**Background**

The Ngaanyatjarra Pitjantjatjara Yankunytjatjara Women’s Council is an Aboriginal Corporation whose Board members are drawn from women in the Central Australian cross border region. NPYWC has been working with the families of this region since 1980.

People’s culture, lifestyles and circumstances in the remote communities of Central Australia are different from those in mainstream Australian society. People speak one or more Aboriginal languages as their first language and live in an orally based traditional culture environment. Rates of disability are extremely high and services are limited. Poverty is common in remote communities and many people are focussed on where their next meal is coming from and on finding a safe and warm place to sleep.

**Carer Support on the Lands**

In order to ensure that carer support is provided by people who understand the culture and living conditions of people in remote communities, it is imperative that support be provided by Aboriginal organisations with experience of this style of work. Although *the service pathways focus on accessing the ICSS services via phone and online service channels*, carers in remote communities expect workers to interact face to face rather than digitally. People from community need to build trusting relationships with workers before they are comfortable to discuss family matters with them.

Carers in remote communities need ongoing assistance with the negotiation of complex service provider systems and rules in order to maximise the quality of help they receive. They request and require practical help to assist with day to day problems.

At present, carers in remote communities are supported in a variety of ways. They receive goods (bedding, clothing and basic equipment), respite help (transport, accommodation and sometimes paid carer assistance) and transport through the Comonwealth Home Support Programme (CHSP). Older clients receive this through My Aged Care, and younger people with disabilities are supported under grandfathering arrangements through the CHSP. Older carers receive social support through the CHSP as well. As people with disabilities transition to the NDIS and older people take up more aged care packages, there will be less and less opportunity for people to be supported in the way they need and want. There will also be a lot of people with lower level disabilities who are unsupported, and whose carers will also receive little or no help.

**Carer Gateway**

Using a website as a carer gateway is inappropriate for supporting Anangu and Yarnangu (aboriginal people of the Central Australian cross-border region for a number of reasons:

* People speak English as a third or fourth language and levels of understanding vary. This is particularly so for older people, who make up a major part of the carer cohort. In a recent study[[1]](#footnote-1) 85% of carers interviewed were over 40 years of age in a population where 50 qualifies as “aged”.
* Anangu and Yarnangu culture is orally based. Communication is face to face. People need to develop a relationship with service providers before they feel comfortable to discuss matters of concern with them

Consequently, people have limited literacy both in their own languages and in English.

* People are not technologically literate. They do not have computers in their homes, and are not going to use a computer to find information or support. If they were to use computers, they would require extensive in person worker support. As well there is the issue that any computer available for access is likely to be in a public place such as a community office or clinic.
* Anangu and Yarnangu are extremely practical and prioritise immediate concerns. For many, this means finding the next meal or a safe place to sleep- for themselves and those they care for. Many carers in remote communities also experience chronic illness and disability themselves. In these circumstances they are not going to look at a complex website in a foreign language for support and education around caring for their family members.

**Services for carers**

*Carer Pathway Navigator*

*a process proposed to understand carer needs to determine the services that would best suit their situation and a personalised support plan.*

As mentioned above, for people in remote communities this service needs to be performed by an Aboriginal organisation with experience of working with people with disability and their carers in the NPY Lands of Central Australia. In addition, there needs to be ongoing support regularly reviewing any plan as carers in the Ngaanyatjarra Pitjantjatjara and Yankunytjatjara Lands require ongoing support to negotiate service providers and systems, to respond to changes in circumstances, and to ensure their needs are met, and they can continue to care for family members with a disability on the Lands.

*Digital Counselling*

*a service that can be delivered online and over the phone to assist carers to manage their own health to remain effective and avoid crisis events.*

Not useful to carers in remote communities for the reasons outlined above. In particular, people from communities do not use online or phone contact to talk to strangers about issues. Because people are focussed on the present, and on their immediate needs, they do not seek general advice looking at a longer term view. In addition, there are language and literacy barriers.

*In-Person Counselling*

*a service intended to be delivered through a series of counselling sessions in person with a professional counsel to support carers experiencing difficulties because of anxiety, stress, depression and low mood.*

Not useful to carers in remote communities for the reasons outlined above. In particular, people from communities do not use online or phone contact to talk to strangers about issues, and particularly personal matters. In addition, there are language and literacy barriers. Online or phone counsellors will not be aware of cultural and lifestyle norms in community and therefore would be unable to contribute effectively

If this counselling is delivered face to face by Regional Service delivery partners, to be effective, it would need to

* Involve building a longstanding relationship between the carer and the counsellor, who should therefore be aware of the situation in which the carer is living
* Contain a component looking at practical solutions to everyday problems such as lack of food and bedding

*Carer Online Resources*

*to provide information, tools, resources and access to a range of digital services to help carers in their caring role.*

The issues in this respect are covered in the discussion relating to the Carer Gateway. If resources could be accessed with the assistance of an advocate, they are unlikely to relate to the culture or lifestyle in remote communities.

*Carer Coaching Service*

*service, intended to assist carers to acquire skills and resilience needed in their role. The service will be delivered in two different formats:* ***facilitated******coaching*** *through face-to-face interaction with a coach, and* ***self-guided******coaching*** *with the help of online resources.*

Will not be used by remote community members for the reasons given under Carer Gateway above.

*Online peer support*

*an online forum available to assist carers to connect with their peers to provide emotional support.*

Will not be used by remote community members for the reasons given under Carer Gateway above. Again, if such a process was able to be mediated by an advocate or support worker, the mediator would need to have extensive experience in and a good understanding of remote communities and the situations and issues carers encounter in those communities.

*In-Person Peer Support*

*a facilitated forum intended to connect groups of carers locally.*

This is not a culturally appropriate way of looking for emotional support. People live in small (mostly less than 200 population) communities several hundred kilometres apart. They operate within extended family networks. Communities are and are concerned around privacy, so are not going to participate in a forum

*Carer-Directed Support*

*a directed approach to supporting carers through the provision of either one-off practical support or packages of practical support such as cleaning, planned respite, cooking, assistance with transport, etc.*

Carers in remote communities are in need of this type of support, and this would be the focus of their uptake of the proposed services. However, there are limited services available in communities, so the provision of services such as cleaning or assistance with transport would depend on the availability of service providers and their staffing levels.

Currently people frequently request and basic equipment including bedding and clothing from NPYWC as well as allied health aids such as shower chairs and walkers. Requests for food are also common. NPYWC is currently funded to provide food through the Commonwealth Emergency Relief Fund (ERF) which ran out in February for the current financial year. Limited funds are also available for emergency food for elderly people in the APY Lands through the CHSP. However, over 90 percent people interviewed for the *Walykumunu Nyinaratjaku* study referred to above wanted practical assistance such as bedding, meals, clothing, minor equipment and respite. People utilise respite services and insisted that this was of prime importance in enabling them to continue caring for their family members with disability

*Emergency Respite Care*

*intended to support carers experiencing an urgent, imminent and unplanned event that restricts their ability to provide care.*

The availability of emergency respite is crucial to maintain carers’ ability to look after people on the Lands. Emergency respite enables people to manage crisis situations including sudden illness, and conflicting caring needs (many people care for more than one person).

1. Walykumunu Nyinaratjaku: A Good Life “ NPYWC. In publication [↑](#footnote-ref-1)