**WSLHD Carer Program Response to 2016 Summary – Service Concepts & Considerations, Designing the new integrated carer support service**

|  | **Section** | **Questions – Design Considerations** | **Responses** |
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|  | **General** |  | * It is good this document recognises why carers need support and highlights the need to support carers wellbeing in their own right, not just to keep them caring and opens the possibility of funded carer packages * Clarification of how the Service Concept support carers as partners in care by consistent identification of carers through electronic medical records, and structured support for carers to be engaged throughout health & community care delivery. * Ensure there is an ability and responsibility to identify carers across all services and to establish what their needs are and how they can be met. * Build in responsiveness to changing carer needs over time and make certain that the needs of the carer are incorporated into all areas of care planning. * Where possible integrate support for the carer’s needs with those of the person cared for example Meals on Wheels. * There is little reference to the evidence available from the UK experience (Legislation about Carer Assessment and support, working carer groups etc.) * There is little discussion on the scope of planned respite- suggests that the expectation is respite will be covered by NDIS/Aged care reforms. This needs to be clearer and to be available. * The document contains references to lack of research about outcomes of carer support- but no suggestion that this could be included. * Carer Choice needs to be emphasised. |
| **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. | * NSW Health is one of the primary services which carers engage with. In NSW the Ministry of Health Carer Support Services have been funded to support the recognition of carers as partners in health care for the past thirteen years. A consistent state-wide strategy for carer identification on patient medical records needs to be implemented to embed carer identification and awareness and to quantify the number of carers supporting patients which may begin to identify the many hidden carers and offer access to supports and services. * Design of new health care facilities should include consideration for carers to stay overnight with patients where appropriate. * 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. * There needs to be recognition of the ongoing caring given when patients are admitted to hospital for long term rehabilitation or to Residential Aged Care Facilities. * 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 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 and NGO sector as well as schools. * Why is the Young Carer program going to NDIS? What supports would be made available to young carers of a grandparent or ageing family member? |
| **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. * Developing an online assessment tool to show the individual what entitlements they may be eligible for and the support and information they may need. There also needs to be considerable education and review of the role in Centrelink regarding Carers pensions/Allowances and other entitlements. * Individualised face to face recommendations for carer support services from all service providers would be the gold standard for information delivery as it would show the carer is embedded in the consideration of the patient/client needs and plans. This would require education for service providers and a requirement for this to happen. |
| **3.** | **Intake** | Given this, when should intake be a mandatory process? | * 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). * Carer and caree records linked. This is especially important in Palliative Care as the carer may need bereavement support after a patient has died. |
| **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. * Make education accessible by 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 replace and / or supplement existing education programs * Peer education and support. * Ask current or former carers what would have been useful for them? |
|  |  | 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 learning’s. Carers find it difficult to get ‘respite’ to enable them to attend support groups where the shared journey is a valuable tool. * Ask carers what education would be useful and how they would like to access it. |
|  |  | 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. |
| **5.** | **Peer Support** | Given this, how can a peer support model be designed which encourage carers to participate and remain engaged? | * Carer support groups as already supported by Carers NSW provide peer support. * When people are in a caring role their capacity to support others would be minimal. Former carers may have more to offer this role. * Facebook * Twitter * There should be clarity about the evidence that this is a needed or useful use of peer support. Carers clearly identify the benefit of carer support groups and often establish mentoring/peer support relationships within these groups which may be informal and time bounded. |
|  |  | Should peer support be a service able to be accessed without pre-conditions or structure processes | * Yes, however resources, support & educational strategies will be required for peer leaders (see above). |
|  | **Needs Identification and Planning** | To what extent do you think goal based planning should be used at the assessment stage of the process? | * How skilled are the assessors to facilitate goal based planning? * Does goal based planning address the carer needs or will it look for a problem to fit the solution? * Do we have the services to meet goals identified by carers or will we be offering goals we have services for? |
|  |  | 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? | * Offer carer funded package to meet carer goal needs * Could this type of assessment be linked to the GP Medicare item numbers? Thus providing an incentive for GPs to identify carers and undertaken an assessment of their need to drive the development of a Carer Primary Health Plan. * What happens when goals are met? |
|  |  | 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). |
| **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? | * Very much agree with a shift to prevention and away from crisis-led. Concern is expressed that services cannot be funded for everyone and can only go to those with greatest need. Impossible to determine this in advance. However, if prevention is done well, the numbers needing more expensive services should be less. But prevention needs to be done well. * A combination of carer and service provider assessment. 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? | * Consider counselling to be another item under Medicare for the GP to include in EPC. * Telephone counselling has proven effective for carers, avoid a process of re-tendering for this service. It is not broken – no need to fix or review. * Carer counselling needs to be easily accessible and at no cost.   .   * 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. |

Submitted by

Wendy Cain

Patient and Carer Experience Officer: Western Sydney Local Health District: Tel 98459925 [wendy.cain@health.nsw.gov.au](mailto:wendy.cain@health.nsw.gov.au)