Carer Support Network SA
LEADERS IN CARER SUPPORT

Carer Support Network SA Comment on:

Department of Social Services (2016). Designing an Integrated Carer Support Service: A draft model for the delivery of carer support services

THE CARER SUPPORT NETWORK SA

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

- Carers SA
- Carer Support
- Northern Carers Network
- SA Country Carers
- Carers & Disability Link

The Network operates 20 carer support centres across 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, carer's 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.

Comments Inclusive of Recommendations

GENERAL COMMENTS

The *Carer Recognition Act 2010* must underpin the new carer support service 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 person who is being cared for.
- 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.

STATEMENT OF NEED

Who are our carers?

The Network agrees with the inclusive definition of "carer" provided throughout the research– maintaining a focus on all carers, regardless of who they are or what amount of care they provide.

Drivers for Change

- The Network members fully support the National Disability Insurance Scheme (NDIS) and My Aged Care (MAC) as important steps towards improving freedom and choice for the person who is cared for. Likewise, it is paramount that the new carer support service system offers carers the freedom to access services free of constraints imposed by the package of the person who is being cared for.

A shift towards prevention

- Caring experiences are unique and across a broad range of age groups and caring roles. All caring journeys are different and 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 the Network'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

- The Network 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.

OBJECTIVES

- The Network agrees with objectives set out for the service system but is concerned by some of the mechanisms for achieving these, specifically the greater focus on online services and the implied reduction in funding for local infrastructure making it harder for carers to receive face to face to service and drop in to a physical location.
- The online focus will impact carers from regional and remote more than their metropolitan counterparts as often internet and mobile phone access is not possible. It is incredibly important that these areas have a local base and face to face services.
- The objectives and mechanisms make this proposed model a service provision model, rather than a support and capacity building model. A model focussing on service provision will lead to greater service dependency than under the current Carer Support Model in SA. An objective about empowering people is needed- supporting, equipping and skilling them to find their own way of supporting themselves and each other (communities looking after themselves).

STRUCTURE OF THE SERVICE

Block Funding vs Fee For Service Model

The Network is cautious about the mention of the regional hub's moving to a fee for service model as it believes this level will be the foundation that decides the level of quality for the provision of services to carers and should be block funded. A move to a fee for service model for the regional hubs could result in many carers being excluded or unable to access essential services as a result of a non-viable market. Market failure, as it is referred to in the NDIS, will be high in regional and remote settings in a fee for service model because of the reduced carer buying power and a lack of provider choice.

Recommendation

1. DSS ensure the regional hub function continues to be block funded

3 levels within the service structure

- There is concern that with the high level of focus on online services within the system
- The Network welcomes the reintroduction of face to face counselling at the local level.
- There is a concern, even though face to face services *can* occur for certain cohorts at a local level, many other carers will be excluded from receiving a service because of a lack of ability to access, or available access to technology caused by issues with; skills and knowledge, wealth, regional location and lack of suitable or available internet access.
- Concern is evident within the Network about the impact on the local carers and carer support service providers as a result of the majority of services being delivered and coordinated via the hub

Recommendation

1. The implications of the Regional Hub being both a provider and funder of services and the conflict of interest issues that this scenario would then present, must be explored;
2. The full impact of the regional hub development on local services must be explored to ensure a viable carer sector is in place and able to be sustained going forward.

Interaction with State Government Funded Services

- The Network is concerned about how this national service model would interact with State funded carer services.
- There is considerable concern as the South Australian Government has the development of this model on a watching brief as it will not want to replicate services provided by federal funding.

Recommendation

1. Consult with State and Territory Governments as to what impact the ICSS will have on carers, state and territory funding and local services.

Interaction with NDIS and My Aged Care (MAC)

- The Network agrees that the new model must interact with both the NDIS and MAC but is wary of non-carer specialist assessors and planners within these systems conducting needs identifications and assessments.
- There is concern that if a carer is assessed outside of the ICSS that it will result in the carer having to tell their story multiple times once they enter the ICSS which is contradictory to the purpose of an integrated model.
- It is paramount that the new carer support service system offers carers the freedom to access services independent of the package of the person who is cared for.
- There are many instances where carers access services without the knowledge of the person they care for, because such knowledge could compromise the care relationship. In some caring relationships, particularly, but not limited to those involving mental illness and dementia, the carer is not recognised or accepted in that role. This occurs even though the carer has a significant impact on the wellbeing of the person they care for. Hence it is vital that carers have access to confidential services, free of the involvement of the person who is being cared for.

Recommendation

1. That detailed needs identifications and assessments do not occur outside of the Integrated Carer Support Service System
2. That discussions occur with Regional Assessment Services and Local Area Coordinators with the aim of learning from their experience regarding interaction occurring between systems

Regional Hubs

- The Network would like to highlight that the responsibilities allocated to the regional hub in the draft model are significant and that the FTE associated with each hub should be commensurate to the workload.
- The Network is concerned with the lack of detail about the regional hubs in the draft model, in particular the points below.
    - The number of regional hubs that will be present across the country and particularly the number that would be located in South Australia.
    - The number of FTE that would staff the regional hubs
- The Network is concerned that carers at a local level will fall through the gaps if there is not sufficient local staffing structures in place. The model lends itself to a casualised local workforce and that because of cost considerations insufficient staffing levels and structure could heavily impact carers. A casualised workforce could make it extremely difficult to recruit and support the ongoing professional training and development of staff in regional and remote areas with workers wanting and deserving more stable employment.

Recommendations

1. That there be a minimum of four regional hubs in South Australia in the following areas; southern country, northern metropolitan, southern metropolitan and northern country
2. A fifth hub be provided for the APY Lands
3. That consultation occur with the sector, via the Subject Matter Expert Working Group, when deciding the number of hubs and their geographic reach and subsequently the determination of the level of FTE required for each hub
4. FTE requirements for current service delivery requirements are strongly taken into account when formulating FTE levels for hubs
5. Fund local infrastructure to ensure regional and remote carers and volunteers are not lost to the system

Needs Identification and Assessment

- The function of a 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.
- The Network is concerned by the medical language being used and want to reinforce that carers are not sick by default due to their caring role
- The Network believes there are a number of lessons that can be learnt from MAC, and soon the NDIS, as to how registration/assessment/needs identification can be integrated with local service provision. Suggestions include:
  - Ensuring that the central carer record system is simple and user friendly
  - Ensuring that the needs identification and assessment asks for the right information
  - Staff utilising the services have an appropriate level of knowledge about carers

Recommendation

1. That significant consultation with service providers occur when developing the needs identification and assessment.
2. Carers must also be included in this development phase as well as final testing

Service Mapping

- The Network would suggest using a multi-pronged approach to local service mapping which would include utilising
  - Local service provider networks
  - Employing local staff who know the region well
  - Undergo a significant local awareness raising campaign utilising various mediums

Recommendation

1. DSS give serious consideration to ensuring local knowledge and experience is a pre-requisite to the regional hub tender
2. Providing significant funding within the tender for the awareness and community linkages component of regional hub activity

Respite

The Network is concerned that planned respite services for carers are located within a number of government systems resulting in a fragmented and often non-existent delivery of planned respite to carers.

Recommendation

1. That respite dollars be taken out of both the Commonwealth Home Support Program and NDIS and placed in the ICSS

Outcome Measurement and the Delivery of Quality Services

- The Result based Accountability (RBA) framework is one way to address the required components within a quality service outcome.
- The Network wants to highlight that the use of outcome measurement should be only be for those services that have a medium to long term interaction with the carer. A once off contact should not require the measurement of an outcome.

TRANSITION TO THE NEW MODEL

- Assuming the model will be approved it is vital that the transition from old to new be gradual and disruption to carers is kept to a minimum.
- Consideration should be given to transitioning selected funding programs individually rather than all at once. This will assist in continuity of service for carers and assist in maintaining a viable carer support sector.

How could we establish this operating structure in SA?

- All members of the Network currently provide an integrated service within their geographic region and often work collaboratively across regions and with other organisations to ensure this occurs.
- The Networks existing regional and local delivery of support to carers already has the capacity to implement this model with no disruption to Carers, no additional cost, and the opportunity to research its effectiveness immediately.

Detailed Service Description Comments

THE DRAFT SERVICE MODEL

General

- 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.
- 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 the carer to connect with local service providers enabling entry to the assessment process.
- Emergency planning is available to all carers providing 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 person cared for) need to be considered in the planning process.
- 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.

Awareness and Community Linkages

- 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 are isolated due to the demand of the caring role and/or geographically located.
- Awareness raising in local communities through engagement and education is effective in reaching hidden carers, carers in rural and remote areas, and carers of Aboriginal and Torres Strait Islander and Culturally and Linguistically Diverse (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. While it is understood that the extent of this grant transition varies across regions, the impact on these carers is expected to increase along with the number of hidden young carers with reduced supports available to them.
- Hospitals could be targeted to reach carers in the early stages of the caring journey, because carers commonly accompany the person cared-for 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. Operators at the national level of the model 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 and Advice

- 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.

Education and training

The Network'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 Commonwealth Home Support Program (CHSP)
    - Life after and alongside caring

- 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 staff within the model 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.
- 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 Assessment and Planning

- The needs assessment and planning at the national level of the system should only capture high level registration (i.e. personal details, carer status and relevant information about cared-for person), then the carer should be guided to their regional hub or local provider for in-depth assessment. The provider will be in a position to offer an immediate benefit in exchange for the information given.
- 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.
- Staff doing this work need to be aware of available services and gaps in the local area, in order to understand and respond to the carer's circumstances.
- The 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.
- 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.
- Needs Assessment and Planning 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.
- 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.

Targeted Financial Support

- The Network support that this service has been suggested as a trial within the model.
- 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 coaching and mentoring

- 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 Consumer Directed Respite Care (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. It must be noted the CDRC program that was funded once the pilot ceased has continued with the same framework and resource focus and allocations.

Respite (emergency, short term and planned)

- The Network is very concerned about the ongoing transition of carers’ funding into the NDIS and CHSP and believe this will further exacerbate difficulties currently experienced by carers trying to access planned respite.
- The Network believe that planned respite is an essential component of early intervention for carers and should be included in the model.
- 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 of 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 making available 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 effective but as previously mentioned the Network is pleased that face to face counselling has reappeared, however limited, in the model.
- 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 Aboriginal and Torres Strait Islander carers.

Counselling approach

- The Network is pleased that there has been acknowledgment that therapeutic counselling will occur and that there has not been a focus on one particular approach. It is important to recognise that many counselling approaches can be useful for carers. 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 should still be considered and are effective for many carers, particularly carers from Aboriginal and Torres Strait Islander 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 acting facilitating the recharging of a persons batteries.
- 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 re-join the workforce after their caring role has ended.

Contact

David Militz

Interim CEO

Carers SA

08 8291 5600

david.militz@carers-sa.asn.au