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# Designing the new integrated carer support service

Access Care Network Australia (ACNA) welcomes the release of the draft Service Concept for the delivery of interventions to improve outcomes for carers.

ACNA, a subsidiary of the Silver Chain Group, is an independent, leading assessment agency providing unbiased, holistic, wellness based assessments. These are complemented by appropriate referral to provide support to enable people to continue living in their own homes and communities. ACNA works intimately with carers through our operation of Commonwealth Carelink and Respite Centres in Western Australia which saw us assist over 2,750 carers with respite over 2015-16. We also provide in-home assessments through our operations as a My Aged Care Regional Assessment Agency in both Queensland and South Australia, a Regional Assessment Service for home and community care in Western Australia, a provider of Veterans Home Care assessment services throughout country WA, and as a broker of ComPacks support packages for people leaving hospital in New South Wales. Over 2015-16 we assisted over 35,000 people and their carers with assessment and support services.

ACNA’s key area of difference is in our application of wellness and reablement based approaches to the provision of both assessment and support. This expertise has arisen out of the work of our umbrella organisation, the Silver Chain Group, in developing an evidence based approach to employing wellness and reablement strategies within aged and disability care within Australia. This expertise has been widely recognised both across the industry and by the Commonwealth government[[1]](#footnote-1). ACNA has taken this expertise into the assessment field and is currently validating results shown via our Responsive Reablement Project that such approaches at the point of assessment can vastly improve outcomes and reduce further reliance on services. Assessment of the care recipient always includes consideration of the carer’s role as detailed support plans are developed which may incorporate a range of informal as well as formal supports. ACNA undertakes a holistic consultation with the care recipient, and their carer and family as appropriate, which considers what the care recipient can do for themselves and what they need assistance with during a ‘show me’ (not ‘tell me’) wellness based assessment. Clear and detailed support plans result which aim to foster independence, provide reablement strategies where appropriate and recognise also the carers’ needs.

We have reviewed the draft Service Concept for carers in light of our experience and expertise and offer below both some general comments and comments on each category of proposed supports.

ACNA would like to commend the delivery of this Service Concept and the process of consultation being undertaken in the further development of the more comprehensive service design. ACNA would greatly welcome the opportunity to participate more fully in this design phase and in particular any opportunity for further discussions with the Commonwealth around the role that can be played by assessment and respite support agencies. We are particularly interested in lending our expertise in the design, development and implementation of holistic, wellness based assessments and look forward to further discussions.

## 1 General Comments

### 1.1 Identification and registration of carers

Early identification / registration of carers is critical and particularly beneficial on the basis that should the carer become stressed and in need of additional support the information has already been provided.

Existing structures which provide access to large parts of the carer population – such as My Aged Care Regional Assessment Services (MACRAS) and the National Disability Insurance Scheme (NDIS) Local Area Coordinators (LAC) could be leveraged as carers usually participate in the assessment of the care recipient. Efficiencies can be created through identification / registration of carers (for the majority of carers) through these existing systems. However, this information should be able to be transferred to the Carers’ Gateway (if this is the primary tool to capture registered carers and those eligible for emergency respite) without the carer having to repeat their story. This sharing of information to the Carers’ Gateway would need to be electronic and occur at the time of assessment of the care recipient via the assessing agency to ensure that records are available at any time should the carer then directly contact the Carers’ Gateway. The support officer taking the call could then search the Carers’ database and immediately have access to much of the carer’s details and story without them needing to repeat themselves. This will improve both the carers’ experience and ease of navigation of the system as well as provide cost and productivity efficiencies throughout the system.

As recognised in the Service Concept, there is a great need to identify carers other than those identified via assessment of care recipients. This could be a combination of Centrelink, a national registration system (such as Carers’ Gateway) with promotional tools and activities being utilised to encourage registration, and outreach at a local level. We currently receive significantly less referrals from Centrelink than we would expect based on Centrelink payments to carers so referral via Centrelink needs further consideration. Local outreach is particularly important for young carers, CALD carers, indigenous carers and those supporting people with a mental health issue. Locally based support programs and agencies, including the local knowledge and foundations laid by CRCCs, can be of great benefit here and should be leveraged as we move forward into the new system design.

### 1.2 Separation of funding packages

Of particular importance to ensure the ability of carers to continue undertaking their caring role is the recognition of their needs via a separation of funded supports. Funding for carer respite and other supports needs to be provided as a distinct, separate funding package and not be derived from part of the care recipients’ funding package. Where funding for carer supports are tied together with care recipient funding packages, our experience with Consumer Directed Respite Care (CDRC) packages suggests that the carer will always prioritise spending on the care recipient. A 2014 UK report[[2]](#footnote-2) details a range of results which reinforce concerns that carers are likely to put their own needs last. The bulk of monies are then spent on the care recipient with the carer not prioritising access of funded supports that would enable them to continue to function both healthier and longer in their caring role.

### 1.3 Wellness based approaches

Our evidence shows that a wellness based approach that is holistic and caters for the individualised needs of the carer is as effective in delivering outcomes as it has proven to be for care recipients. It is important to recognise the differences between carers – whether these are age, cultural or linguistic backgrounds, gender, sexual identity, or their individual differences in how they manage ongoing stressful situations, their coping mechanisms and their access to supports. The Service Concept notes the impact of caregiving on carer health including increased burden on the overall health system and the ability of carers to continuing their caring role. Wellness based approaches have proven extremely effective in enabling care recipients to better manage their own health and in limiting dependence and reliance on services. The Silver Chain Group has been an acknowledged leader in this field and ACNA has been a leading force in extending these approaches into the assessment space. ACNA supports the use of wellness based approaches with carer groups as theseoffer potential to deliver similar outcomes and also align with the Service Concept Guiding Principles (in particular evidence-based supports and innovative, flexible and tailored support) and shift towards prevention as outlined on page 18.

## 2 Comments on categories of support

### 2.1 Awareness

There is an acknowledged challenge with young carers that when the care recipient is a parent or adult relative they often will not want to admit that they are being cared for - for a variety of cultural or social reasons or even a fear that the government may take their children away.  There needs to be some form of clearly 'safe' space where care recipients can admit to their child's caring role. Furthermore, when a young carer is identified assessments need to carried out with care and delicacy.  CRCC has been successful in assessing young carers when parents do not want other organisations (such as disability services) to be involved. Schools may provide a viable approach to identifying young carers through provision of resources that could be used in appropriate curriculum areas such as health. There could also be encouragement for schools to engage in awareness activities around National Carers Week. As already discussed, using existing structures such as NDIS LACs, MACRAS, Centrelink or hospital discharge programs to identify carers early in their caring role is also critical.

### 2.2 Information Provision

ACNA agrees that carers are already under stress and don't need to be given large amounts of information. However, an assessment is useful to determine if further information and referrals are indicated and to provide these if needed. Sometimes it can be effective simply to leave a resource such as a fridge magnet or leaflet with a phone number to call if any questions arise or the situation changes. Utilising the assessment phase of other services to provide a small amount of tailored information and advice provides an efficient means of giving the carer an entry point for access to further advice, information or support.

### 2.3 Intake

ACNA believes that the point of intake is critical to ensuring smooth pathways to support and to being able to effectively deal with emergencies as they occur. Our experience shows that carers are understanding of the process when it is explained that "we gather information for when emergencies happen so your loved ones receive the level of care that you desire and they require." ACNA supports the view that there should be a clear process for intake of information and sharing between agencies to minimize the frustrating experience for carers of having to provide the same information multiple times to different organisations. As described above, we believe that assessment agencies could undertake this intake role with information then shared electronically to the one central gateway point. Intake could also be undertaken via phone or online to ensure availability to all carers. At the point of intake, it makes sense for this to be a brief capture of basic information which can be built upon in the needs assessment and planning phase as required.

### 2.4 Education

In ACNA’s experience carers frequently decline education due to the difficulty of finding someone to look after the care recipient when accessing the education. Our experience suggests that carers are unlikely to make or find time to undertake online training but are more likely to engage in education if it is delivered in person with organised respite as part of an education/respite package. Often carers who have attended an educational session once are more likely to want to return after meeting and socialising with others in similar situations. Therefore, additional incentives to attend the first session could be considered (e.g. assistance with petrol). For many carers who live with financial stress or in remote areas it is difficult to travel to the training location. Incentives may also help with this but innovative solutions to encourage online group sessions would also be beneficial. The knowledge and resources built up by local CRCCs can be of critical benefit in finding a local and individualized solution for particular carers. Education can also be linked to other health services provided in the local region and this is where multi-disciplinary and agency approaches to community wellbeing are vital.

### 2.5 Peer support

ACNA has found that peer support requires a highly individualised approach tailored to each person’s needs and preferences. Some people prefer online peer support where they can remain anonymous and thereby feel more free to discuss their situation. Others prefer to meet with carers in similar situations face-to-face as this gives them the most emotional support. It is crucial that consideration be given to cultural and language barriers when accessing peer support services. For this reason, we advise that there needs to be a variable approach to peer support which caters for these many needs. Our experience in providing carer support groups through our CRCC operations suggests that any form of face-to-face peer support must be structured otherwise it is not beneficial. For example, peer support works well when combined with guest speakers for educational purposes where the guest speaker presentations are short and form the trigger for discussion between peers. In terms of providing cost effective tools and supports (and recognizing that professionally facilitated models may not be cost sustainable) we suggest that video based resources (for e.g. similar to Ted Talks) could be developed and made available for widespread use both online and via support organisations. These tools could provide a focal point for discussion, sharing and education across a variety of peer support settings. The evidence tends to support this multi-faceted approach to peer support.

### 2.6 Needs identification and planning

ACNA agrees that providing opportunity for identifying needs and planning supports can greatly assist carers in managing their caring role and particularly in responding to crises or periods of intensive need. However, our experience also indicates that the primary goal for any carer is to continue in their caring role and when goals are introduced they tend to create more work and stress for the carer.  This can be due to a fear, real or imagined, that if the goal is not met then respite funding would be reduced. Therefore, it is crucial that it is made clear to carers that any goal setting at this stage is not at all related to continuation of any financial payments they are receiving due to their caring role. It is possible to have a consumer led approach based on carers identifying their needs and putting supports in place to help them cope without these necessarily being predicated on formal goals. Information recorded at the intake stage and shared through the Carers Gateway (see both general comments and intake) can provide a seamless shift into the needs identification and planning stage for carers and carer agencies alike. This information gathering phase can serve as a crucial indicator in identifying those with the greatest need for further needs identification and planning thereby ensuring resources are directed where they are most needed. As discussed previously, current structures involved in assessment of care recipients have both the expertise and opportunity to undertake this intake stage in ways which are most cost effective and also convenient for carers. Self assessment of needs and support planning can provide a viable alternative as it can be done cost efficiently and when convenient for the carer. Suitable resources linked to centralised records (e.g. via the Carers Gateway) will be most effective in these cases as they can then be accessible to assessment and support agencies as needs change or increase over time.

### 2.7 A multicomponent intervention

In designing an approach to the allocation of multicomponent interventions ACNA notes that these would be based on the carers needs assessment and should consider the following:

* Whether carers are interested in particular services and likely to participate over the long term.
* Whether some of the components will be available to the carer through other channels, for example, extended family support structures.
* The number of care recipients at home.
* The degree to which the introduction of multi-component support would improve the life-time prospects of the carer, for example, ensuring longer term prospects for young carers to get a good education and job.
* Whether it is possible to assist the carer to return to part-time or full-time employment.

We have already noted above the importance of any financial package for supports to the carer being separated from the package funding allocated to the care recipient. The design considerations referred to in the Service Concept support this view. Our experience in operating CRCCs in the provision of respite packages has been that there are significant administrative overheads involved also in the booking of respite which can often take between 30-40 calls to find an available respite space or bed. This is simply not within the carer’s capacity to manage especially in an emergency situation. Our advice is that planning of supports on a six monthly basis (we have found this period of time to be ideal in terms of anticipating future need) and pre-booking respite care is the most effective approach. This could form part of the support planning phase with booking of supports being noted at this time with the support agency signing off on access as a simple cross reference to provide acquittal of funded packages. We do not recommend extensive need for acquittal of funds as this will be too onerous for many carers.

In relation to carer mentoring, coaching programs are most effective when the carer reaches a 'steady state' and is aware of the problems they are facing. While emergency respite can be a trigger for coaching, it should only occur once the carer is able to take on board the new information. Coaching should not be mandatory and it should only be at a time when the carer has capacity.

Consideration of the inclusion of respite support within a multi-component support package is supported but there needs to be very clear and very simple rules around the expenditure of money from packages (e.g. the amount available for respite and the amount available for mentoring) otherwise carers sacrifice part of their package to meet the needs of care recipients.

ACNA’s experience shows that with carers who have reached the end of their tether and are ready to give up their caring role, a two-week respite provided the opportunity to recharge and enable them to re-engage with their caring role. This supports the view that respite is often the most critical component of any such package.

Our experience also shows that when people have packages they tend to budget for emergencies thus making these easier to manage. However, if an emergency does happen the amount put aside is often insufficient due to the cost of organising respite on short notice. This means that funds for all future planned respites are put into the emergency leaving them without respite for the rest of the year. If an emergency does not happen this money remains unused where it could otherwise be benefiting the carer. For these reasons emergency respite should be covered outside of the package (for example as an insurance pool for all carers) so that the package can provide maximum benefit to the carer.

### 2.8 Counselling

Online groups for counselling should be considered especially for CALD carers as online groups that include people from their country of origin may be more effective than trying to engage with local people with different cultural backgrounds. Online channels such as Skype may be more effective than over-the-phone as it is possible to read body language and facial expression. Group counselling or education around therapeutic approaches such as CBT or mindfulness can be considered as a basic requirement for all carers, and also can provide an opportunity for professionals to identify those needing individual interventions.

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1. For e.g. see Living Well at Home: CHSP Good Practice Guide, Department of Social Services, June 2015 [↑](#footnote-ref-1)
2. In Sickness and in Health: A survey of 3,400 UK carers about their health and wellbeing. Carers UK, 2014. [↑](#footnote-ref-2)