**CAREWEST LTD RESPONSE TO THE DRAFT SERVICE CONCEPT**

**‘’DESIGNING THE NEW INTEGRATED CARER SUPPORT SERVICE’’**

**Feedback on Design Considerations for Integrated Carer Support Service (ICSS):**

**Awareness**

* National advertising campaign must focus on the unique identity of the carer with emphasis on the importance of their role as care provider – clearly separated from the needs of the person being cared for. The campaign would be most effective in portraying the carer role in the form of stories and scenarios in which an individual might recognise aspects of their life, or the life of a family member, friend, etc. The campaign must also reach out to Aboriginal and Torres Strait Islander, CALD, rural and remote and LGBTI carers. Specific campaign messages need to relate to young carers and their families. A concentrated campaign allowing for variables in the carer cohort should still provide a consistent message and pathway to information and support
* The Carer Gateway (or any entry portal) must define the target group – those people who provide *sustained* practical and emotional support to an older person, or a person with a disability or chronic illness - NOT families requiring child care; NOT families where the person seeking care is recuperating from a short term injury or illness. The portal should filter out inappropriate enquiries at the earliest point so that unrealistic expectations do not arise
* Apart from the ICSS, carer identification needs to be facilitated by the first responder – GP, Pharmacist, hospital, service provider, allied health professional, etc. GPs have traditionally been difficult to engage in carer identification and referral. Targeted education and promotion to reach these potential first responders should form part of the National campaign. These people are influential in the lives of carers and have the potential to provide early identification
* What can search engines such as Google, Bing, Yahoo etc do to ensure carers reach the most relevant sites first? Ensure that the Carer Gateway is the first listing/source to appear when certain search criteria are entered by a consumer (e.g: the word ‘carer’...)  **Can these organisations engineer this as part of their good corporate citizenry?**
* It is critical that the National Contact Centre gets it right the first time – competent needs identification, relevant and appropriate information, clear direction – carers not diverted down the wrong pathway. Those carers who need help now receive timely access to practical support such as respite, counselling. First impression is a lasting impression and carers who are disillusioned or feel that their time has been wasted, will not approach the Gateway and will not provide positive feedback to others
* In raising awareness of young carers, it is necessary to allow the young carer to see themselves and their circumstances reflected in any advertising campaign; as well as allowing families to recognise the presence and role of young carers within the family unit. The education system provides a vehicle for identification and support for young carers, but only if their personal circumstances are known and only if the young carer seeks out support, or is flagged when academic, social or behavioural issues manifest. Perhaps the issues of a caring relationship within the family should be identified on enrolment in primary and secondary school, with flags set for follow up where appropriate. Child and Adolescent (mental) health workers, school counsellors, GPs, school dental clinics, teachers would ideally receive targeted training around identification and support of young carers. The topic of young carers could form part of school based peer support/buddy programs; be included on agendas for staff meetings, be included in parent/teacher interviews; and be promoted through school intranets. School intranets could provide safe options for young carers to seek reliable information and provide a conduit to self identification and support if required.

**Information**

* Provide targeted, relevant and accurate information which is easy to find, in plain language and is accessible to the carer without foregoing their anonymity
* Provide direct and visible links to specific interest areas and organisations such as Peak Bodies, targeted disease support, palliative care support, mental health services
* Provide direct links for young carers to youth services including emergency accommodation, suicide prevention, sexual health, Kids Helpline
* Printed materials should be in plain English, be visually interpretive and give clear directions to the primary information source
* Materials designed for special needs groups should be designed in consultation with those cohorts. Dissemination of information among specific target groups may rely heavily on community participation.
* System failure occurs when My Aged Care fails to recognise the role of carers and to direct them either to appropriate supports or the Carer Gateway.
* Another consideration for carers may be prohibitive mobile phone charges, especially where the call is likely to be lengthy. Many carers use pre-paid plans, or can receive incoming calls only. Are carers put off by the cost of making a call on their mobile phone? Are there any avenues for carers to access a free call service or internet access at locations such as Councils, libraries, Service NSW Centres (or equivalent), Neighbourhood Centres etc?

**Intake**

* Intake should not be mandatory – carers should be able to maintain their anonymity when researching, seeking information, searching for local peer support and/or education programs etc. Many carers will start out with a ‘’fishing trip’’ to see what information can be mined from the portal. If information is readily available, and obtaining that information is not confronting, then carers will feel more comfortable about engaging with the system.
* In emergency situations, intake may be cursory and sufficient only to determine the most appropriate avenue of support. Referral to a service for emergency respite, counselling etc. would then result in a more comprehensive assessment at the service provider level. There may be a feedback mechanism for the service provider to update the client record following this assessment (with the consent of the carer)
* If carers are required to provide basic demographic information for statistical purposes, then initially this information should be innocuous data such as a postcode or age group. For the most part, it is no longer considered invasive to be asked for this type of information – it occurs frequently in the retail setting
* Self-service on-line intake could allow carers to step through the intake stages – with more comprehensive information required to unlock different levels of support. This should be self paced for the carer, with entry to their record via a simple *key*, so that they can reconnect with the process at any time.
* The development of emergency plans should be an option available to carers, including through a self-service intake process – the carer should be able to complete, review, change and remove emergency care plans as required. The dissemination of the information contained in the emergency care plan should be a decision for the carer, with one option being the facility to email the plan to a GP, family member, service provider etc.
* Intake should be a mandatory process where financial support is required to facilitate access to carer support

**Education**

* Carers often report being time poor. In order for carers to invest time in education it must be relevant to the carer’s needs and goals. Education should be ‘’normalised’, not just cover topics relating to caring, and offer carers a choice of courses which are relevant to their personal circumstances
* Carers should be encouraged to utilise education available in the community through local networks, community colleges, support groups etc.
* The logistics of accessing education need to be considered including transport, respite, financial support, resources, mode of delivery
* Carers accessing on-line education may still require respite in order to free up time to participate. It can be difficult to maintain impetus to complete on-line education and difficult for the carer to find the motivation when tired/stressed. Guided on-line education, with group facilitators, ‘’study buddies’’ or other peer support options, may increase participation and completion for some carers
* Self guided on-line education should also be available to carers as their needs change – again accessed through their own individual key, with facility to step through education modules as desired
* The Carer Gateway should provide direct links to educational tools provided by specific organisations such as Schizophrenia Fellowship, Alzheimer’s Association, MS Society, Cerebral Palsy Alliance etc. This information should be easy to find in search facilities, and ideally links to an external organisation will provide a loop back to the Gateway rather than creating a ‘’dead end’’
* Utilise social media for access to peers support, expert information and forums/groups
* The Gateway needs to provide information about social/hobby/education courses in local communities as well as formal services. Perhaps community noticeboards on the Gateway could be considered for this purpose – screened and managed by the Gateway to ensure privacy
* Education should include a focus on carer wellbeing and preventative health. As well as formal health information and services, links should be available to local services such as sporting clubs, gyms, special interest groups, etc.,

**Peer support**

* Peer support design needs to be flexible enough to accommodate the individual carer and their circumstances. Many carers already participate in Carer Support groups or phone based peer support activities. However, some carers find this type of active group participation too confronting and lacking in privacy. For carers who are socially and/or geographically isolated, attendance at a face to face peer support activity may not be possible
* On-line peer support offers a degree of anonymity and allows the carer to choose their level of participation. On-line peer support groups would ideally be managed by a moderator to ensure privacy and weed out trolls and other inappropriate membership such as advertisers (although in the future advertising may become a vehicle for sustainability and development of peer support mechanisms)
* Some carers may wish to join an on-line peer support group as an observer in the first instance, and should be able to do so before committing to membership of any group/forum
* Providing carers with the opportunity to ‘’find’’ each other through an on-line forum or network would allow carers in similar circumstances, or with similar interests and concerns to provide peer support that did not require external intervention
* The Gateway should provide linkages to local peer support – not forgetting that for many people simply participating in *any* group activity (physical, intellectual, spiritual) provides a level of peer support
* Social media provides a vehicle for peer support through blogs, expert groups and local groups with closed membership

**Needs Identification and Planning**

* Carers should be encouraged to utilise goal based planning as a tool to enhance their control, resilience and decision making. Carers should be supported to design and implement strategies to achieve short term and medium goals with long term goals moveable and flexible as the carer’s needs, opportunities and barriers change. Some carers will require assistance with goal based planning, and other carers may simply wish to be provided with a format and guidelines to start developing their own plans.
* Self assessment must be part of any future model and be available in printed form and on-line. Self assessment should take a staged, self-paced approach and provide guided instructions and tools, opportunities to step out to external information sources and rejoin the assessment, and an ability to terminate the self assessment at any point, and switch to a formal assessment process. Self assessment should be available through the unique carer key referred to above.
* Self assessment could also include an optional carer skills audit which could identify areas where carer education would be useful, or to assist those carers considering entering or re-entering the workforce

**Multi-component intervention**

* Needs identification will support the priority for multi-component intervention and could include criteria such as isolation, socio-economic circumstances, carer stress, informal supports, carer health, etc.,
* As a preventative measure, multi-component intervention may be used earlier in the carer lifecycle, to facilitate access to education, mentoring and respite with an aim of increasing carer resilience, skills and decision making capacity.
* A consideration in determining access to multi-component intervention could be the likelihood of carer breakdown if the approach is not offered to the particular carer – again this will be done through needs identification and/or formal external assessment

**Multi-component support: Financial support**

* Financial support will link to the carer’s needs, priorities and goals. – which are often to obtain more services for the care recipient. Historically funding has been about supporting the care recipient, so there will be a need for education (for the carer and in some cases for the care recipient) to ensure that funds are utilised to meet the carer’s personal goals, to support knowledge and skill building and if desired by the carer, to cover contingencies.
* The Consumer Directed approach helps carers to focus on goals, opportunities, resources and priorities. It provides the carer with a degree of control and allows them freedom to choose the supports which best meet their individual circumstances. Carers are accustomed to limited resources and have a good understanding of the need for prudent management of financial support. Those carers who wish it, should have access to education around planning and budgeting to get the best from any funding package.
* The guidelines for CDC must provide sufficient flexibility to allow the carer to use funds to purchase goods and services which enhance their capacity to cope, improve their health and wellbeing and decrease their social isolation – e.g: a carer may wish to purchase an iPad with WiFi access in order to stay in touch with their family members or their peer support group, do on-line shopping, undertake their own research, participate in web based wellbeing programs etc
* Carers who wish to have their funding fully managed externally should still be able to do so, with the full understanding that administrative costs will invariably be associated with this type of funding arrangement
* Needs identification will highlight those carers who require financial support. The form of payment made to the carer under CDC will be determined by the needs assessment, and the carer’s reported desire/capacity to self manage these funds. The community will expect that carers are accountable for the funding they receive. Is it possible to link accountability for funding to Centrelink, Medicare or the Carer Gateway, so that those carers who receive CDC may report their expenditure through a safe portal? For carers who do not have access, or do not wish to access, a web based portal, there could be an option for face to face transactions at a local Medicare office or pharmacy.
* A Carer Card has often been suggested and may be suitable for some carers. This approach would allow transactions to be easily reported but may be difficult to control in terms of how funds were used.

**Multi-component support: Mentoring**

* Mentoring should not be a mandatory component of the model. Carers should be able to opt in and out of mentoring. Carers may seek short term mentoring – e.g: financial mentoring to assist with planning and establishing a budget under CDC.
* The need for mentoring may be triggered by a life event, and should be available to carers at any stage in the carer journey
* Compulsory mentoring would be intrusive to some carers and conflicts with the philosophy of consumer directed care

**Multi-component support: Respite support service**

* Supporting the carer to proactively plan respite care in order to avert carer burn out is an important step in maintaining carer resilience.
* Under CDC carers can plan respite which allows them to participate in family and social events, and may also benefit the care recipient through increased stimulation and social interaction. The ability to access brokered respite provides the carer with the ability to have a break when and where it is needed (within the limits of available resources).
* Consideration should be given to permitting the utilisation of funds to pay family members or friends to provide respite where this is appropriate in a cultural context or due to an absence of alternative appropriate support (e.g: remote communities)
* Emergency respite should be accessible as a standalone service, but must have objective and measurable guidelines attached to access. Repeated emergencies may flag the need for intensive carer mentoring/counselling, review of needs assessment and review of financial support (in addition to a review of the supports provided to the care recipient)
* Respite should be available to carers as a stand-alone option without the need to access the other components of the approach

**Counselling**

* Access to counselling needs to be available through various models, including individual and group face to face sessions, phone and web based groups (where anonymity can be maintained if preferred), social media groups, blogs
* Consideration must be given to the context of counselling within culturally and linguistically diverse groups, Indigenous communities, etc., There may be barriers to seeking counselling and an individualised approach, working within the community, may be required
* On-line self assessment referred to previously, may flag counselling as a priority support for the carer, and provide pathways to appropriate peer and formal supports
* On-line and phone counselling may be the only option available to more remote carers or those who are socially isolated. **A consideration for all telephone and web based support for carers is the capacity to access reliable conventional mobile phone and internet coverage, with several areas experiencing large blackspots and no access in more remote communities.**
* It is necessary to overcome the negative connotation around counselling – the need to access counselling is often construed as a weakness and a failure to cope, particularly among males. A campaign promoting the benefits of counselling for good mental health and wellbeing, rather than for ‘’fixing’’ problems, may improve the perception of this support in the community – as has been the case with the advertising campaign to raise awareness of men’s mental health in rural communities.
* Counselling may take the form of physical programs coupled with a spiritual/mental health focus – yoga with mindfulness training; walking groups; social groups etc. Carers may be more receptive to activities which are perceived as ‘’normal’’ rather than formal counselling.
* Clinical counselling support will be determined on needs assessment or review, and financial support will be required for carers to access this service, including provision of funding for respite, travel and other ancillary costs for more isolated or incapacitated carers
* There is a need to investigate avenues of support for males through the network of Men’s Sheds, farming groups (State and National Farmers Federations), sport and leisure clubs, MensLine Australia etc.

**Other Considerations**

**Support when caring changes or ends**

* Access to face to face and on-line training for carers wishing to join or re-enter the workforce; skills audit
* Access to grief and loss and financial counselling
* Recognition that for many older carers where the care recipient enters permanent placement in a Commonwealth Approved Aged Care Facility, the caring does not cease. In the aged care arena, carers are reporting that they attend the facility each day to help with feeding, interpreter services, culturally appropriate meals, behaviour support, emotional and social support for the older person. This may be a significant impost on the carer, especially in terms of fuel costs, public transport costs, inability to work, personal health etc. Whilst the remedy is higher staffing levels in aged care facilities, the reality is that without the contributions made by family members, many older people would not receive personalised support to maintain an acceptable quality of life. This is also true for carers where the care recipient spends significant amounts of time in hospital. Perhaps for this cohort, the Carer Allowance should remain in place.
* In view of the significant contribution carers make to the Australian economy through the amount of unpaid care they provide, a superannuation scheme should be available to carers who cannot work or have to reduce their work hours in order to meet their caring responsibilities. Many carers spend most of their adult lives caring, and in that time accumulate limited or no savings to provide for their own support in later years. Caring has a quantifiable value and over the lifecycle of the caring relationship, carers make a very real contribution to the economy. In recognition of this, a National Carer Superannuation Scheme should be established to ensure that carers have access to some independent financial support as they age – funds which they have earned, not funds which arise from benefits. Many carers are rewarded for years of caring, by having their pension reduced, Carer Allowance removed, and no access to any savings or Superannuation. This is inequitable and needs to be considered.

**CAREWEST LTD**

**Respite@cw.org.au**

**1300 227 393**