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Importance of Land, family and culture for a good life: Remote Aboriginal people with disability and carers

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Abstract

Worldwide health and social outcomes of Indigenous people are poorer than those of non-Indigenous. In Australia, the Indigenous population experience disability at more than twice the rate of the non-Indigenous population, and a quarter live in geographically remote areas. The challenges associated with accessing services and supports in remote communities can impact on a good life for Aboriginal people with disability. Interviews were conducted with Aboriginal people (Anangu) with disability and family carers from remote Central Australian communities and service workers. Thematic data analysis determined factors Anangu viewed as essential to living a good life: connection to their Lands, being with family and engaging in cultural activities. Workers' support for a good life involves "Proper Way" help and an understanding of Anangu culture. Three culturally relevant strengths-based concepts are important in supporting Anangu with disability to live a good life: being connected to the Lands and family, sharing together and working together.

KEYWORDS

Aboriginal, culture, disability, good life, remote

1 | INTRODUCTION

Indigenous peoples are found in nearly all regions of the world. The World Health Organization defines Indigenous peoples as those who inhabited a geographical area at the time when people of different cultures or ethnic origins arrived (Alderete 1999). The health and social outcomes of Indigenous peoples are generally poorer than those of their non-Indigenous counterparts (United Nations 2009; Schofield & Gilroy 2015; Anderson et al. 2016). Further, there are known relationships between social determinants, such as colonisation and racism, and the prevalence of mental illness and disability (Sherwood 2013; Schofield & Gilroy 2015; Avery & First Peoples Disability Network 2018; Kingsley et al., 2018).

In Australia, Aboriginal and Torres Strait Islander peoples are the Indigenous peoples and account for 2.8 per cent of the Australian population (Australian Bureau of Statistics 2016a) with around a quarter of the population living in remote or very remote communities[1] (Australian Institute of Health & Welfare 2014). It is known that Aboriginal people experience more ill health which results in higher levels of impairment and lower levels of quality of life (Biddle, Gray, et al. 2013; Biddle, Yap, et al. 2013). The Australian Bureau of Statistics (Australian Bureau of Statistics 2016b) defines disability as "a limitation, restriction or impairment, which has lasted, or is likely to last, for at least 6 months and restricts everyday activities." The term disability includes long-term physical, mental, intellectual or sensory impairments that impact on an individual's participation in his or her community (Digiacomo, Davidson, et al. 2013; Anderson et al. 2016). Identifying indigeneity and disability is contentious issue for data collection, and this is compounded in Indigenous communities where "disability" may have a different cultural interpretation and the term itself may not be used or accepted (Gilroy et al. 2016; Ravindran, Brentnall & Gilroy 2017). Estimates are, therefore, likely to understate the extent of disability among Aboriginal people.

Aboriginal and Torres Strait Islander people with disability are also less likely to access services than non-Aboriginal people (Digiacomo, Davidson, et al. 2013; Digiacomo, Delaney, et al. 2013; Avery & First Peoples Disability Network 2018). There are a number of reasons for this lack of engagement with disability and other services, many of which are related to the negative impacts of colonisation. These reasons include services not recognising and responding to cultural difference, stereotyping on the part of service providers, differences in understanding of the concept of disability, the distrust many Aboriginal people have of government and services based on historical and contemporary events (e.g. the removal of children), the lack of availability of services, a focus on meeting immediate basic needs such as housing and food, and the limited knowledge and awareness people may have of available services coupled with a lack of confidence and understanding of how to access services (Kendall & Marshall 2004; Digiacomo, Davidson, et al. 2013; Digiacomo, Delaney, et al. 2013; King, Brough & Knox 2014; Greenstein, Lowell & Thomas 2016b).

In rural and remote areas, these challenges are compounded by a lack of infrastructure, limited availability of service providers and related workforce challenges such as high staff turnover, as well as the significant additional costs associated with delivering goods and services in geographically isolated locations (Veitch et al. 2012; Dew et al. 2013). In spite of the high rate of disability, previous research found that the specific needs of Aboriginal people with disability living in remote and very remote communities are not well understood (Dew et al. 2012). Many Aboriginal people with disability living in rural and remote areas are faced with the dilemma of having to leave their Country and family to access disability services thus trading off "better access to services in a metropolitan location with the detrimental health and well-being consequences of leaving Country and community" (Avery & First Peoples Disability Network 2018: 93). The relationship between connection to Country and the health and well-being of Aboriginal people is now widely recognised in the literature (Woenne-Green et al. 1995; Burgess & Morrison 2007; Ganesharajah 2009; Kingsley et al. 2013). Numerous studies illustrate that a greater sense of identity, social cohesion and control is experienced by Aboriginal people who maintain a connection to Country (Senior et al. 2018), and significantly poorer mental and physical health for those disconnected from their Country.

Few researchers have sought to unpack the incongruence between Western models of disability service provision and the supports which Aboriginal people with disability find most valuable to live a good life. Furthermore, research related to Aboriginal people with disability has been critiqued for reinforcing academic neo-imperialism whereby non-Indigenous academics impose their own values and judgements on Aboriginal people with disability (Gilroy, Uttjek, et al. 2018). Few studies have explored the needs and experiences of Aboriginal people with disability from their perspective using decolonising community-controlled methodologies (Centre for Disability Research & Policy 2014; Greenstein, Lowell & Thomas 2016b; Avery & First Peoples Disability Network 2018). The research on disability in Aboriginal contexts, both in Australia and in other countries, has often focussed on identifying problems and barriers, emphasising poor mental and physical health, a range of social problems and difficulties accessing services (Hardie 2009; Bourke et al. 2013).

1.1 | Missing voices: Aboriginal people with disability

The traditional research and service provision discourses outlined above that have largely overlooked the voices of Aboriginal people means little is known about how Aboriginal people with disability living in remote Australia perceive a good life, or about their perceptions of the services and supports that they want and need to facilitate their well-being. An Audit of Disability Research in Australia published in 2014 and updated in 2018 found that research related to Aboriginal and Torres Strait Islander people with disability was lacking, particularly in relation to research involving Aboriginal community control, and research focused on informing policy (Centre for Disability Research & Policy 2014). The audit identified a gap in the literature on what Aboriginal people with disability in remote communities consider to be a good life so required supports and services can be provided if necessary, to assist them to achieve this. The absence of such information makes it impossible for governments and service providers to plan for and deliver context and culturally appropriate supports and services.

The lack of voices of Aboriginal people with disability in Australian research is in direct contrast to the principles of self-determination, choice and control which underpin the National Disability Insurance Scheme (NDIS). The NDIS seeks to operationalise Australia's obligations under the United Nation's Convention on the Rights of Persons with Disabilities (United Nations 2006). The NDIS represents a significant reform in response to historic high levels of unmet need for quality supports and services identified in the 2011 Productivity Commission Report (Productivity Commission 2011) into Australian disability care and support. The aim of the NDIS is to provide the "reasonable and necessary" supports required to enable people with permanent and significant disability to live an ordinary life, participate in their community and achieve their goals via individualised funding (Australian Government 2013).

Under the scheme, people with disability have choice and control over the supports and services they access. Concerns have been raised however about the appropriateness of an individualised model for Aboriginal people with disability, especially those living in remote communities where few services exist for them to purchase (Biddle et al., 2014; Gilroy et al. 2017). Many Aboriginal people hold a collectivist world view that is incompatible with the individualised NDIS approach (Stewart & Allan 2012). Within a collectivist worldview, peoples' identity is inextricably bound with extended family ties and culture and is related to social and emotional well-being (Stewart & Allan 2012; Avery & First Peoples Disability Network 2018; Senior et al. 2018). In recognition of the specific situation, and to guide implementation of the NDIS for Aboriginal people with disability and those living in remote locations, the NDIS governing body, the National Disability Insurance Agency (NDIA), developed an Aboriginal and Torres Strait Islander Engagement Strategy (National Disability Insurance Agency 2016a) and a Rural and Remote Strategy 2016–2019 (National Disability Insurance Agency 2016b). These two strategies aim to address the inequities experienced by people with a disability who live in remote and very remote communities through affirmative action approaches. In order to explain how best to support Aboriginal people with disability, the NDIA uses the term "proper way" which is described as:

> *. . .a colloquial phrase used to describe a way of doing business in Aboriginal and Torres Strait Islander communities in a manner which is compatible with the community's values and customs. It can be difficult to define in conventional terms, as in addition to observable behaviours, it encompasses an intangible, spiritual aspect.*
>
> *(National Disability Insurance Agency 2016a: 10)*

Criticisms have also been raised regarding the approach taken by the government in relation to supporting Aboriginal and Torres Strait Islander people with disability under the NDIS. A recent study published in this journal by Gordon et al. (2019) compared government documents relating to the NDIS and submissions from Aboriginal organisations regarding their perceptions of best practice under the NDIS and found that government policy did not recognise the exceptional status of Aboriginal people with disability. This tendency to view Aboriginal people as simply one of many groups who are vulnerable has potential to result in a failure to recognise their unique history and the impacts of colonisation, and to weaken attempts to implement Aboriginal specific solutions under the NDIS.

The aim of the study reported here was to describe a "good life" for Aboriginal[2] people with disability from remote communities in the Ngaanyatjarra Pitjantjatjara Yankunytjatjara (NPY) Lands of the Australian Central Desert region to inform the provision of disability supports and services. This paper reports on how A<u>n</u>angu with disability and their carers define a good life and how workers perceive their roles in supporting people to achieve this. Understanding this is important to the NDIS achieving its objectives for Aboriginal and Torres Strait Islander peoples.

2 | RESEARCH PROCESS

The project received ethics clearance from the Central Australian Human Research Ethics Committee, the Western Australia (WA) Aboriginal Health Ethics Committee and the Aboriginal Health Research Ethics Committee of South Australia (SA). This project used a decolonising community-controlled approach through which Indigenous people have control and governance over the research. This approach is consistent with ensuring Aboriginal and Torres Strait Islander people's voice is primary. A full description of the decolonising community-controlled research methodology applied to this project has been previously published (Gilroy, Dew, et al. 2018).

2.1 | The research setting

The NPY Lands consist of 26 very remote communities with three main languages, covering 350,000 km^2 of land in the cross-border region of the NT, WA and SA. Population statistics for these communities are imprecise; however, it is estimated that An̲angu represent over 80 per cent of the total NPY Lands' population (Australian Bureau of Statistics 2016a). All of the communities are classified as remote or very remote according to the ASGC (Department of Health & Aged Care 2001). Remote and very remote areas typically have extremely limited access to goods, services and opportunities for social-interaction (Department of Health & Aged Care 2001). An̲angu typically access services from Alice Springs, Kalgoorlie, Port Augusta and Perth (Australian Bureau of Statistics 2016a).

2.1.1 | Community control

In 1980, the NPY Women's Council (NPYWC) was formed by the women of the region to deliver advocacy and services to An̲angu. The NPYWC, based in Alice Springs, is governed by senior Aboriginal women from the Lands. The term "on the Lands" refers to people living in their home community. "Off the Lands" describes the movement of people away from their home community to larger centres. A specific NPYWC team, established in 1993, provides services to An̲angu who are aged and/or have a disability. Services include practical help with equipment, clothing, bedding, case management and coordination and referrals for financial advice, individual and systemic advocacy.

2.2 | Recruitment

Inclusion criteria for the project involved two participant groups:

1. An̲angu from the NPY Lands (living on or off the Lands), over 18 years of age who have a disability; or care for an adult with a disability.
2. Workers from services that support An̲angu with disability and family members either on or off the Lands.

2.2.1 | An̲angu recruitment

The NPYWC Directors and staff regularly spoke informally about the project in the communities prior to recruitment commencing. Using purposive sampling techniques (Palys 2008), a contracted interviewer chosen by NPYWC Directors made initial visits to communities during which she distributed project information flyers. The interviewer was a non-Aboriginal woman with an extensive history of working with people on the Lands, was known to participants and spoke the local languages. During community visits, she spoke to An̲angu whose names had been provided by the NPYWC Directors as having a disability or as carers for a person with disability. Once recruitment and interviews commenced, snowballing (Bryman 2001) occurred with the interviewer being approached by additional people interested in participating. To determine eligibility to participate, the definition of disability used for the roll-out of the NDIS was adopted which relates to a restriction or loss of function due to physical, sensory or cognitive impairment or mental illness. A verbal summary of the information sheet was read to participants who then provided written consent to participate.

2.2.2 | Worker recruitment

Workers were recruited by the researchers making contact with managers of known disability, health and community service provider organisations working with A<u>n</u>angu. Managers who approved the research within their setting distributed information about the project to their staff. Interested workers then provided written consent to participate.

2.3 | Data collection

A<u>n</u>angu and worker participants were invited to take part in either individual or group interviews according to their preference. Interviews with A<u>n</u>angu occurred both across the NPY Lands and off the Lands in larger centres and were conducted in the local language or English depending on participant preference. The interviews with A<u>n</u>angu on the Lands were conducted by the interviewer described above, and interviews with A<u>n</u>angu in regional centres were undertaken by research team members. Interviews with A<u>n</u>angu were conducted in a place chosen by the participant and tended to be short, lasting between 15 and 40 min. Interviews with workers were all conducted by research team members in English, took place in participants' workplaces, or via online videoconferencing, and typically lasted approximately 2 hr. All interviews were digitally recorded, transcribed and, where necessary, translated into English by a suitably qualified translator.

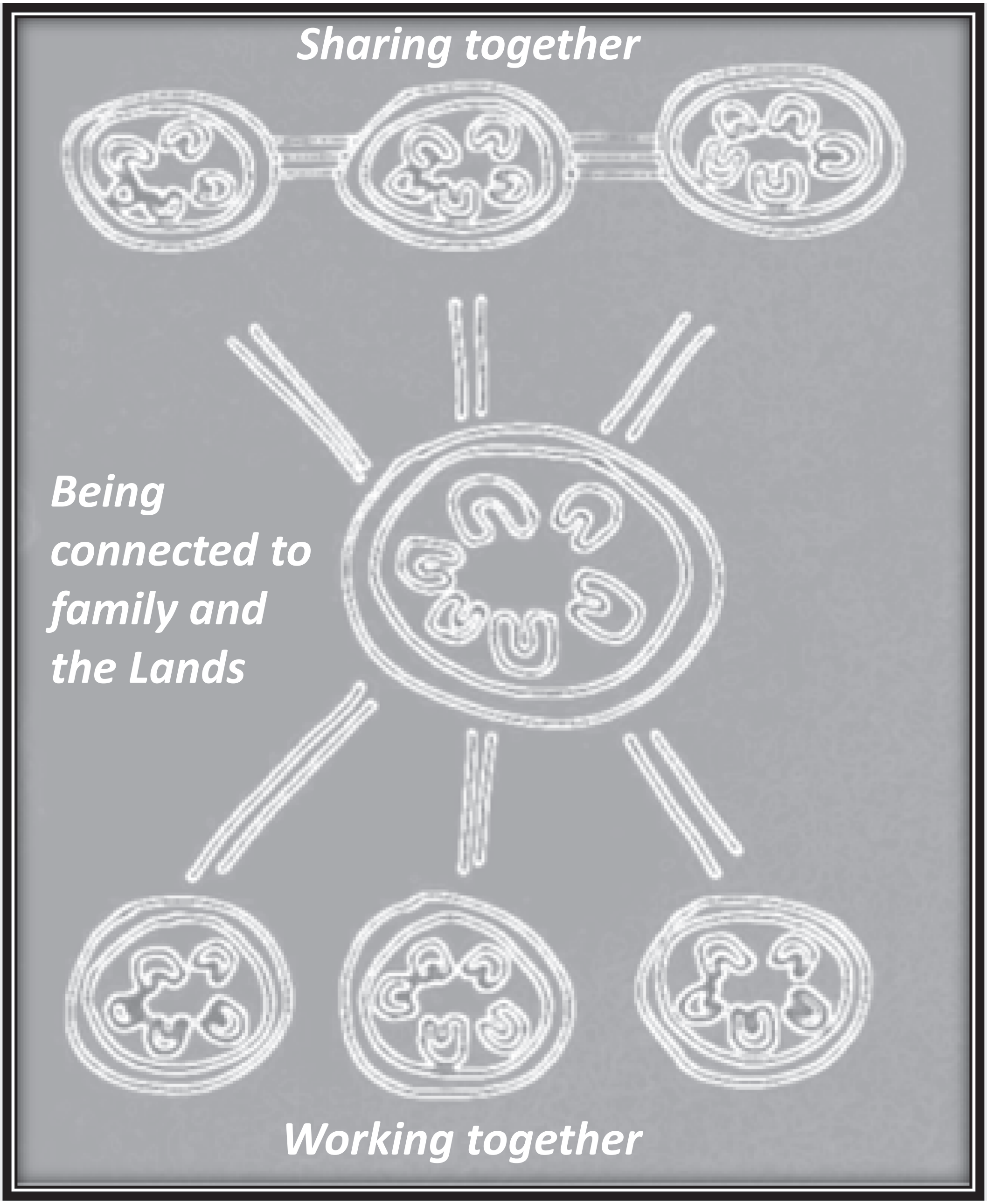
2.4 | Data analysis

Five research team members (JG, AD, RB, LR & HJ) with expertise in qualitative research methods formed a data analysis working group to conduct all the initial data analysis using an inductive thematic approach (Braun & Clarke 2012). Each transcript was imported into NVivo11^{TM} and coded independently by at least two members of the group. Notes were kept regarding coding decisions and where there was uncertainty about the meaning of a statement made by participants. A large number of descriptive codes were generated with regular meetings to review the codes, discuss concerns, eliminate repetition and ensure consistency and reflexivity. Through an iterative discussion process, the significance of each code and the interconnections between codes was decided, and themes were identified. The analysis group then presented this analysis to the full research team for further discussion.

A group of senior women from the Lands known as malpa were paid for their time and expertise and met four times to verify the research results and to provide an additional layer of cultural understanding. Some were trained in the basic elements of research by KT, a research team member experienced in working with A<u>n</u>angu. The malpa group used de-identified and consolidated research data to assist with interpretation of the findings, contextualisation of participants' words and phrases, and consideration of possible principles of support to enable A<u>n</u>angu with disability to live a good life. The group also assisted in developing culturally appropriate research dissemination strategies (e.g. Figure 1).

A service provider group, consisting of government and non-government agency representatives who support A<u>n</u>angu with a disability, was also established and met twice to assist with interpretation of de-identified and consolidated research results from a service provider perspective.

FIGURE 1 A good life for Anangu with disability. This is a visual representation of the research drawn by Aṉangu artist and member of the malpa working group



2.5 | Participants

A total of 109 participants included 34 adult Aṉangu with disability, 28 Aṉangu carers of adults with disability and 47 workers representing 16 organisations, of which four were Aboriginal-led. Seven adult Aṉangu with disability were living off the Lands when interviewed, with the remaining 27 on the Lands. The overwhelming majority (94 per cent) of carers were female while participants with disability were evenly divided between female (54 per cent) and male (46 per cent). Participants with disability ranged in age from 20 to 85 with a mean of 47 years. Carers of adults with disability ranged from 27 through to 83 with a mean age of 54. Diverse causes of impairment were described including acquired brain injury, physical, sensory, intellectual/developmental (Down syndrome, cerebral palsy, foetal alcohol spectrum disorder), psychological and chronic health conditions (renal failure, lung disease, Parkinson's disease).

3 | RESULTS

Two overarching themes explain what constitutes a good life for A<u>n</u>angu with disability and how they may be supported to achieve a good life. The first theme, *A<u>n</u>angu connection to the Lands*, is demonstrated by the sub-themes of *living on the Lands*, *being with family* and *being surrounded by culture*. The second theme, *Services connecting with A<u>n</u>angu*, identifies the preferred supports for a good life demonstrated by the sub-themes *desire for "*Proper Way*" help* through sharing together and working together; and *workers' understanding of A<u>n</u>angu culture*. The themes and sub-themes are interrelated and are presented using quotes. All participants with disability and carers are A<u>n</u>angu. The numbered descriptors after each quote demonstrate the range of participants' voices of both A<u>n</u>angu and workers, reflecting the unique focus of each group.

3.1 | A<u>n</u>angu connection to the lands

A<u>n</u>angu were clear that, to have a good life, they want to live on the Lands with family and engage in meaningful cultural and other activities, despite the limited availability of health care, education or employment opportunities in their remote geographic communities.

3.1.1 | Living on the lands

A<u>n</u>angu with disability and their carers described their connection to the Lands as a lifelong relationship with the country. One A<u>n</u>angu said

> *This is my home. My ngura (homeland), my own community. I was born here a long time ago, right here. (Person with disability 7)*

Living on the Lands allows A<u>n</u>angu to fulfil cultural duties which another A<u>n</u>angu described as

> *... looking out for my country. (Person with disability 34)*

A few carers stated that supporting people with disability on the Lands is essential to happiness and good mental health. For example, an A<u>n</u>angu carer said:

> *If [person] get upset, you know, I always take him a long way...with my car. I take him to an outstation, one hundred kilometres, and still take [person] to all the country. I always show him, that's how happy [is] for me, happy for him and other family too. (Carer 28)*

The important spiritual connection to the Lands was demonstrated by another A<u>n</u>angu who said:

> *I can, you know, stay out here and look at the Rock and the sun shining and smell the free air, whatever, you know, like, I am finally here. I can walk somewhere. I can go out bush.* *(Carer 25)*

For some A<u>n</u>angu with disability, living on the Lands in small, closely knit communities afforded them a level of inclusion that may not have been found in larger centres. A worker commented on this level of community acceptance:

> *…there was an older guy…he would have been 25, 30 with an acquired brain injury and it was just accepted in the community that he did certain things. You know, that he cruised around, stayed at different places and had little systems set up around the town for getting what he needed through the day.* *(Worker 1)*

Another worker reported:

> *I can think of a particular client that, despite her disability, is really engaged in community life…in the Arts Centre and all the programs there.* *(Worker 6)*

3.1.2 | Being with family

Connection to the Lands is intrinsically linked to being with family as described by a participant who summed up his connection to the Lands through his family as:

> *My mother and father were here, and my older brother …so, we've always been connected to [this place].* *(Person with disability 8)*

Another A<u>n</u>angu with disability who had lived away from the Lands demonstrated the impact of this separation by saying:

> *[I was] in a home [institution] once, and I was so sad … so when I came home here to my home and my family I was happy again.* *(Person with disability 16)*

A<u>n</u>angu relate to specific places on the Lands which are important to them and have links with their family, past and current. For example, an A<u>n</u>angu with disability who was living off the Lands said:

> *I want to go to [remote community] and stay in [there] forever.* *(Person with disability 2)*

For A<u>n</u>angu, being with immediate and extended family is an integral part of life on the Lands. Almost all A<u>n</u>angu with disability living on the Lands did so with family members. Meeting up with other family members was an anticipated daily event:

> *… sometimes I meet up with my family at the store.* *(Person with disability 12)*

Family supported and celebrated the achievements of the people for whom they were caring. For example, a mother talked about her disabled daughter cooking an egg:

> *… she gave it me and I said, "Hey, who made this?" And she said, "I did!"… She was confident! She been do it good way. She made it like a woman would!* *(Carer 16)*

Reflective of the collective, intergenerational nature of care for An̲angu, a participant with disability described how

> *…they [my family] put me in the bed and empty my [catheter] bag and just like that. I get put into the bed, and the children help me like that, to get into the bed.* *(Person with disability 7)*

And another said:

> *I'm staying in [remote community] because my mother's grave is here. She was a great painter, and I'm like my mother, following her way, painting all her dreaming stories.* *(Person with disability 3)*

3.1.3 | Being surrounded by culture

Another important facet to living a good life for An̲angu with disability involved being surrounded by culture and participating in culturally meaningful activities, such as taking part in ceremony, traditional singing and dancing (inma), hunting and going to

> *…collect all the ashes [for mixing with bush tobacco] from the bark, [and to] make bush medicine too.* *(Person with disability 20)*

Many communities have an arts centre where people gather to create art to sell providing both employment and social meeting places. A carer expressed a wish for the person with disability she cares for to be able to make art:

> *I work at [the arts centre]. She'd do it too, but for one thing, her hand. She can't do it because of the hand. But perhaps with a bit of help she might be able to.* *(Carer 18)*

A worker explained her understanding of the importance to An̲angu of engaging in cultural activities:

> *…it's all about being, following the law the right way, looking after sacred sites properly, mutual obligations between you and your family.* *(Worker 23)*

Many An̲angu described the importance of carrying out cultural activities on the Lands, for example hunting:

> *I go often to see my family on the weekends, and we go out hunting for meat, we go hunting turkey. We travel around, and then we come back home with the meat. We roast the meat*

> *and bring it back in the motorcar. We go out every Saturday or every Sunday. Like that, we go. That's what we do.* *(Person with disability 23)*

If disability restricts a person's ability to partake in these activities, the loss is keenly felt and impacts on the person having a good life, as described by the same worker quoted above:

> *If people don't have access [to the Lands], and if that's an access lost because of physical disability, if it's a loss because you're tied to that dialysis machine three times a week, if it's because you've got this big heart problem and the clinic says you're too unstable to be back out on country, then it's the loss of all that is significant for being Aṉangu.* *(Worker 23)*

Another worker spoke about ways services assist people with disability to take part in cultural activities:

> *…so it's about how can we get that person into an appropriate vehicle to go out to Country. It might be about you know how we can get that male to be with the men for whatever that [men's] business is.* *(Worker 44)*

3.2 Services connecting with Aṉangu

Aṉangu expressed clear ideas about what the NPYWC and the NDIA refer to as "Proper Way" help which involves workers listening to and responding to Aṉangu – a process of sharing and working together. The NPYWC enacts "Proper Way" help through the malparara co-worker model. As referred to earlier, NDIA documents espouse a commitment to this approach but there is limited evidence of this in practice. Workers identified issues with their understanding of Aṉangu culture.

3.2.1 Desire for "Proper Way" help

Aṉangu with disability and their carers identified a range of factors which indicated "Proper Way" help for a good life. "Proper Way" help involved workers taking the time to listen to Aṉangu and being consistent, kind and dependable. "Proper Way" help was essential in making sure the person with disability was able to live a good life on the Lands with family and community. The ability to form trusting relationships with consistent workers was described by this carer who talked about her mother needing someone:

> *… who is really kind to her and will take her out…that's when … she starts trusting that person. That's when it builds up and she will say, "Hey, you are a good person! I like you! I want to go out with you".* *(Carer 25)*

Aṉangu emphasised the need for workers to spend time with the families and people they had come to see:

> *We don't want the people to just come here see the person and … just go away again. We want someone to come here and talk good way and help. That's what we want, you know?*

> *Talk to my daughter. Tell us what to do . . . what they have to do for us when we tell them what we want. This is what she wants.* (Carer 13)

Indicating cultural differences in relation to time, another Aṉangu said:

> *If a person is, you know, busy, [the worker's] got to have patience. You know, wait around and come back later. Not coming around, "Oh come on! Come on! We gotta go!" No. Come and wait and come back later.* (Carer 3)

Aṉangu repeatedly indicated that to help "Proper Way" workers should be interested, kind and really listen and respond to the needs of people:

> *We want kind people to come. To take them around to places, like the creek or something, to cook kangaroo tail and potatoes, in the afternoon. Kind people to talk to them nice way. Friendly. Not just coming here and giving a talk and then go. Useless. That's useless. No good.* (Carer 5)

Many Aṉangu expressed frustration at repeatedly telling workers what they want but then not getting the help they ask for, as this carer explained:

> *One man [worker] has already written down my entire history…and because of that I had the understanding that there would be some help and things would improve, and I felt optimistic for a while. But nothing happened and my spirits crashed, and I got really depressed after that. I am worn out from being the sole carer for all these years, no aunties, no cousins. I am always recounting my story to piranpa (whitefellas) who come and ask me questions, asking if I need any help. But it never comes.* (Carer 2)

When workers are viewed as falling short of providing help "Proper Way," it is often due to cross-cultural misunderstanding as reflected by this Aṉangu quote:

> *And sometimes other people [workers] are not very nice, and I don't get on with them. They don't do anything helpful. We might ask for some canvas, but they don't give it right away. They say they have to wait for the boss to say so. They make us wait. They tell us we have to wait to get permission and only then will they give it.* (Carer 26)

The effective use of language and cultural interpreters are also essential in working "Proper Way" to ensure that workers understand what Aṉangu are asking for. Some Aboriginal organisations use a co-worker approach known as malparara which embodies the idea of "working together Proper Way" as a worker explained:

> *I do definitely think that our malparara [co-worker] system puts us at a huge advantage…when I first started even saying "I work with [Aboriginal organisation]" put us at a huge [advantage]. We are an Indigenous organisation that's governed by the women from these communities so it kind of comes with this automatic "We can trust this worker".*
> (Worker 12)

3.2.2 | Workers' understanding of Aṉangu culture

Reflecting major cultural differences, Aṉangu spoke about "Proper Way" to help, whereas workers reflected on the challenges of understanding Aṉangu culture. Illustrating this fundamental difference, a worker said:

> *I remember sitting down with this Aboriginal family and thinking … I don't know if this is actually worth a trip…because we're actually not in tune with each other at all.* *(Worker 7)*

Another worker expressed frustration at Aṉangu who she perceived as not being explicit about the help they need:

> *I would just like to be told. Like what do you want? We may not be able to do everything straightaway [but] where possible, we'll try and do something…what do you need to stay at home and to be able to do this on Country? I think there must be more to it than what…they tell us or feel comfortable telling us…[maybe] it's a shame thing or whether they just don't know themselves [or] are they afraid to ask for it…what am I doing that is culturally not okay and, is culturally okay? I'm certainly no expert. [I'm] happy to be told by family and community what's going to work for them.* *(Worker 28)*

Other participants, possibly with more experience of working with Aṉangu, described how, to truly understand the cultural context, workers must suspend their western perspectives of family, culture and disability and learn about Aṉangu family and community structures. For example, one senior manager with years of experience working in the area said:

> *We've got an environment that we're trying to deliver a service [within] these parameters of "first world" doctrine. So, funding requirements, policy requirements, legislative requirements etcetera but we're working in an environment where this community isn't mainstream…there's a whole set of other traditional and cultural parameters and structure to this community. So how do we engage? The first thing that I do is to make a connection with people…build a relationship with them first and then from there try and engage. But you can't engage until you've built the capacity to communicate. Your capacity to communicate comes down to that trust factor that you've built with them first.* *(Worker 44)*

Another experienced worker described:

> *I think [workers] need to be very adaptable. You can't be rigid…have a very flexible approach and a couple of backup plans for how the day's going to go. Also, be quite resourceful. Because we're remote, there's not always resources out here. A willingness to work with other agencies and to partner with and collaborate with other agencies and, I suppose most importantly, don't be racist.* *(Worker 10)*

The same worker commented on the need to employ and support Aboriginal workers:

> *We need that willingness to employ local people and invest resources in building their skills so they're able to do these jobs in the future.* *(Worker 10)*

Indicative of the need for more Aboriginal workers on the Lands, some workers perceived that Aṉangu were suspicious about the motivations, intentions and practices of the often short-stay non-Indigenous workforce as indicated in this worker's observation:

> *I think initially I was just seen as, "This will be another blow-in [short term worker]. When you gone?" So, there isn't a trust factor that [workers] are committed. The damage that we can potentially do to Indigenous communities thinking we're here to do the right thing but in turn it's very disempowering [for Aṉangu]. (Worker 5)*

Another worker acknowledged that cultural mistakes are inevitable and appreciated the generosity of Aṉangu to forgive these:

> *I'm a whitefella so for some people…there might be perhaps a little bit more leniency, a bit more slack allowed. These people are very generous. They know we white fellas [are] a bit ignorant and so we make mistakes all the time… I'm very impressed with how many accommodations they make and how many allowances they make for [white fellas]. Generally, when they get angry, when they get upset it's usually born out of frustration. They feel they haven't been heard or they make the mistake of thinking that the white fella misled them because they haven't understood from the other end. It's just really a display of their own frustration that they cannot cross these boundaries that they cannot get the white fellas to understand. One person said to me "the trouble with white fellas is they just don't listen."*
> *(Worker 15)*

Workers identified that to effectively support Aṉangu with disability and carers, workers need to adapt their professional knowledge to this new understanding, bring non-judgemental attitudes to their practice and learn how to *bend* the systems in which they work. One worker said:

> *…so it's about your ability to contextualize to a local community that fits back to the mainstream boxes that you have to report against. (Worker 44)*

Nonetheless, a cultural divide between mainstream services and Aṉangu culture was a recurring issue as articulated by another worker:

> *Bureaucracy, and the confidentiality, and the lack of understanding of the cultures here is a massive hurdle. [We need] more culturally appropriate services, more understanding about what the demands are. [Workers] don't know anything. [Workers] are like, "Why did you miss your dialysis?" [Aṉangu] need to be [in their community] for that sorry [business] (funeral). So, they're going to miss two dialysis [sessions], but then they go to the hospital, and they're just berated by nurses, "You're cheeky. You're naughty. You missed." (Worker 23)*

Reflecting the issue of different conceptions of time which was identified by Aṉangu and reported in the "Proper Way" sub-theme earlier, a worker explained cultural differences with reference to time:

> *My culture is more time sensitive whereas [for] Indigenous [people], communities and families [are] more important. The event is more important than what time. I know I've offended Indigenous people because I only had an hour that I delegated to be with them. I*

> *had to go after that. And that was like I didn't make time for them when they needed more time, because I wasn't focused on just being with them…I had an agenda outside of that.*
> *(Worker 14)*

The value of having Anangu act as cultural guides was explained by another worker:

> *She does a lot for me…on the basis of our personal friendship. She's not paid but she considers herself a malpa [Anangu co-worker] to me. She is very open and very generous, and she took to me very early on. I was very fortunate to meet her within my first year of being out here and she guided me culturally. She led me through the intricate maze of cultural do's and don'ts and she protected me from my own ignorance and gently made me aware of things that I needed to be aware of. I owe a great deal to her…we became extremely close.*
> *(Worker 15)*

Another worker described how "sharing together" to develop cultural understanding is a two-way street involving the recognition of rights and responsibilities on the part of Anangu and non-Aboriginal workers and policymakers:

> *So, it's about non-Indigenous getting culture education, it's about Indigenous getting culture education, just on the other end of the door. They're [Anangu] a very strong culture. But they don't have the knowledge of, how do you say, mainland [non-Indigenous] culture as well. It goes both ways. Like, they…need to be attached with their roots as well, but…they need to have…some kind of western culture as well.* *(Worker 9)*

4 | DISCUSSION

This study extends the previous work with Aboriginal people with disability living in remote areas of Australia by highlighting the integral connection Anangu have to their Lands. The study confirms the challenges of delivering disability services in these geographic areas (Veitch et al. 2012; Dew et al. 2013) and in particular reveals the loss of connection and well-being experienced by Anangu when they leave remote communities due to limited services and support (Avery & First Peoples Disability Network 2018; Senior et al. 2018). The study also supports earlier work which identified the lack of engagement in services by Aboriginal people with disability due to the negative impacts of colonisation making people reluctant to use agencies perceived as culturally inappropriate (Kendall & Marshall 2004; Digiacomo, Davidson, et al. 2013; Digiacomo, Delaney, et al. 2013; Greenstein, Lowell & Thomas 2016b). Additionally, this study highlights the different priorities of Anangu and workers and the lack of understanding on the part of some workers who do not appreciate the cultural importance for Anangu of building trusting relationships with workers. This study extends previous work to address a research gap identified by Avery and First Peoples Disability Network (2018), the audit of Australian Disability Research by the Centre for Disability Research and Policy (2014) and Greenstein, Lowell and Thomas (2016a, 2016b) by providing the perspectives of Anangu from remote communities in Central Australia about the support approaches they value to enable them to live a good life on the Lands.

The themes and sub-themes coalesce around three culturally relevant and accessible concepts illustrating the key aspects to supporting A<u>n</u>angu with disability to live a good life. These concepts are as follows: 1. being connected to the Lands and family; 2. sharing together; and 3. working together. To aid dissemination of the findings to A<u>n</u>angu, a member of the malpa group created a visual depiction (Figure 1) of this conceptualisation using a culturally appropriate arts-based format and language.

Despite recognition of the importance of the Lands, family and culture for A<u>n</u>angu, our study showed that the fundamental relationship between place and family is often poorly understood and overlooked in remote community service provision (Senior et al. 2018). Workers focus on providing what they think will be useful based on their professional knowledge and skills and on the scope of their service. These approaches may not really address the importance of the spiritual and cultural connection to the Lands and family or be perceived as working in "Proper Way" for A<u>n</u>angu (National Disability Insurance Agency 2016a).

Our data, particularly the first theme, highlighted the central position and fundamental importance of connection to the Lands for A<u>n</u>angu. This is demonstrated in the sub-themes of importance of living on the Lands, being with family and being surrounded by culture. Our work and that of others (Avery & First Peoples Disability Network 2018; Senior et al. 2018) indicates that Aboriginal people's well-being is severely affected whenever people from remote communities leave their Country/Lands and family because of the lack of disability or health services. For A<u>n</u>angu, the interconnections between family and culture *on* the Lands are fundamental to health, well-being and a good life. Historic familial, spiritual and cultural connections to place were evident in the descriptions by A<u>n</u>angu with disability and their carers of what they needed to live a good life. Indeed, physical disconnection from the Lands, for example for people utilising health or disability services in larger centres, was acknowledged by all participants as detrimental to psychosocial and physical health.

The concept of *sharing together* relates to A<u>n</u>angu with disability and their carers sharing knowledge and, over time, developing mutual understanding with workers of what constitutes a good life and how this can be supported in a culturally appropriate and responsive "Proper Way." This sharing of knowledge can help to bridge the cultural divide that was so often described by participants. Both workers and A<u>n</u>angu recognised the value of not only sharing together, but also *working together* to support a good life. One model of working and sharing together that was reported to be effective is the malparara model (Woods et al. 2000). Furthermore, working and sharing together require different agencies to cooperate and communicate with each other, to be accepting of and responsive to cultural differences, and for workers to be flexible and creative in their approach.

As depicted in Figure 1, the ability to *work together* to support A<u>n</u>angu with disability to maintain connection to family and the Lands requires *sharing together* where workers require multi-layered knowledge and supportive systems to deliver services that are meaningful, as well as useful, to A<u>n</u>angu with disability and carers. As reported in this study, this knowledge is often lacking particularly among workers new to working with A<u>n</u>angu from geographically remote communities. Systemic cultural awareness and safety training which refocuses organisations' and workers' attitudes is required. Ideally, this occurs alongside more grass-roots approaches such as malpa as mentors who, as described by one participant, can smooth the path for a new worker by modelling and teaching culturally appropriate behaviour. To support these approaches, flexible and innovative service funding models including within the NDIS will also need to be considered and the socioeconomic disadvantage experienced by A<u>n</u>angu will need to be addressed.

4.1 | Limitations

This study was conducted in one area of Australia with Aṉangu. The findings may not be applicable to other Aboriginal people in Australia or to Indigenous people in other parts of the world.

5 | CONCLUSION

This paper provides a strengths-based conceptualisation of what living a good life means for Aṉangu with disability from geographically remote Aboriginal communities. The paper focuses on consideration of mental and physical health and well-being alongside service access and delivery for people with disability living in these communities. This study demonstrated the fundamental importance to Aṉangu with disability and carers of receiving "Proper Way" help delivered on the Lands where people are embedded in their family and culture. This perspective provides policymakers and service providers with unequivocal evidence of the need to, in the NDIS era, develop bespoke, place-based and culturally specific options in conjunction with and for this group who face a unique set of challenges related to an isolated geographic location and the detrimental effects of colonisation.

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CONFLICTS OF INTEREST

The authors declare no conflict of interest.

NOTES

[1] The Australian Standard Geographical Classification (ASGC) system ranks remoteness according to size of a community, distance from population centres and access to services.

[2] In this study, we used the term Aboriginal reflecting the fact that most people living in the NPY Lands identify as Aboriginal rather than Torres Strait Islander. Aṉangu is the Pitjantjatjara and Yankunytjatjara, and Yarnangu is the Ngaanyatjarra word for "people." Aṉangu is used throughout this paper to encompass this meaning for all language groups of the NPY Lands and to distinguish Aboriginal people from the NPY Lands from non-indigenous people.

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