when socially connecting with other carers is significantly undervalued. Activities are merely the tools used to increase the health and wellbeing of carers. Carers gain increased knowledge and skills through information sharing, exchanging of experiences and their individual stories. This early intervention approach uses outings, retreats, art groups, support groups and other creative activities to encourage carers to become well educated and empowered to manage their individual life circumstances.

**Peer Support**

*Connect carers to provide informal support networks through relationship building and shared experiences between carers with similar circumstances*

* Peer support delivered in a meaningful, non-patronising way is of enormous benefit to carers. Carers should retain the right to choose *how* their peer support is delivered to them in order to best meet their needs. Examples may include: 1:1 peer support, access to peer led information sessions, 1:1 in home support, phone based support, social media groups, local connections support groups, agency facilitated support groups
  + It should be noted that there needs to be skilled staff to support any group peer support activities due to the added stress which may be felt by carers where they have elected to lead a group. This may be covered by the block funding of carer support activities.
* We feel that the mentoring type activities such as support in making a plan, how to access certain programs etc would be better suited to specific volunteers or paid planners (with lived experience or a good understanding of the caring role) who work with carers seeking assistance for specific things. This would be similar to the current Home Care Today (COTA) Peer-to-peer educators.

**Multi-Component Intervention**

*Deliver a single package of interventions (including carer mentoring, financial support and respite support) tailored to meet the needs of the carer)*

* We recommend that the term “mentoring” is investigated further as there has been some negative response from carers to this term. They felt that it was patronising as everyone is an expert in their own situation and the term “mentor” implied that there was someone who knew more. Those who had a negative response preferred the term peer support.
* There is some merit in adopting the CDRC model.
  1. Key considerations though are how to make the service fair and equitable to ensure fair distribution of funding packages and values
  2. Suggest ‘trigger links’ between self-individualised packages and emergency respite eg if a carer has a package and has also accessed a significant amount of emergency respite outside of their package, a trigger or alert occurs and someone contacts them to discuss options. Such responses may include a higher level of support, or reassessment of the person they care for.
* We support the move towards goal-based assessment and evidence-based interventions. The move towards multi-component intervention packages may certainly improve for some carers, their access to capacity and skills building activities.
* To determine in advance what carers will need is almost impossible due to the fluctuating nature of caring roles. All carers should be eligible to access preventative supports. Block funding for carer support activities such as support groups, group education activities and therapeutic groups, will likely be more cost effective in regards to economies of scale. It will likely also increase equity and access as carers can move in and out of carer support services as their individual situation changes.

**Counselling**

*Individual and/or group counselling sessions*

* A new system would need to ensure it recognises that counselling can take many forms and is often delivered or accessed spontaneously. Formal counselling is also valuable in many situations and it is recognised that incidences of stress, depression and anxiety are higher in carer populations than in the general population. For these reasons we recommend that counselling options across a continuum should exist and be accessible through an integrated system of support
  + We acknowledge that a more clinical type of counselling will not suit Aboriginal people and CALD communities.
* Our experience has been that carers find counselling very valuable, but are for more likely to access it in a less formal setting. If this option is removed or limited, we believe this would have a detrimental impact on carers
* In considering counselling can often take the form of informal discussions with planners, coordinators, peers – and in social groups or 1:1 settings, outcomes measures for this will need to be somewhat flexible and reflective of the type of counselling provided
* Current methods of non-therapeutic counselling implemented by Carer Support Services are working well. To complement this, more formal counselling services available to carers. This type of counselling focus on specific and more complex concerns a carer may be experiencing in their lives.
* We feel there is no need to reinvent services in this area. However from our experience, a more clinical type of counselling will not suit Aboriginal people and majority of CALD communities.

**Needs Identification and Planning**

*Gather information about a carer’s situation and assist them with planning their personal and service based supports*

* Assistance to manage self-directed packages is often vital to their success. Carers can achieve far more effective outcomes by self-managing, but it is important this does not impact on an already time-poor and burdened group. Self-selected assistance should be optional and fluid to allow for interim support during times of increased fatigue or stress
* This could be a great use for the previously discussed mentors, who could help new carers or carers accessing self-management for the first time to get the most out of their plans.
* In consideration of our experience, we would expect that **emergency respite would be exempt from goal based assessments** as this will primarily be in the case of medical emergency for the carer and so will have a different outcome. Emergency respite simply does not have a place in a consumer driven, pre-planned environment
* Stand-alone education activities as the only type of support a carer chooses to access require a modified, simpler version of a goal based assessment as the outcome measure will be reflective of that activity - and not of a holistic goal plan

**Further Considerations**

* Much of the integrated carer support program activity cannot be decided until the Information, Linkages and Capacity Building Program inclusions and Local Area Coordination activities are finalised through the NDIS. Education programs are predicted to be available within the ILC so there needs to a concerted effort to avoid duplication between the two programs. **We suggest that Integrated Carer support does not implement its education component until the ILC is finalised**.
* The definitions of **respite** need to be adapted. The move towards consumer directed support and respite being used as a complementary response means that respite should no longer be classified into older definitions such as direct and indirect, but be described in terms of their outcomes for the person, creating a ‘respite effect’. For example a carer may choose to purchase a blender with their respite package. Whilst this may seem an odd use of respite funding, if the carer had previously spent 3 hours per day preparing a smooth diet for the person they care for and that purchase can reduce that time to 1 hour, this would lessen the impact on the carer, thus providing a ‘respite effect.’

The term respite has been reported to have negative connotations for some people. We suggest the term could be adapted for this program and a generic term such as carer capacity building, or a ‘support effect’.

* NDIS, CHSP and HCP should all have a complementary carer support component which can be attached where needed. This component needs to be completely separate from the support component designed for the person holding the NDIS, CHSP, HCP.
* Carer support packages should have a list of exclusions rather than inclusions to ensure the highest level of choice for the carer and ensure that the right supports are put in place to benefit them.
* The transition of the Young Carers programme to NDIS will be a significant loss to existing carer support. The carers supported by these programs are at particularly high risk of developing mental health conditions themselves, and would benefit immensely by the early intervention strategies proposed by the integrated carer support plan. With these programmes transitioning to NDIS, special consideration will need to be made for these unique groups of carers.
* The paper, especially the sections describing respite, is skewed towards the carers of older people. Whatever model is promoted for the integrated carer support scheme, it needs to reflect inclusive processes for all carers.
* Any supports for carers should not replace things that already exist such as programs delivered through CHSP. We would support the removal of funds which currently target carers being removed from existing mental health, aged and disability programs and pooled into a comprehensive Integrated Carer Support Model.
* The integrated carer support system needs to have a multi-platformed delivery. Carers need to be able to access support in a way that meets their needs be it web, telephone, face-to-face or skype. The face-to-face benefits of therapeutic services should be acknowledged in the development of the model. However telephone and skype based services will make it easier for carers living in rural and remote areas to access the things they need.

In summary, we know from research, experience and evidence that current carer support services are effectively working to the benefit of carers across all age groups and sectors. With the introduction of the new model of Integrated Carer Support, we recommend consideration is given to the following:

* Customer (carer) choice being the primary driver
* Fairness and equity principles
* Any proposed model is governed by evidence based outcomes
* The model is responsive, flexible and easily accessible
* Carers from all backgrounds, regions and ages can access relevant, appropriate support at the time they need it
* Considers already existing effective infrastructure and well evidenced, quality service delivery
* The new system is flexible, responsive and relevant.

Kind Regards

*Trudy Dosiak*

Manager Communities Carers & Social Inclusion

Uniting Care Wesley Bowden

*Kylie Hutchinson-Macgowan*

Executive Project Manager

Uniting Care Wesley Bowden

*Maria Ross*

Chief Executive Officer

Northern Carers Network

*Sharon Hoffmann*

General Manager of Client Services

Northern Carers Network