Report:
Profiling capacity to support older people in remote communities to age in place.

Dr Heather Gibb
Dean Dempsey
Evaluation & Knowledge Impact
Northern Institute, Charles Darwin University
Contents

Report: Profiling capacity to support older people in remote communities to age in place. ........................................ 1
  Introduction ......................................................................................................................................................... 3
  Rationale for this study .................................................................................................................................... 3
  Methods ........................................................................................................................................................... 4
  Findings and discussion .................................................................................................................................... 4
  What are the achievements so far? .................................................................................................................... 5
  What are the current challenges to service delivery? ......................................................................................... 6
  What lessons can be learnt? ............................................................................................................................... 10
  Conclusion ...................................................................................................................................................... 11
  References ...................................................................................................................................................... 14
  Northern Institute ............................................................................................................................................. 16
Introduction

In recent years there has been acknowledgement by governments in Australia, of the challenge of supporting growing numbers of frail older people requiring social and personal support, living in remote communities (Department of Health and Ageing, 2011). Moreover, there is now greater recognition of people with a disability also requiring support services, who live in remote communities (Department of Human Services, 2016).

The stated aim of the Commonwealth government is to ‘ensure that all frail older Australians have timely access to appropriate care and support services as they age’ (Productivity Commission, 2011). In support of this aim, the Commonwealth government has developed a unique funding arrangement – the National Aboriginal and Torres Strait Islander Flexible Aged Care Program (NATSIFACP) - to allow remote Indigenous communities to care for their own people in ways that are appropriate and respectful of culture and customary lifestyle (Department of Health and Ageing, 2011). This system of funding is intended to be more flexible and easier to administer (AACQA, 2015).

A recent senate review of aged care services (Department of Health, 2017) has made two recommendations for aged care in remote places. The first is to extend the availability of the NATSIFACP funding to remote communities generally; the second is a review of the effectiveness of Consumer Directed Care (CDC) as a system for delivering services of support to people ageing in remote communities (Belardi, 2017). This follows on from the Productivity Commission’s report in 2011, which questioned the effectiveness of an age care funding system based on care packages.

Rationale for this study

Two key objectives underpin the Commonwealth government’s funding system for remote Indigenous communities. The first is to make the funding system more flexible and stable, to ensure that delivery of services in small communities is cost effective and sustainable. The second is to enable the funding to be used in the development of culturally appropriate support for older people, shaped by customary values and practices. The purpose of our investigation was to examine against these objectives, the practical reality of delivering support for ageing in remote Indigenous communities in central Australia. In short, our study questions were: In the light of the current funding arrangements, what forms of service delivery for older people ageing in remote communities, have been developed? What are some of the key achievements and challenges in supporting ageing in place in remote Indigenous communities?
Methods

Interviews were conducted with senior representatives of several kinds of organisations, associated with the provision of remote health and extended support services:

1. Local Government Association of the Northern Territory (LGANT)
2. Central Australian Remote Health Development Service (a Commonwealth funded registered training organisation (RTO))
3. Regional local government councils based in Alice Springs and Tennant Creek, where the councils had indicated that they provided aged care or ageing support services in remote regions, in central Australia. This included: MacDonnell Regional Council, Central Desert Regional Council, Barkly Regional Council.
4. Aboriginal Controlled Health Organisation: Western Desert Nganampa Waltyja Palyantjaku Tjutaku Aboriginal Corporation (WDNWPT). This organisation offered services targeting senior community members needing renal dialysis.

These interviews were not audio recorded; instead, the researcher took extensive notes during the interview. Questions were open ended, within a semi-structured interview format that allowed interviewees to direct the nature of the discussion. Each person used stories and anecdotes to illustrate their position on a range of topics to do with policy implementation and services delivery, as well as the capacity within remote / very remote (e.g. – outstations) communities to provide care to older people, or those with a disability.

Meeting notes were returned to interviewees along with a draft of the report findings. They were invited to validate the meeting notes and make any changes or additions they wished, in order to clarify or elaborate on any points. They were also invited to make suggestions about improvements to the presentation of findings in the report.

Findings and discussion

The discussion of findings is based around three questions:

1. What are the achievements so far?
2. What are the current challenges to service delivery?
3. What lessons can be learnt?
What are the achievements so far?

Provision of care has been enhanced by three Commonwealth programs specifically aimed at helping small remote Indigenous communities take control of services related to older people in their community:

1. The National Aboriginal and Torres Strait Islander Flexible Aged Care Program (NATSIFACP) ensures that funding is provided to communities in a flexible manner to meet their unique aged care needs. Associated with this funding system, the Australian Aged Care Quality Agency establishes contact with providers of remote services to ensure they are able to meet regulatory standards, set as a condition of funding by the Commonwealth government.

2. The Central Australian Remote Health Development Service (CARHDS) is funded to assist communities to take over control of the health of their community with on the job training in remote community settings.

3. Provision of extensive advice to providers of services to remote communities is available through the Remote Aboriginal and Torres Strait Islander Aged Care Service Development Assistance Panel (SDAP).

Through these programs, the Commonwealth has funded providers to work flexibly with communities, to assist them in taking control of their own aged care, while ensuring that there is the capacity for communities to receive flexible types of training and advice to help them achieve this end.

Regional local government councils and Aboriginal controlled organisations offer most of the direct services to older people in the remote central regions of Australia. Three communities – Kintore, Yuendumu and Wadeye – provide aged care services within their own, internally developed programs. There is also a not-for-profit provider of aged care to remote regions – Australian Regional and Remote Community Services (ARRCS – formerly known as Frontier Services or Uniting Care) – that is actively engaged with communities in remote central Australia.

This report summarises the major services that are commonly being offered by the organisations that were interviewed. It also highlights aspects of service delivery specific to each of the organisations.

Meals on Wheels

Generally, some form of Meals on Wheels is offered. Food is acquired in bulk and brought to the community. Meals are provided from Monday to Friday and include at least one meal freshly cooked onsite. Meals covered are generally breakfast and lunch.
hamper is provided for meals on the weekend. In most cases, local community members are involved in cooking and delivering meals. Some regional councils offer extra activities for older people. For example, Central Desert organise BBQs and bush trips.

Home Care

Personal care and housework support is offered in most remote communities and is provided, where possible, by local community members. Residential aged care facilities are offered in a few communities, such as Docker River and Mitijula. Both communities are managed by Australian Regional and Remote Community Services (ARRCS) with other community services provided by MacDonnell Regional Council. Generally, however, there are no residential care facilities in communities. Central Desert Regional Council will have an overnight respite centre at Ti-Tree functioning as at July 1st, 2018 with up to one week’s accommodation being available.

While it has not been considered possible so far for regional councils to offer level 4 or ‘high care’, they are working to find creative ways to offer this higher level of care within a remote community. Barkly Regional Council for example, is working with SDAP to find creative ways of working to provide in the communities, high care with Level 4 funding. Central Desert Regional Council are working with SDAP in capacity building associated with offering respite services that include overnight accommodation.

Local community staffing of services

A commonly accepted view is that aged care services are best delivered by appropriate people within the community. Central Desert has Indigenous coordinators who oversee the work of a small number of care workers. Staff housing is provided in only a few communities (for example, Yulara offers staff accommodation). In other cases, there is housing provided for external workers but not locally employed workers. As one council representative pointed out, given that ageing and disability services are delivered on Indigenous land, the services need to be culturally relevant. They are delivered most effectively therefore, through local people. Care needs to conform to culturally appropriate practices, not merely comply with mainstream expectations or requirements.

What are the current challenges to service delivery?

Respite and palliative care

Respite centres and palliative facilities in towns such as Tenant Creek and Alice Springs are generally full and therefore not accessible to older people from remote communities. What is needed are respite and palliative care services in remote communities. This would mean that as people’s need for support services progresses to this stage, they can remain close to family.
Maintenance and other ancillary responsibilities associated with providing care

In practice, a range of broader issues can challenge the successful provision of aged and disability care to remote communities. Examples include maintaining power and water utilities (recurrent power failures result in loss of expensive food stock), or the staffing of overnight respite services.

The costs of running ageing support services to remote communities is high in relation to purchasing and delivering food for provision of meals. Food is transported from cities via refrigerated transport over long distances to regional council depots. From here it is packed onto smaller refrigerated vans for delivery to remote communities, over long distances on partly sealed but mostly unsealed roads. Distances to transport food are between 250 to 700km from the depot. Further costs can result from power failures and the loss of food stock, as well as the occasional need to transfer resources to remote communities by air transport, when road transport is inaccessible.

Seasonal inaccessibility, due to roads flooding, requires extra creativity in these situations to continue to maintain service provision. Barkly Council described how they have had to seek food from local community stores, in order to keep providing meals for older people during road closures in the wet season. (October to April average rainfall is over 500mm)

The marketization of services in aged care has led to most not-for-profit or private providers withdrawing from servicing remote communities, on the basis of it not being cost effective. In these circumstances, regional local government councils with limited budgets, somehow have to step in to fill the breach.

While Commonwealth funding covers new infrastructure to build and extend services, the Northern Territory (NT) government is tasked with overseeing funding of ongoing operational and maintenance of services. Regional councils carry the cost of the extra maintenance work that is unique to working with remote communities and for which they receive no additional funding. The councils consider that they are not well understood or supported by territory or federal governments. Further to the point, communication between local government and the NT government lacks a formal platform. While the current NT government intended to form a local government ministry to enable the two tiers of government to work together more closely, this has not eventuated.

As a result, there is the sense within local government (including regional councils) that there is little understanding within higher levels of government, of these hidden servicing and maintenance costs. However, these responsibilities are fundamental to regional councils supporting local Indigenous communities to manage extended care associated
with ageing and disability. As a result, funding that could be invested in front line service delivery, is diverted to meeting these other costs.

Queries surfaced during interviews as to who has the responsibility to keep runways clear of wandering agricultural animals, with regard to the safe landing of service aircraft. Even though airport runways are not the responsibility of local government, regional councils are currently required to place a staff member on a 4-hour call-out, a cost borne by the regional councils.

There are also questions related to who maintains the community morgue. These are critical maintenance concerns that aged care providers elsewhere in the country never have to deal with. While funding strategies and policy have addressed the training of people in communities to work directly in aged care, attention to these other critical ancillary roles has been ignored. Within community life, these diverse responsibilities are considered to form vital links in a chain connected to health and ageing service delivery. The silos of Canberra fail to accommodate this reality; similarly, these issues fail to be grasped within the offices of the NT government.

**Home Care packages**

Councils providing aged care services operate with funding from mainstream aged care packages in addition to NATSIFACP funding. Service funding from the mainstream Commonwealth Home Support Program requires providers to work within the Consumer Directed Care (CDC) system. Under this system, once older people have been assessed individually and deemed eligible for care, council staff are required to construct individualised budgets and to contact these people receiving service under CDC, to discuss the services they receive. In some reported cases, people form a working relationship with care providers directly, and do not want this contact from someone external to their community. The logic of CDC is anathema to the way a community develops its own services locally, in support of older people and those living with disability. Several advocates for older people and service providers have recently spoken out in national forums about how CDC does not achieve a good fit with the lifestyle of small remote communities (Belardi, 2017; ACSA, 2017).

Mainstream aged care funding is associated with a heavy administrative load that puts a severe drain on the resource capacity of small regional councils. With limited capacity, they are required to administer complex bureaucratic processes to do with the governance and regulation of the service. As demonstrated by the NATSIFACP, a much simpler process would be effective in remote communities. Regional council staff sometimes have more than one role, and the administrative load they carry can result in other aspects of service delivery being neglected.
Care workforce

Provision of services to Indigenous communities is replete with workforce challenges. Hands on Indigenous service providers, especially women care workers, are squeezed between their employment in health care training and service delivery, and their more traditional roles and cultural responsibilities. Hence, there is a high turnover of people through these service positions. This adds to overall cost through the need to continuously recruit and train new staff members. Moreover, in the interim, fly-in and fly-out staff are needed to fill the gap.

Burnout of Non Indigenous staff due is high due to harsh and unique working environments in regional and remote communities. They are faced with inequities in accommodation, compared with workers in less remote communities. They are also confronted with the enormous task of delivering appropriate and effective services for aged care and disability under these conditions.
What lessons can be learnt?

Mainstream aged care funding models are generally poorly adapted to providing aged care and care for people with disabilities, in remote communities. It is considered better to ‘bulk’ fund remote communities on a service basis, not on an individual basis through packaged care.

There is a pervasive sense from all interviews that neither the Commonwealth nor Northern Territory Governments really understood remote communities and their needs. Remoteness encapsulates being isolated, seasonally cut off and inaccessible, sometimes uncontactable by usual telecommunications, and long to very long distances from the main centres of population. Nor do the Commonwealth and NT Governments appear to understand the ways in which regional councils are required to work with communities to sustain services that support ageing in place. The Commonwealth for example has not yet demonstrated an understanding of the importance of adopting an alternative funding system for regional councils compared with that for city based providers.

As aged care funding is now positioned within a market economy. The challenges in delivering sustainable care services to remote communities have intensified, leading to the withdrawal of not-for-profit or private providers from remote areas. Alternatively, there is general acknowledgement of the success of the NATSIFACP funding system, which is quarantined somewhat from the marketization of aged care. This latter system offers a viable model to regional councils that could result in sustainable ways of providing aged care in remote communities.

There appears to be a shared understanding among these regional councils, that community based approaches are needed in developing appropriate ageing and disability support services. It has been suggested that giving care to older people in the community and those living with a disability, needs to be compatible with other forms of community activity and cultural responsibility.

All activity needs to be part of community life. For example, care roles can be taught to the very young, integrating mainstream forms of care work with kinship responsibility and cultural practice. Communities should be involved in defining and evolving care approaches for older and disabled people that incorporates regard for community control and cultural comfort. If not, these activities will be considered anathema to the rest of the community life. Workers in the ‘aged care industry’ will continue to suffer the fallout from partitioned responsibilities of one’s caring job and caring for one’s family.

There are costs of running ageing support services to remote communities that are not incurred in city based services. These include costs associated with purchasing food for provision of meals in remote and very remote
communities. There is the requirement to provide safe, appropriate accommodation, not only for workers external to the community, but also for local workers who do shift work. These costs need to be formally budgeted in funding allocations to regional councils and Aboriginal controlled health organisations that offer care services to older people and those living with a disability.

Those people interviewed conveyed a shared impression that public servants and policy makers working within the National Disability Insurance Agency have very little understanding about the conditions and experience of people living with a disability, in a remote community. Sometimes the community is so remote and small it is considered to be an outstation that together with other outstations, form what is considered to be a community. The following describes the situation of the community of Utopia in the Barkly Council region: *Utopia in the Barkly region is made up of 16 outstations, some with distances from each other that take four and a half hours of travel by vehicle.*

Anecdotes were shared of inappropriate targeting of funding and delayed resourcing, all related to NDIS funding. This lack of understanding about circumstances in remote and very remote communities can only be resolved by these people spending more time in communities, assessing the nature and severity of the challenges people face in living with a disability in very remote places.

Finally, representatives from Barkly Regional Council shared a story which depicted how an older Indigenous person developed her own way of ‘ageing well’ on her land, which would not necessarily appeal to an elderly person in a mainstream city lifestyle. It is a vivid example of the differences between people in their preferred way of living, which endures through older age. Yet differences in preference can be made to work, when the older person’s wishes are respected. It is necessary to ensure the last period of their life is as meaningful as the life they led independently, in former years. It takes communicative effort as well as flexible ingenuity on the part of care workers, to ensure – at a minimum - the person is safe and well nourished, while being supported to pursue their lifestyle preferences. Other resources will then be activated through the person’s own resilience and sense of purpose.

**Conclusion**

This study has found that people attempting to age in remote communities require specific forms of basic personal care, in order to avoid having to leave or be sent elsewhere as they become frail. The most critical need is for a reliable respite care system, to assist carers and those being cared for over difficult periods, where the care relationship is interrupted. An associated need is for local palliative care so people can access care support to reach the end of their life, in places where they choose to live. A palliative care ‘hub’ in a remote community requires minimal cost in infrastructure, but would have appropriately prepared local palliative care staff. Given that these resources are similar to staffing requirements related to primary health care, aged and disability care support can be recognised as a form of primary health care. An example of the kind of partnership envisaged here involving NT and

Involvement includes the Department of Trade, Business and Innovation along with business partners, Aboriginal community organisations and local government. It also includes senior representation from Prime Minister and Cabinet and the Department of the Chief Minister.

Stories shared during these interviews indicated how, through creative ingenuity, resilience and resourcefulness, provider organisations, can deliver aged care and disability support in the most remote of settings. Service provision is achieved through versatility and lateral thinking. Examples were given of how unconventional ‘on the ground’ partnerships are forged and cooperation is negotiated between aged care providers and other organisations operating in the regions, out of the necessity of finding ways to sustain services.

All participants in the interviews expressed – either explicitly or implicitly – a frustration with the lack of understanding by the NT and Commonwealth Governments, of the realities facing remote communities attempting to care for older frail people or people living with disabilities. Moreover, their frustration was exacerbated by the lack of a forum for candid communication and regular, genuine consultation between governments, local community and Indigenous organisations, all of whom are directly involved in the delivery of services.

A recommendation from this study is that a formal partnership of ‘mutual benefit’ (Johansen, 2017) be established based on mutual concern and focus of achievement, between the three tiers of government. The focus of such a partnership would be the practical delivery of support for ageing in place and living with disability in one’s place of choice. Each of these three tiers of government have unique assets to bring to this partnership. Such an alliance goes beyond the hierarchical relationship (the master – slave relationship coined by Rogers, 2006) that has development of policy and funding directions occurring at a higher level (Commonwealth and Territory governments), separate from the ground level where policy is operationalised and service needs are identified and responded to (Regional local government councils).

There are a number of examples of case studies demonstrating excellence and leadership in remote aged care, yet their success is rarely showcased within the public domain. Once in the public domain, these ideas can be discussed and debated, then adapted and trialled in other sites, in a climate of cooperation in pursuing innovation and invention. Such a partnership between layers of government would need to mandate the value of cultural respect and community ownership, along with a commitment to the sharing of ideas respectfully, leading to continuous development and breakthrough on ways to support living through older age and disability, in remote regions of Australia.
Findings from this study also endorse the recommendation from other aged and disability advocate organisations as well as the Tune Review (Department of Health, 2017), to consider the NATSIFACP funding system as the most appropriate model for use across all remote communities in Australia.
References


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T: +61 8 8946 7468
F: +61 8 8946 7175
E: thenortherninstitute@cdu.edu.au
W: cdu.edu.au/northern-institute

CHARLES DARWIN UNIVERSITY
Darwin, Northern Territory 0909 Australia
CRICOS Provider No. 00300K (NT/VIC) | 03286A (NSW) | RTO Provider No. 0373