**2016 NSLHD Comments**

**Service Concepts & Considerations -Designing the new integrated carer support service**

|  | **Section** | **Questions – Design Considerations** | **Responses** |
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|  | **General** |  | The service concept needs to address the need to routinely identify carers and explore their needs as an essential component of responsive care & support for all recipients of care when carers contact the healthcare system.  Where there is a caring relationship the needs of the carer must be acknowledged and incorporated as part of the total care planning and provision, rather than being seen as an add-on.  True “integration” needs to integrate carer supports with services for the person they care for. Most carers are time-poor and less likely to access separate services for themselves, therefore the services need to be able to reach carers where carer frequent.  Page 15 outlines that *“participants from the Carer Working p reported that once they were connected with a carer support organisation they felt supported and had a sense of comfort knowing where to go for assistance.”* This is reflected in carers from the local area, highlighting the importance of local services being available, contactable and aware of carer issues. The Service Concept doesn’t recognise that counselling is often the term used for a range of less threatening support, not involving CBT therapy.  Page 19 – *“Given that the objective of the future mode; will be to assist as many carers as possible, it will be necessary to identify those carers who will require a higher level of support so as to target Government assistance for the most in need”* - this does not reflect a true understanding of the fluctuating nature of the caring role. Carer needs change overtime and at times of crisis – they are not static or always at “most need.”  The Service Concept should support carers as partners in care, through consistent identification of carers, and structured support for carers to be able to be engaged throughout health & involved in community care delivery.  If the carer gateway is seen as the first point of contact it needs to be correct. The data base should link with the My Aged Care data base. The Carers Gateway has a lack of information/support or referrals for Aboriginal carers or Culturally Diverse carers.  There is a lack of understanding of the on the ground work, and the different service models. |
| **1.** | **Awareness** | 1.1 If the proposed model is to achieve a preventative focus, it will be important to identify carers early in their caring journey and connect them to potential supports. For many carers, this occurs within a healthcare setting, where the person they are looking after may be diagnosed with a condition. | In NSW the Ministry of Health (MoH) Carer Support Services have been funded to support the recognition of carers as partners in health care for the past thirteen years. An enormous body of work has been undertaken to promote carer identification; however this is still difficult to both measure and record, and is not consistently completed across the Local Health District.  A uniform approach to obtaining carer information via the Electronic records and registration systems is required to normalise the process for each and every admission to services.  A systematic approach using a validated carer stress assessment tool across NSW by community health and hospitals to assess carer stress and identify and link to supports required would improve the identification of carers in the public healthcare system.  To ensure effective referrals and linkages to services information provided to carers needs to be supplemented with verbal advice and reinforcement by health and community care staff. This should be offered by all clinicians on all occasions of service. Follow-up should be routinely undertaken to check on the progress of referral pathways.  The Service Concept needs to highlight an awareness of the diversity of carer roles, including the significant and ongoing role of carers when care recipients are “placed” (ie Residential care and supported accommodation) or the carer is supporting the care recipient who has a long stay in hospital / rehabilitation.  The need for greater recognition of workplace carers needs to be detailed in the Service Concept and consideration given to the promotion of workplace reform to better support working carers. |
|  |  | In considering support for young carers, to what extent should awareness be raised through schools and how could this best be achieved in a cost effective manner? | Awareness of young carers should be raised at enrolment in schools, with parents, and incorporated into the curriculum of schools.  Awareness of the needs of young carers in the Tertiary sector should be documented and promoted as a routine aspect of support for students. Awareness of young carers needs to be raised in both the healthcare sector as well as schools.  The Service concept makes little or no mention of young carers who may be caring for an older parent/grandparent, with funding for the program going to the NDIS. This will increase the numbers of hidden young carers and reduce the supports they are currently able to access, through programs run by Carers NSW, or the Benevolent Society. |
| **2.** | **Information provision** | 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? | Online and written resources are of limited value if carers are not aware of their role and the need to be proactive in order to sustain it.  The new Carer Gateway needs to become a more responsive and comprehensive repository of information to support carers to navigate the service system.  It could include an online assessment tool to show the individual what entitlements they may be eligible for and the support and information they may need.  Clinical information /education for carers about the care recipients condition/health status needs to be accessible (available, understandable) and supplemented with discussion with health professionals |
| **3.** | **Intake** | Given this, when should intake be a mandatory process? | There needs to be care taken not to make intake compulsory for every carer, nor too early in the process. Many carers will not share details etc until a level of trust is established with the listener. Carers should be clear why intake processes and data collection is required and carers need to know where their information is being linked to.  More effective methods of data sharing across service sectors need to be explored so that carers are not required to “re-tell” their story (Automatic population of appropriate datasets).  A method of linking Carer and caree records could be developed. |
| **4.** | **Education** | Given this, how can we encourage carers to access education support? | Provide education on an ongoing basis, normalise it rather than it being seen as a failure, provided before the crisis, and the provision of respite for carers to attend.  The need for hyperlinks within online one-stop information sources (Carer Gateway & My Aged Care) to link carers to local services & providers who maybe providing education to meet their needs.  Consider telephone support & education to supplement existing education programs  Many Carers receive education from Allied health and nursing for the clinical care and treatment required at home, this needs to be acknowledged, much work has been undertaken by the Carer support Service to establish this form of education. |
|  |  | If education were to be offered online, how can we encourage carers to participate and complete an education programme? | Provide carers with access to the resources (eg Computer, the time, & expertise) to access and explore information sites.  Online cannot substitute for shared experience and learnings, rather it provides another avenue to reach some of the hidden carers. Carers often find it difficult to get ‘respite’ to enable them to attend support groups.  Education, training and information provision must be targeted to local needs rather than provided only on a national website. There is good evidence of success where local organisations research and consult locally, then tailor programs accordingly.  Sharing with other carers is a valuable tool. |
|  |  | Given this, 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? | Ensure there is a “central” well publicised location for carers to learn about what is available to them, and not just online.  Use the National Carers organisations newsletters (encourage membership) to promote local events via links. Incorporate into core business avenues for information about education via existing National agencies such as Centrelink (eg newsletters / bulk mail outs).  Provide grants for specialist areas to develop carer education, for example Chronic Obstructive Pulmonary Disease and host a central venue such as the Carer Gateway where it can be accessed.  Ensure that there is a point of integration with services such as the NSW Ministry of Health funded Carer Support Services. |
| **5.** | **Peer Support** | Given this, how can a peer support model be designed which encourage carers to participate and remain engaged? | Skills and planning are required to facilitate peer support groups, including ongoing networking, organisation and facilitation. The capacity carers to provide peer support on an ongoing basis would be very limited, due to the nature of caring, as well as the time they need to rebuild their own lives when the caring role ends.  Consider online (eg Facebook) / telephone to assist with some aspects of peer support. Need multiple methods of peer support, not a one size fits all approach. |
|  |  | Should peer support be a service able to be accessed without pre-conditions or structure processes | To establish and sustain peer support group resources are required, including support & educational strategies for peer leaders (see above). This is a role for local carer support services, to be sure the groups are ongoing and sustainable. This is a cost effective model, providing carers with a reliable support, rather than expecting them to also take on the role of running their own support groups. |
|  | **Needs Identification and Planning** | To what extent do you think goal based planning should be used at the assessment stage of the process? | There is concern that evidence / health professional assessment may differ from what carers say they need- needs to be carer centred, based on the carers voice.  Assessment needs to be undertaken following the development of a trusting relationship. Many carers have involved with institutions and may not have had good experiences. Deciding when and who undertakes the Assessment Stage, at what stage is Carer health & wellbeing being assessed, and the making of appropriate referral is key in providing seamless support for carers. |
|  |  | Goal based assessment and planning approaches are common to Consumer Directed Care principles, usually in conjunction with a funded package or financial allocation of some form. Given that a carer may not necessarily receive this, would a goal based planning approach be worthwhile? | Consideration should include what is “goal based assessment” and who supports the completion of the assessment, as well as what happens when the goals are achieved. This option should be available to be ongoing if the carer wants it to be.This type of approach should not occur at the time of emergency or crisis.  If this was linked to the GP Medicare item numbers, GPs would have a greater incentive to identify carers and develop a Carer Primary Health Plan.  Recent changes to hour provision of CHSP in Level 1 -2 providing approx. 3 hours of care and level 3-4 providing approx. 8 hours, leaves the provision of support inadequate for many caring journeys. Too much time and money could be wasted on this approach. |
|  |  | To what extent should self-assessment form part of the future model? | May be viewed as a cost effective option – however the self-assessment format would need to be sensitive to carer understanding of the service system jargon ( eg using terms such as counselling & education alone would not necessarily be meaningful to all carers).  This could be completed alone, or with a support worker. It should be shorter and less invasive than other methods of assessment. |
| **7.** | **A multicomponent intervention** | 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 shift to prevention and away from crisis-led response is good however it is of concern that the Service Concept states ”*services cannot be funded for everyone and can only go to those with greatest need.”* This isImpossible to determine this in advance especially given the fluctuating nature of caring. However, if prevention is done well, the numbers needing more expensive services should be less.  All carers should be eligible to access a model that applies preventative thinking. A good understanding of what is available, combined with an appropriate self-assessment should assist in providing what is of benefit to carers. Thus not all carers will see everything as necessary for them, at that time.  Consideration should be given to carers with multiple caring roles, as they may be the most likely to benefit from this approach. |
| **7.a** | **Multi-component Support:**  **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? | Instigate the mentoring system to support carers with self-assessment and the means to argue for what they need to sustain their role, then streamline the processes to obtain what is indicated as a result of assessment, reduce the barriers/roadblocks. |
| **7.b** | **Multi-component Support:**  **Carer Mentoring** | When would a coaching programme be most effective for a carer? | Before the crisis, normalised and provided on an ongoing basis. |
|  |  | 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? | Carers should determine needs and coaches should enable them to achieve them |
| **7.c** | **Multi-component Support: Respite support service** | What might these be and how can they be mitigated? | May increase carer stress (for fund administration / self-assessment) however this could be addressed by coaching and / or mentoring and education to develop carer independence in the administration of the funds & access to services.  Rather than direct payments to carers – payment for desired services could be administered centrally without debilitating challenges / roadblocks / barriers / rules. Regulate or eliminate administrative costs for carers accessing CDM to minimise benefits to providers that may reduce the benefits to the carer.  The funding should not be used for crisis or emergency purposes – that service must be provided elsewhere and include appropriate follow-up mentoring & support.  Flexibility and responsiveness would be the mitigating factors |
| **8.** | **Counselling** | 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? | Carer counselling needs to be easily accessible and at no cost.  There can be negative perceptions of “counselling” by carers, consider a change in the name or increased promotion and a normalisation of counselling as “OK and healthy for carers”. Perhaps incorporate counselling as an aspect of Health & Wellbeing.  Current methods of providing counselling are working- including telephone counselling which has proven effective for carers. It would be ideal to avoid a process of re-tendering for this service. Consider counselling to be another item under Medicare for the GP to include in EPC.  The need for specialisation in counselling services eg. mental health, bereavement, complex family dynamics. The health & wellbeing benefits of counselling should be promoted and support for early intervention with counselling encouraged. |