



**FEEDBACK RECEIVED
DEPARTMENT OF SOCIAL SERVICES
DESIGNING THE NEW INTEGRATED CARER SUPPORT SERVICE**

CLOSING DATE: 16 JUNE 2016

**DIANNE BROWN
CONSUMER REPRESENTATIVE – MIDWEST**

Page 8 Caring is stressful

This is so true and yes all of these things do happen, It is much worse when there is only one person doing the caring.

Another challenge is when the person being cared for is middle aged, because all of the groups available for social support are mostly very elderly people, they have a very different mindset to a younger people. The worst thing is the feeling of helplessness, not being able to fix it being a parent you should be able to.

Page 9 Carers need support

There must be some way to get information out to carers more efficiently:-

Doctors could be more proactive.

Practice nurses could be another way to get the information to the people concerned. They are in the prime position to do this because they see patients on a regular basis and in a small town tend to know what is going on

Carers need to have a break away from their job as carer. This can be very difficult when the person who is being cared for refuses to go into respite.

From personal experience we spent thousands of dollars in employing a person to care for our middle aged Son.

We became aware of Commonwealth Respite through our local HACC co-ordinator and were able to access a carer to come to our home and care for our Son. It enabled us to have time away and I cannot emphasise the positive effect it had not only ourselves but also on our Son.

It is even more relevant for a lone carer and should be as often as possible.

Page16 The system is hard to navigate

If a person is unaware what is available then in many cases they don't know what they need or can use. There must be a way of getting this information out to people.

The Commonwealth Respite has morning teas for carers and do an excellent job of disseminating this information but the carer needs to know when the morning teas are on. May be that's where the practice nurse comes in.

The information I received has been just so valuable.

It would be helpful to cut down on the amount of forms one has to fill out. Maybe one standard form that can be filled out and then photocopied, would save a large amount of stress.

Page 46 Carers in Regional, Rural and Remote Settings

Not always ! Considerable travel / costs to maintain access to various services also if the carer is unable to drive or does not have a car this can add extra stress.

Page 48 Support when caring changes or ends

Carers put their life on hold. The care of their loved one becomes their life so there is not much time for anything else and then when that love ones dies there is nothing, it can be very difficult and they may need support for the next few months.

A visit or a phone call from agencies that have been involved with the carer would go a long way to help with the grief.

The in home respite gives a life to carers and is one of the most important rolls that the Commonwealth Carelink Centres can provide.

Lana I hope this is of some help if not I won't be offended.

Solange
KACS Respite Coordinator - Kimberley

Integrated Carer Support Services - having my say

In regards to extending to other services under a future model for the Carer support organisations who work with Aboriginal and Torres Strait Islander carers and Carers in regional, rural and remote settings I wish to have my say.

1. The existing model used at present in the Kimberley is providing core support for the carers, such as
 - a. To have regular visits by the same staff members builds trust, consistent and effective communication is something I strongly agree with from my eight years' experience in the field of Kimberley remote communities.
 - b. Building long term relationships has allowed the carers to be more open and able to ask for what they need. It's a stepping stone to them becoming more self-reliant and independent
 - c. Carers were encouraged to become members of Carers WA and when they received their newsletter I sensed a strong sense of pride. At the monthly carers group they brought their newsletter and chose the article they wanted to be read out and discussed (as some are challenged by literacy this activity was always requested)
2. Design Progression feedback
 - a. Face to face would definitely work and telephone interviews would not be a choice
 - b. Financial support for remote carers to be accompanied to attend the co-design workshops in the model

Lana Warren
Coordinator Midwest Commonwealth Respite and Carelink Centre

Hidden carers

- the loss of Carelink has reduced visibility and promotional activities. Local people, local services in the local community
- local relationships and partnerships with CALD groups, Aboriginal and Torres Strait Islander groups not supported by Carers Gateway/ WA LGA Carers Directory

Accessibility

- many services are recipient not carer focussed as discussed in the paper, the need for Carer advocacy at its greatest need currently
- local services a necessity, state run programs while do their best to visit, are not currently funded to provide the service needed to regional areas (let alone remote)
- NDIS carer organisations reporting less dedicated assistance and systems in place
- Low levels of uptake for respite services
 - Paper suggests lack of information and difficulty navigating the system
 - Further consideration of available respite in regional and remote areas incl. facility, staff and choice of appropriate options
 - Data may also be a little skewed, indirect respite achieved through successful support groups/wellness activities

Multi Component Supports

- Financial, respite and education
 - One without the other not effective
 - Complete package supports Carer wellbeing and reduces crises
 - Each carer individual, requiring varying levels of each component.

Young Carers

- Previous indicators that Young Carers might get lost in NDIS was concerning, recognition in this paper and future service delivery is paramount

Regional/Rural and Remote Carers

- In addition to comments made the following need consideration
 - Large Aboriginal communities
 - Isolation and stigma (culturally)
 - Travel and distance for providers / carers and recipients

Education

- Needs to be flexible to carers needs
 - Aboriginal specific
 - Disease specific eg. Dementia/parkinsons
 - Other carer needs depending on what is highlighted locally through networks and carer relationships
- Suggested 10 week program – not practical
 - Consider regional and remote
 - Travel to access or travel to provide
 - Reduced services so more time poor

Local vs National Level Support

- Significant need for local service delivery to continue to
 - Empower carers
 - Demonstrate value to carers
 - Assist those who require face to fact
 - Allow rapport and greater 'sharing' of required supports

- Clients visit office to clarify information found online or for assistance with online access
- Many hidden carers are supported / identified during a crisis situation, this could not be supported via a national service
- Many carers come to us seeking support to navigation through processes, phone contact and support does not support a stressed carer
 - This is evident just on a regional approach, the value of face to face – even if it is bi monthly, is seen consistently through service delivery
- A region that supports remote, regional and rural districts can easily demonstrate how 'different' each area is, including the support they require.
 - There needs to be significant acknowledgement of the differences between metro/regional/rural and remote
- People
- Lifestyle
- Culture
- Educational levels
- And socioeconomic status

Suzanne Millar
Manager Aged Care – WACHS Pilbara

The National CRCC and Subject Matter Expert (SME) Working Group are recognising the challenges with the development and implementation of the Integrated Carer Support Service for rural remote areas, CALD and ATSI communities. During the draft design I have been flagging that electronic access to services will not be suitable in rural remote WA and Kimberley also the DSS are taking it on board that one model will not be suitable for all areas. Face to Face and a flexible service provision requires to be included in the concept design.

The National Commonwealth Respite CareLink Centre working group will be submitting a national response to the Draft Integrated Carer Support Service Concept paper. This is some of the feedback that has been identified across the board:

1. Feedback from carers has been that this Concept paper has been difficult to understand, so much so that individual carers reported that they gave up and only read the first few pages. Carers commented that the documents used a great deal of jargon for example, terms such as 'carer-driven', 'drivers for reform'. Perhaps consideration could be given, in future consultations, to providing a plain statement executive summary.

Service providers and CRCC were able to understand and thought the paper brought together research and information. Also a summary of the issues & design challenges.

2. The working group endorses the guiding principles and the elements of the proposed support system which reflects the service mix required by carers.
- 3.1 National campaign to raise the awareness, resourcing existing carer support organisations or statewide networks that have established presence in their local communities. Identifying carer needs through health system, GPs, hospitals, NDIS or My Aged Care.
- 3.3 Carers to be able to access information, education, mentoring and peer support without going through an intake process. The Department of Social Services to

determine what type of data is required and consider a layer approach to data collection where intake is used to collect only basic demographic data.

- 3.4 Carer education can take a variety of forms and purposes. This is face to face, electronic, via phone or VC. Education to take into consideration to up skill young carers to improve those in transition from caring role to re-enter the workforce, for carers to be able to self- manage and education to enable carers to understand the condition of the care recipient. Link carers to National Accredited training. Education to be accessible to carers in remote communities and ensure the education is culturally appropriate to carers from ATSI or CALD communities.
- 3.12 CRCCs throughout Australia recognise that the contexts within which carer support is delivered are diverse. For these reasons a critical element of the proposed service design will be the flexibility built into its implementation and structure to respond to Australia's diversity.

The carer support needs of carers living in rural and remote communities are often impacted by the availability, quality and size of social capital and community infrastructure in the local community. Residential respite options, for example, may require transport across considerable distances to access. Twenty-four hour/7 day a week services, such as in home respite, may not exist.

Supporting carers within indigenous communities is often a complex process, requiring an investment in time to build trust between community members, indigenous agencies and carer support provider.

Trisha Power
Regional Aged Care Manager – WACHS South West

I think the idea of designing a new integrated carer support service is fabulous and the paper describes the need to bring all the various different carer programmes together and having an intake services where carers can go to facilitate carer support but this is not new is this not what Red Cross Carers do now?

The inclusion and description of all the services:

Education ,Peer support, multicomponent intervention (financial, carer mentoring and respite) is great and the model which combines financial , carer mentoring and respite seems like a good idea and its preventive thinking is fabulous. The recognition that the introduction of direct payment may have an impact on some carer workload and stress is reassuring and combining this with mentoring is sensible. The need for respite to be more flexible is also great.

Overall the paper poses a very good concept based on research and learnings from other countries, it raises a number of questions for considerations, what will be interesting is how this will develop on the ground (a very thought provoking service concept).

Hazel MacKenzie
Manager Aged & Subacute Care – WACHS Great Southern

I think this is a well-designed discussion paper overall and I think it provides a good framework for discussing the issues. If anything it is so comprehensive that it will be a real challenge to design a system than can incorporate all the issues in a way that the government is prepared to fund. The section on respite highlights the benefits of respite being planned, and it would be worth exploring the option of having a respite coordinator to

liaise between providers and carers to make sure people have equitable access to respite before they reach crisis point, as part of an overall carer support plan.

Ideally the person coordinating this in rural areas would be able to work across NGOs, for profit organisations and MPS. Offering some sort of funding premium to providers for offering emergency respite might be worth considering too, so that they are rewarded for being flexible enough to provide respite in a situation that isn't necessarily going to be revenue-positive for them or lead to permanent placement.