



## **Carer Support Network SA Comment on:**

### **Department of Social Services (2016). Designing the new integrated carer support service: A draft Service Concept for the delivery of interventions to improve carer outcomes**

#### **THE CARER SUPPORT NETWORK SA**

The Carer Support Network SA (CSN SA) consists of five regionally-based carer support organisations that cover South Australia for carer support. They are:

- Carer Support
- Northern Carers Network
- SA Country Carers
- Carers SA
- Carers Link Barossa and Districts (incl. Adelaide Hills and Yorke Peninsula).

CSN SA operates 20 carer support centres across the South Australia and supports in excess of 20,000 registered carers. Member organisations are committed via an MOU to using the *Carer Support Model* as the basis underpinning how carer services are delivered.

#### **The Carer Support Model:**

The carer support model is based on the recognition of the value of caring and the need for carers to maintain a balanced quality of life. It recognises that carers are unique individuals capable of shaping their own destinies, and seeks to provide support by walking alongside carers to help them find the strength and information they need to maintain their caring roles and lifestyles.

#### **The key characteristics of the model are:**

- It is aligned with social justice principles, carers legislation and the State Strategic Plan.
- Carer support organisations are locally-based, community-owned and managed, and directed by carers, with carers forming a majority of Board members.
- The focus is firmly on the carer and their health and wellbeing. Support provided is carer-driven and aims at assisting the carer to develop resilience.
- Support is designed to help overcome carers' isolation and disconnectedness, and to give carers opportunities to link with other carers.
- Information is provided that is relevant to the caring role and which will help carers access the support, services, information and/or skills training they need.
- Supports provided by member organisations are positive and encouraging, and designed to assist the carer to express their personal interests outside of their role as a carer.
- Carer Support organisations form strong partnerships with other service providers and community organisations for the benefit of carers.

## GENERAL COMMENTS

The *Carer Recognition Act 2010* must underpin the new carer support system, what it delivers and who delivers it. For the development of the model this means the following:

- Carers have a right to a life outside of the caring role and require support in their own right, outside of what is needed to sustain the care relationship. Therefore, carer services must be delivered through carer-focused programs, not embedded within schemes designed to serve the care recipient.
- Carers are as diverse as their individual caring journeys and need to be able to dip in and out of the service system throughout that journey. Therefore, carer services must be flexible in both approach and timing.
- Carers' primary needs are not of a clinical nature. Therefore, services must adopt a preventative not a medical model.

Approach to the design of the new integrated carer support service system

- The function of the proposed national carer needs identification tool needs to be clear from the outset; i.e. will it be a needs assessment tool only, or will it be used to determine eligibility? A national eligibility assessment tool may:
  - create an entitlement for a service. What would this entitlement be and how would it be funded?
  - make some carers who are currently receiving services ineligible to continue receiving them. What alternative support arrangements would be available to those carers?

### A. STATEMENT OF NEED

#### Who are our carers?

CSN SA agrees with the inclusive definition of "carer" – maintaining a focus on all carers, regardless of who they are or what amount of care they provide.

#### Drivers for Change

- CSN SA members fully support the National Disability Insurance Scheme (NDIS) and My Aged Care (MAC) as important steps towards improving freedom and choice for care recipients. Likewise, it is paramount that the new carer support system offers carers the freedom to access services free of constraints imposed by the care recipient's package.

#### A shift towards prevention

- *"Given that the objective of the future model 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" (p. 19)* - this does not reflect a true understanding of the fluctuating nature of the caring role. Carer needs change over time; they are not static or always at "most need." Consequently, consideration should be given to standalone carer support programs that offer integrated supports such as non-therapeutic counselling, advice and information, and linkages to a range of services as an alternative to packaged services.
- There appears to be a contradiction between the paper's fixation on scientific evidence and the Government's commitment to develop the new service concept through a co-design process that recognises carers and service providers as experts.
- Caring experiences are unique and across a broad range of age groups and caring roles. All caring journeys are different. In addition, carers' needs are rarely of a clinical nature. These factors may explain why there is little scientific research into the most effective supports, and why research that has been undertaken has been inconclusive.

- In CSN SA's experience, low-level activities that are accessible at the carer's discretion are an excellent preventative strategy. Low-level activities, such as information, linkages and peer support, ensure that carers feel connected with the provider and confident to initiate contact should their situation change.
- Preventative supports should be provided informally in a non-clinical environment and based on community development principles.

### **Guiding principles**

- CSN SA fully supports the guiding principles and believes that the *Carer Support Model* in operation across South Australia already reflects these. For example, the *Carer Support Model* successfully combines a state-wide approach with local responsiveness. Under the model, regionally-based providers offer a consistent suite of supports; however, each provider has discretion to adapt the way they are delivered to the local context. Services include, amongst others, information, referral, advocacy, education and training, non-therapeutic counselling/emotional support, peer support, carer groups, respite and retreats.

## **B. THE DRAFT SERVICE CONCEPT**

### **Awareness**

- National media campaigns may help raise awareness of carers and available supports broadly. However, to translate awareness into referrals and/or carers coming forward themselves, raising awareness informally within local communities has proved essential.
- Many carers do not see caring as their primary responsibility and therefore do not actively seek help, even if they need it. The success of the new system will depend on reaching these carers.
- 89.5% of carers visit their GP at least once every 12 months. Therefore, GPs should be targeted in awareness raising.
- Awareness raising/promotion of workplace reform to better support working carers may help reduce the number of working carers losing their jobs and becoming welfare dependent.
- Mass media (radio and TV) may be beneficial to reach those carers who rarely get to leave their home.
- Awareness raising in local communities through engagement and education is effective in reaching hidden carers, carers in rural and remote areas, and ATSI and CALD communities.
- Young carers who are caring for a parent or grandparent are not noted in the paper, and funding currently available to support these carers is moving to the NDIS. It is expected this will increase the number of hidden young carers and reduce supports available to them.
- Hospitals could be targeted to reach carers in the early stages of the journey, because carers commonly accompany the cared-for person to appointments around the time of assessment and diagnosis.
- If the model is to be preventative, it will be important to identify carers early in their journey. Carer Gateway operators should therefore provide guided referrals to locally based carer support agencies to streamline how carers access the support they require in the most efficient manner possible.

### **Information provision**

- The Carer Gateway needs to become a responsive and comprehensive repository of information to support carers to navigate the service system. Within this, priority should be placed on assisting carers to find specialist services in their local area.
- As stated in the paper, it is vital that information is targeted to the carer's circumstances and the point at which they are on their journey. Therefore, information should be provided by people who have a good understanding of carers as well as the local area.
- It needs to be recognised that some aged carers are not IT-savvy and need to receive information face-to-face, via phone or in hard copy.

- Standardised information, for example brochures about particular services or entitlements, could be available online, in hospitals, medical practices, community centres etc.
- It cannot be assumed that all carers are empowered by information about services; in fact, many carers feel overwhelmed with information and need assistance identifying what is relevant for them.

### **Intake**

- Intake should not be mandatory. Many carers will not share details until a level of trust is established with a service. Only for some services, such as respite, there would be a requirement to formally register the carer.
- Intake staff need to be aware of available services and gaps in the local area, in order to understand and respond to the carer's circumstances.
- Intake staff's primary focus should not be on prioritising workloads and resources. It should be on linking the carer to the supports they need at that moment.
- Feedback to the Carers SA's Carer Information and Support Service (CISS) has shown that carers appreciate talking to a person at the first point of contact. Web-based or otherwise automated systems should complement, not replace human interaction.
- The national intake system should only capture high level registration (i.e. personal details, carer status and relevant information about cared-for person), then put the carer through to their local provider for in-depth assessment. The provider will be in a position to offer an immediate benefit in exchange for the information given.
- A self-assessment tool could be used as a starting point – to increase the carer's awareness of common needs amongst carers, affirm their recognition of these and encourage their connecting with local service providers to enter the assessment process.
- Emergency planning is more appropriate for ageing carers to provide them with peace of mind in the event of an emergency.
- The planning process must have the capacity for re-assessments and alterations as carers' needs increase or otherwise change over time.
- Carers' family members (not only the cared-for person) need to be considered in the planning process.

### **Education**

- CSN SA's experience supports the evidence of the need for carer education provided in the paper. Specific topics include but are not limited to:
  - dementia, autism and mental illness
  - carer self-care
  - assisting carers to navigate the NDIS and/or CHSP.
- The Carer Gateway website could provide information about education sessions run by carer support providers.
- Whilst some education can be provided online or via other forms of correspondence, face-to-face sessions also have peer/group support outcomes and particularly benefit those carers who are socially isolated.
- The availability of digital literacy training would help encourage the uptake of online education programs, especially by older carers.
- The new system can help carers access education outside of the carer support system by:
  - educating Gateway operators on the kind of education carers are likely to ask for and/or benefit from – existing providers could share their knowledge of this
  - referring carers to their local provider as swiftly as possible – the provider will have knowledge of education options available in the area.

### **Peer Support**

- For carer self-help groups, professional facilitation has proved useful to prevent groups diverting from their purpose. A funding model for this should be considered.

- Responsibility for establishing and supporting peer support groups should rest with local carer support providers, to ensure that group leaders can access training and assistance as required and prevent groups failing.
- It is important to maintain linkages between peer support and mentoring/coaching programs offered as part of the multicomponent intervention.
- Many types of peer support can be provided partially or fully by volunteers who are often former carers.
- Low-level, informal peer support arrangements have proved powerful and cost-effective in improving carers' wellbeing and sustaining them in the caring role. An example would be a group of carers getting together regularly to provide one another companionship and reassurance.

### **Needs Identification and Planning**

- It is important that the needs identification process maintains a preventative focus by considering risk factors that are likely to lead to future problems, alongside a carer's immediate support needs.
- As carers' needs tend to be non-clinical, a self-assessment approach would be suitable to collect superficial information. However, carers can have limited understanding of issues that affect them and of their own responses to these. Carers are also known to "minimise" their own needs. Consequently, any self-assessment needs to flow into an in-depth assessment conducted by experienced staff. These staff do not need to be highly qualified but must have a good understanding of carers.
- Within the planning context, thought needs to be given to how emergency situations are dealt with. This should include a clear pathway for emergency supports and respite.
- It is important that the assessment process is not too cumbersome/lengthy for carers who are already time and energy poor and need quick and easy links to supports.
- The process should be non-invasive and target carer health and wellbeing.
- Effective information-sharing systems need to be in place to avoid carers needing to tell their story multiple times.

### **A multicomponent intervention**

#### General

- Identifying carers with the "highest need" for multicomponent packages will be unfeasible, because of the fluctuating nature of caring. All carers should be eligible to access preventative supports, the availability of which can only be guaranteed via a block-funding model.
- There is a risk that combining the criteria for different programs will reduce the overall efficiency.
- Carers are often capable of moving in and out of services as their needs change throughout the caring journey, as long as they know where to seek assistance and have been made to feel comfortable doing so.
- Whilst mentoring may sit alongside financial support, respite needs to be available as a standalone service, particularly emergency respite.

#### Financial Support

- It is proposed this component is renamed "Consumer Directed Care". Naming it "Financial Support" may create the impression that it will encompass other forms of financial assistance, for example Centrelink payments for carers.
- Consumer-directed care (CDC) packages would work for some carers for some types of services, i.e. respite. In considering their widespread rollout however, a number of factors would need to be considered:
  - CDC packages would need to complement, not replace the community-based *Carer Support Model* described in this document.

- The *Carer Support Model* requires block funding to be able to provide an integrated program that carers can “dip in and out of” as they need.
- Many carers are not able or willing to engage in a process that makes them account for the supports they have requested.
- Carers’ needs, particularly for respite, vary significantly, even between carers with comparable care loads. Distributing funding in the form of CDCs may result in some carers having more than they need and others not having enough.
- In order to be effective, CDCs would need to be flexible and not lock carers into a pre-defined set of supports, some of which they may not need.
- A CDC approach might create an expectation that ALL carers are entitled to a package and create a two-class system between those eligible and those not eligible.
- Carer support organisations or government agencies may need to be resourced to assist carers in managing the funds.

### Carer Mentoring/Coaching

- Coaching is just one type of mentoring, and it needs to be clear what else (if anything) is included in “Carer Mentoring” other than the proposed coaching program.
- Carer Mentoring is beneficial to some carers i.e. managing behaviours of concern; however, it should not be seen as a cure-all for some caring situations where degenerative illnesses will have an inevitable conclusion as illness progresses.
- Within the mentoring program, the concept of a paid staff member who can walk alongside the carer, as determined by the carer, is essential. The previous CDRC Pilot had such a concept in place, the results of which confirmed that this type of mentoring assistance was welcomed by the carers and considered to be a genuine support service for those involved in the pilot.

### Respite Support

- In the paper it is acknowledged that *“as planned respite is funded under the main service systems targeted for care recipients (e.g. CHSP), carers face increasing difficulty in seeking this type of support”* (p.17). CSN SA is very concerned that the ongoing transition of carers’ funding into the NDIS and CHSP will further exacerbate this issue.
- CSN SA supports respite as one component of a multifaceted approach; however, respite needs to be available as a standalone service and not tied to other types of support.
- Discretionary funds should be available for emergency respite to assist carers in crisis situations such as hospitalisation of carers and carer burnout.
- To maintain the high satisfaction rates around respite amongst carers, it will be essential that the ease of access currently provided by Commonwealth Respite Centres is maintained in the new system.
- It is important to establish a clear definition of respite (what it is and isn’t) and its various types (i.e. planned and emergency respite). It is equally important to identify the respite outcomes for carers, for example improved carer health and wellbeing and sustainability of the care relationship.
- Uptake rates for respite could be improved by restoring promotional budgets and strengthening the focus of promotional materials on carers.

### **Counselling**

#### Design considerations

- Goal planning could be a useful part of the assessment, advisory or counselling stage; however, the nature of the goal planning would differ.
- Telephone and Skype counselling can be just as effective as face-to-face counselling. They can be easier to access in some situations and make it easier to match carer with counsellor.
- It is important to have counsellors and staff who are skilled, experienced and knowledgeable in working with specific cohorts of carers, for example young carers, CALD carers and ATSI carers.

### Counselling approach

- Many counselling approaches can be useful for carers, not just CBT. Counsellors need to be carer-centred, and therefore the determination of the counselling approach should be at their discretion.
- Some counselling approaches can be useful in group settings, i.e. Grief and Loss, Mindfulness, Acceptance Commitment Therapy.
- Non-therapeutic counselling approaches are effective for many carers, particularly carers from ATSI or CALD backgrounds.

### **Supporting All Carers**

- The absence of carer retreats in the paper is of concern. As opposed to respite, retreats offer carers an opportunity to get away from the caring environment for several days.
- Many carers need access to specialist support, either because they belong to a particular carer cohort (i.e. young carers) or because they are struggling with issues that can be attributed to their caring role (i.e. losing their job). Further consideration must be given of how these supports will be provided in the context of the new model, in particular:
  - culturally appropriate support for ATSI carers, including in remote settings
  - support for young carers in the family and school environment
  - support for carers transitioning from the caring role – detailed knowledge of other services in the local area is imperative here
  - special assistance for carers in rural and remote areas, i.e. transport and outreach
  - flexible support for working carers
  - support for carers wishing to rejoin the workforce after their caring role has ended.

### **Providing Integrated Support**

- It is agreed that the design of the new system will need to include relationships with other sectors, for example disability, aged care and health; however, in reverse it is important that a culture of caring is inherent to service delivery in these sectors.
- There needs to be clarity about the nature of the relationship between the new carer service and organisations that support the cared-for person; i.e. programmatic linkages would indeed be beneficial. However, encompassing carer funding within the disability or aged care systems would jeopardise carers' ability to access services in their own right.
- There are many instances where carers access services without the care recipient's knowledge, because such knowledge could compromise the care relationship. Hence it is vital that carer services are accessible in a confidential manner, free of care recipient involvement.
- Existing carer support organisations heavily draw on volunteers in delivering services to carers. Many of these volunteers are current or former carers. Their contribution needs to be acknowledged, and consideration must be given to their role in the new system.

### **ANNEX A – Carer Support Service Design Project: Design Progression**

- In progressing the design of the new model, there needs to be a shift from medical to community-based approaches. In their focus on peer support as well as referrals to other organisations that specialise in supporting the cared-for person, community-based approaches can be effective and inexpensive.

### **ANNEX E- Design Principles**

- Whilst it is important that the new system is based upon the best available evidence, it is essential to include not only academic but also empirical evidence. Empirical evidence relates to the experience and knowledge of carers and service providers who engage in the co-design process. This will ensure that the new system remains innovative, flexible, responsive and relevant.