

Research and Practice in Intellectual and Developmental Disabilities

ISSN: (Print) (Online) Journal homepage: <https://www.tandfonline.com/loi/rpid20>

Working with Anangu (Aboriginal people) with disabilities from remote Central Australia. Navigating multiple expectations: “sandpaper and polyfilla”

Rebecca Barton, Angela Dew, Lee Ryall, Heather Jensen, Kerry Taylor, Michelle Lincoln, John Gilroy, Vicki Flood & Kim McRae

To cite this article: Rebecca Barton, Angela Dew, Lee Ryall, Heather Jensen, Kerry Taylor, Michelle Lincoln, John Gilroy, Vicki Flood & Kim McRae (2022) Working with Anangu (Aboriginal people) with disabilities from remote Central Australia. Navigating multiple expectations: “sandpaper and polyfilla”, Research and Practice in Intellectual and Developmental Disabilities, 9:2, 188-203, DOI: [10.1080/23297018.2021.2004381](https://doi.org/10.1080/23297018.2021.2004381)

To link to this article: <https://doi.org/10.1080/23297018.2021.2004381>



© 2021 The Author(s). Published by Informa UK Limited, trading as Taylor & Francis Group.



Published online: 12 Jan 2022.



Submit your article to this journal [↗](#)



Article views: 849



View related articles [↗](#)



View Crossmark data [↗](#)



Citing articles: 1 View citing articles [↗](#)



Working with Anangu (Aboriginal people) with disabilities from remote Central Australia. Navigating multiple expectations: “sandpaper and polyfilla”

Rebecca Barton^a , Angela Dew^b , Lee Ryall^c, Heather Jensen^d, Kerry Taylor^e, Michelle Lincoln^f , John Gilroy^a , Vicki Flood^{a,g} and Kim McRae^c

^aFaculty of Medicine and Health, School of Health Sciences, The University of Sydney, Sydney, Australia; ^bDisability and Inclusion, Faculty of Health, Deakin University, Geelong, Australia; ^cNgaanyatjarra Pitjantjatjara Yankunytjatjara Women’s Council, Alice Springs, Australia; ^dCentre for Remote Health, Flinders University, Alice Springs, Australia; ^eCollege of Medicine and Public Health, Flinders University, Australia; ^fFaculty of Health, University of Canberra, Canberra, Australia; ^gWestmead Hospital, Western Sydney Local Health District, Sydney, Australia

ABSTRACT

The need for cultural safety in the delivery of health and disability services to Aboriginal people is being increasingly recognised. Those delivering services in remote communities face the challenge of providing culturally safe and responsive services with limited resources and a host of geographical and infrastructure challenges. Earlier research identified the importance of sharing knowledge and working together to deliver services to Aboriginal people (Anangu) with disabilities in Central Australia, and workers are also bound by funding and policy guidelines as they deliver services. However, little is known about how workers navigate these different social and cultural expectations and accountabilities when working with Anangu. Interviews were conducted with 47 workers from 16 service provider agencies responsible for delivering services to Anangu with disabilities from the Ngaanyatjarra Pitjantjatjara Yankunytjatjara Lands. Workers invested significant time and energy in strategies to navigate these different contexts, much of which was not formally acknowledged or supported at a system level. Strategies employed included: fostering cultural knowledge and collaborative relationships, delivering creative and flexible services, and critical reflection on practice. Cultural safety and responsiveness of workers is important and warrants investment of time and effort. However, relying on workers to “soften the edges” and create an ostensible fit between bureaucracy and meeting the needs of Anangu with disabilities creates unrecognised burden for workers and fails to address the systemic beliefs, values and social and economic disadvantage that underpin an inadequate support system.

ARTICLE HISTORY

Accepted 6 November 2021

KEYWORDS

Aboriginal; disability; remote; cultural safety; policy; workforce

CONTACT Rebecca Barton rebecca.barton@sydney.edu.au

© 2021 The Author(s). Published by Informa UK Limited, trading as Taylor & Francis Group.

This is an Open Access article distributed under the terms of the Creative Commons Attribution-NonCommercial-NoDerivatives License (<http://creativecommons.org/licenses/by-nc-nd/4.0/>), which permits non-commercial re-use, distribution, and reproduction in any medium, provided the original work is properly cited, and is not altered, transformed, or built upon in any way.

Aboriginal and Torres Strait Islander people account for 3.3% of the Australian population, with approximately 20% (compared to 1.5% of the non-Indigenous population) living in remote or very remote areas (Australian Bureau of Statistics, 2018). Aboriginal and Torres Strait Islander people experience higher rates of impairment and associated poorer quality of life than the non-Indigenous population (Avery & First Peoples Disability Network, 2018; Biddle et al., 2014). However, reported difficulties in accurately collecting statistics around disability and Indigeneity (Avery & First Peoples Disability Network, 2018; Coleman et al., 2018) highlight a range of factors, including different cultural understandings of the term “disability”, as well as changes in scope and definitions across surveys (Gilroy et al., 2016; Ravindran et al., 2017). Notwithstanding these difficulties, the prevalence of intellectual disabilities among Aboriginal and Torres Strait Islander people has been estimated to be around 7% (compared with 1-2% of the non-Indigenous population) (Roy & Balaratnasingam, 2014). Aboriginal and Torres Strait Islander people also report a high level of unmet need in relation to service access (Biddle et al., 2014). Barriers to service access are compounded for people in remote and very remote areas, where services are limited. The transient, disconnected nature of services that are available, workforce shortages and turnover, and socioeconomic disadvantage has also contributed to limited use of disability services (Dew et al., 2020; Trounson et al., 2020). For many Aboriginal people, disability is compounded by issues related to education, housing, justice, and chronic illness, which may be prioritised depending on immediate need (Stopher & D’Antoine, 2009).

Culturally safe service delivery

Growing recognition of the harmful impact of colonisation on Aboriginal people has resulted in organisations embedding cultural safety and cultural responsiveness in contemporary practice (Indigenous Allied Health Australia, 2019; Mackean et al., 2020; Taylor & Thompson Guerin, 2019). Cultural safety, a concept developed in nursing in Aotearoa New Zealand, focuses on recognising and addressing the negative impact of colonisation and power imbalances on health, socioeconomic position, and wellbeing (Mackean et al., 2020; McEldowney & Connor, 2011). Cultural safety requires service providers to reflect on their own values and beliefs, be aware of the ways culture and power influences interactions, and act in ways that respect the culture of others and allows them to feel safe. Several authors note that to be effectively implemented, cultural safety should be embedded at policy, institutional, and individual levels taking into account the specific service delivery context (Mackean et al., 2020; Taylor & Thompson Guerin, 2019). McEldowney and Connor (2011) proposed a new model for understanding cultural safety within nursing as an “ethic of care” involving a constant, iterative process of reflective action, accounting for the varying and ever-changing contextual influences on the healthcare encounter. These influences include the values and context of the practitioner and of the service user, and broader contextual factors such as institutional, professional, and policy influences. In reality, the navigation of these different contexts, with often competing expectations and demands, is problematic. A

scoping review by van der Tier et al. (2021) explored how social workers managed accountabilities to, and expectations of, different stakeholders in their daily practice. They found that at times social workers experienced difficulties implementing accountability mechanisms and used “street-level strategies to work-around” (van der Tier et al., 2021, p. 464) the difficulties in balancing expectations at the administrative and organisation level with the profession’s more relational values.

To support the delivery of culturally safe services to Aboriginal and Torres Strait Islander people, Indigenous Allied Health Australia (IAHA, 2019) developed a cultural responsiveness framework that encompasses practices to enable culturally safe care. This strengths-based, collaborative, and negotiated approach involves knowledge (knowing), self-knowledge and behaviour (being), and action (doing) (IAHA, 2019). It recognises the importance of culture to people’s identity and emphasises the need to work together to determine an individual’s perceptions of culturally safe care. The framework identified six capabilities: respect for centrality of cultures, self-awareness, proactivity, inclusive engagement, leadership, and responsibility, and accountability requiring development at individual and organisation levels (IAHA, 2019).

“Proper-way” help for Anangu with disabilities from the Ngaanyatjarra Pitjantjatjara Yankunytjatjara Lands

Cultural safety frameworks highlight the importance of understanding service users’ perspectives of culturally safe support. For services delivered to people from the Ngaanyatjarra Pitjantjatjara Yankunytjatjara Lands (hereafter referred to as ‘the Lands’, in keeping with local terminology), any exploration of culturally safe practice must therefore involve Anangu (the Pitjantjatjara and Yankunytjatjara word for “people”, which is used in this article to distinguish Aboriginal people from the Lands from non-Indigenous people). Anangu do not have a term for “disability”, rather describing an impairment according to the component of the body affected (Ariotti, 1999). For example, the term often used to describe conditions affecting a person’s thinking, such as an intellectual disability, acquired brain injury, or mental ill health is *kata kura* (which literally translates as “head bad”). Impairments are seen as a normal part of human diversity and kinship system relationships, obligations, and supports apply to all Anangu regardless of their impairment status (Ariotti, 1999).

We have previously presented the perspectives of Anangu with disabilities and their carers on what it means to live a good life with culturally appropriate, or “proper way”, support (Dew et al., 2020). This work identified that Anangu with disabilities wanted to live on the Lands, connected to family and culture. It also identified the importance of Anangu working together, and sharing knowledge collaboratively, with service providers. However, Anangu as well as workers noted significant differences in their perspectives indicating the way services operated did not fit well with Anangu beliefs and practices. While many (e.g., Dew et al., 2020; Indigenous Allied Health Australia, 2019; Trounson et al., 2020) have identified differences in beliefs and practices between Indigenous and non-Indigenous individuals and organisations, and the importance of service providers working to reduce inequities and practice in a culturally safe way, little is known about how workers navigate these different expectations and

accountabilities in remote settings. This understanding is critically important if we are to: identify what work is being done to engage in culturally responsive and safe practice, unpack some of the challenges to engaging in this work, and support workers to deliver more culturally respectful services to Anangu with intellectual and other disabilities.

Research context

The Ngaanyatjarra Pitjantjatjara Yankunytjatjara Women's Council was established in 1980 by senior Anangu women to deliver a range of services and advocacy. The Lands cover 350,000 km² of semi-arid desert in the cross-border region of Western Australia, South Australia, and the Northern Territory, with 26 very remote communities where three main languages are spoken by Anangu who represent 80% of the population. The climate is harsh, and communities, ranging from 100-600 people, are geographically isolated, generally 50 to 150 kilometres apart separated by dirt roads often closed due to rain or for cultural reasons. All have limited access to goods and services; typically, a single store, primary health clinic, school, and community office. Regional service centres - Alice Springs (NT), Kalgoorlie (WA), and Port Augusta (SA) - are between 300 and 1500 kilometres from communities. Straddling three state/territories generates additional challenges with different funding arrangements, policies, and services and limited cross-agency, inter-state communication and collaboration. A major and long-standing service provider in the Lands, the Ngaanyatjarra Pitjantjatjara Yankunytjatjara Women's Council initiated this study to identify what constitutes, and how Anangu with disabilities could be supported to live, a good life (Dew et al., 2020). The aim of this article was to identify workers' strategies to navigate differing expectations, and provide culturally safe and respectful services to Anangu with disabilities and to their carers.

Method

This research received ethical approval from the Central Australian Human Research Ethics Committee (HREC-15-329 and HREC-16-374), the Aboriginal Health Research Ethics Committee of South Australia (SA) (Ref 04-15-625 and Ref 04-16-655), and the Western Australia (WA) Aboriginal Health Ethics Committee (Ref 712 and 713). A decolonising, Aboriginal community-controlled approach was adopted using an Indigenous methodological framework whereby Indigenous cultural values were combined with traditional academic methods, with oversight and direction by the Ngaanyatjarra Pitjantjatjara Yankunytjatjara Women's Council Board. The detailed project methodology is outlined in a previous publication (Gilroy et al., 2018). As this article reports on workers' data, hereafter "participants" is used exclusively to describe workers unless otherwise specified.

Sample and recruitment

Purposive sampling was used to recruit workers employed by government and non-government health and disability service providers, social support organisations, and aged care providers supporting Anangu with disabilities and their family members, either on or off the Lands. The National Disability Insurance Scheme (NDIS) definition of disability was used with a focus on loss of function and need for support. Managers of service provider organisations known to be working with Anangu with disabilities were asked to forward research information to their staff, who then provided written consent to participate.

Forty-seven service workers participated, employed across 16 organisations including health professionals (e.g., physiotherapists, nurses, occupational therapists; $n = 22$), disability service workers ($n = 19$), social workers ($n = 4$) and other government workers ($n = 2$). Participating organisations provided residential support, financial counselling, respite, meals, employment, school support, primary health care and guardianship. Given the generalist nature of remote service provision, organisations provided services to Anangu with a range of disabilities including intellectual disabilities, acquired brain injury, and various physical, sensory and psychosocial disabilities. The most common disabilities among Anangu who participated in the broader study were intellectual disabilities and acquired brain injury with over half of the Anangu participants identifying these impairments. Of the 16 organisations, nine delivered services to a high proportion of Anangu with intellectual disabilities or acquired brain injury.

Participants were employed by organisations with a range of service delivery models. Some were located in regional/metropolitan centres with workers providing outreach services to Anangu on the Lands. The frequency of visits varied from as frequent as every 6-8 weeks or as infrequent as once or twice a year. Other services were located in larger communities on the Lands. Some services did not operate on the Lands meaning Anangu had to travel or relocate temporarily or permanently to larger centres to access these services.

Data collection

Participants were interviewed by research team members individually ($n = 16$) or in small co-worker groups ($n = 10$) in their workplaces or other locations including via phone or videoconferencing ($n = 5$). Interviews, which were audio-recorded and transcribed, were conducted in English, lasted 60-120 minutes, and focused on participants' experiences and perceptions of supporting Anangu with disabilities to live a good life.

Data analysis

A data analysis group included five research team members with qualitative research experience including two who worked with Anangu over many years and one who is Aboriginal. Using NVivo11 to support inductive thematic data analysis (Braun & Clarke, 2012), Anangu and worker interview transcripts were initially analysed separately to ensure each perspective was considered independently. One member analysed

all transcripts with each transcript coded by at least two other members (Nowell et al., 2017). Notes recorded analytic decisions and codes were reviewed at regular meetings where, to facilitate reflexivity and reliability, areas of uncertainty or disagreement were discussed and resolved (Nowell et al., 2017). Through this iterative process the group identified the significance of, and relationships between, codes and nominated emerging themes. These preliminary themes were discussed with the full research team to reach final consensus. To further facilitate reflexivity and support the analysis and interpretation of results, de-identified data and preliminary themes were twice presented to a service provider reference group for verification and clarification of data interpretation and emerging themes. This group consisted of representatives from multiple agencies providing support to Anangu with disabilities.

Results

Many participants were acutely aware of the necessity and challenges of working across multiple different cultural, social and economic contexts. Workers described using a range of strategies, and the often-unacknowledged work that was required, to navigate and bridge these multiple expectations to support better outcomes for Anangu. One worker explained:

What we try to be is like polyfilla ... or the sandpaper. There's a system with really hard edges that cut people up all the time, and we're trying to sandpaper off the edges to make it softer for people, so that the systems can fit people more. Or that there's this great big hole, and there's the system that fills part of the hole, but there's all these gaps around the edges, and we want to be that expanding foam ... But it's incredibly difficult and it's incredibly stressful ... We're playing in both those worlds ... doing the very best that we can for people with really limited resources. (P1)¹

Two themes emerged: (i) key accountabilities workers navigate including: requirements of employing organisations, workers' personal and professional values and history, and the needs and perspectives of Anangu., and (ii) multiple navigation strategies workers use to balance these expectations.

Theme 1: key accountabilities and expectations

Requirements of employing organisations and funding bodies

A key accountability consideration for workers was their need to work within the bureaucratic, administrative, funding and policy drivers of their employers. Workers recognised these systems and policies were developed based on Western, metropolitan-centric values and assumptions and often did not match the needs and desires of Anangu or account for the geographic, social and cultural context.

We've got an environment that we're trying to deliver a service that has to meet 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? (P2)

Identified issues included constraints on the types of funded supports and associated reporting requirements, service eligibility, confusing systems and paperwork processes. The rigid, individual- and diagnosis focused policies around service provision and access were not congruent with Anangu priorities or understanding of disabilities. Other remote context organisational challenges included work health and safety policies, concern about duty of care and some organisations' focus on wellbeing from a medical perspective, and service designs where, for example, frequency of visits did not align with support needs and cultural ways of doing things. All these challenges were amplified by the lack of sufficient funding and resources to provide for basic needs, as well as meaningful disability supports, in a remote geographic context. Despite these constraints, requirements and cultural mismatch, a small number of workers identified their organisation as a facilitator. For example, as one explained:

I think programs like [Aboriginal Community Controlled Organisation's program] are really useful because we ... are in a remote community we're allowed, we're given extra allowances and how our service can operate and that means we can really truly ... listen to what individuals and families want to do and adapt our services to meet their needs. (P3)

Workers' personal and professional values and history

Workers also balanced their personal and professional values, experience and training. Workers were aware of and tried not to privilege their own cultural values, describing for example, the need for flexible time management:

You don't work out here with a diary and say I'm going to work at such and such a place for such and such a person at 12 o'clock and then at 2 o'clock I'm going to such and such a person and then, you can't keep the little diary like you can when you work in a white fella town ... people [here] don't work like that and they won't work with you like that. (P4)

Professional influences, such as concern for duty of care and client safety, as well as ideas relating to the status and expertise of health professionals were also factors to be navigated. One participant's comment highlighted this attitude of professional authority and expertise (which in this case, was not approached with a cultural safety lens): "You can't really communicate with Anangu at times, because even though you know what the right thing is for your clients, they don't ... understand that, they don't see that" (P5).

Some workers reflected on the inappropriateness of their past professional experiences in metropolitan areas in the context of providing services to Anangu. This included their approaches to developing rapport with Anangu with disabilities, the assessments and supports they offered, and their assumptions about and understanding of the factors impacting on a person's life in the context of remote service delivery. Issues such as limited income, lack of access to basic goods and services, government-mandated management of funds, family violence, historically different attitudes and understandings of money, and cultural obligations to share resources, all contributed to the complexity navigated by workers and often were not part of their prior practice. Many workers, although acutely aware of the numerous challenges they faced in their work, identified a range of personal values that sustained them in their roles. These included

a desire to learn from and make a difference in the lives of Anangu, to address injustice and inequality, and to be able to live and work in a beautiful natural environment. One worker explained:

The thing that sustains me or makes me want to stay here is that, you do see little bits of change and I think ... also knowing that there's so little available and if you're doing a little ... so even a millimetre then ... I can still feel like I'm doing a bit more than nothing. (P6)

Perspectives and needs of Anangu

Workers generally demonstrated an awareness of the perspectives, values and needs of Anangu and aimed to provide services in a respectful way. Participants identified the primary importance for Anangu of retaining their connection to the Lands and their culture and acknowledged and respected the value Anangu placed on relationships and the responsibilities associated with these. Additionally, as described by one worker, Anangu had different ways of understanding and valuing time, communicating, and respectful engagement.

There's no right or wrong culture, so understanding someone else's culture it can be humbling. It shows you there's other ways to live. Just simple things like different ideas of time and different uh, non-verbal communication means different things for different people. So, looking at you in the eyes can be respectful or looking away could be respectful ... (P7)

It is important to note that although most workers acknowledged and respected cultural differences, not all had a shared understanding of cultural safety or enacted its principles.

Theme 2: multiple navigation strategies

The types of interrelated strategies and often unacknowledged work used to navigate multiple accountabilities included: fostering cultural knowledge and collaborative relationships; delivering flexible and creative services; and engaging in critical reflection.

Fostering cultural knowledge and collaborative relationships

Participants indicated awareness of differences in cultural beliefs and values impacting on their work with Anangu. Workers sought to increase their cultural knowledge and understanding in a range of ways, including through formal training, drawing on the expertise of Aboriginal colleagues, and developing collaborative relationships with Anangu. Participating in formal training, designed and run by Anangu, was perceived as an important first step in developing cultural awareness and sensitivity.

We're from [different] cultures, and we have to work together, so what are things that we should know about before we start working together? Without us getting it into our minds that our way is the right way, so other people just have to conform. (P7)

Some workers reported they had never been offered training or that training was inappropriate and focused on meeting organisational needs and responsibilities rather than the perspective of Anangu. Other workers explained that it was difficult to ensure

all staff received appropriate training given high turnover, time required to participate in training, geographic barriers, and limited funding. Relationships were seen as essential in providing meaningful services and assisting workers to engage with Anangu and develop a strong cultural understanding. As Participant 2 explained: “You’ve got to make a connection with people first, build a relationship with them first and then from there try and engage”. The connections and relationships heavily influenced the level of trust and nature of expectations placed on a worker. For example, one worker explained that the system employed by the organisation she worked for where non-Aboriginal workers were paired with Aboriginal *malpa* (friend or mentor who works alongside), afforded her a sense of trust within communities that she might not otherwise experience.

An important part of maintaining collaborative relationships involved letting go of control and working with Anangu to find a solution. One worker talked about abandoning a desire to manage all perceived risks and to work with Anangu to determine the best approach for them: “you manage that, and you work with people about what risks they’re prepared to take, because these are the things that are really important to them” (P1). Another worker described the importance of respecting Anangu perspectives in solving problems:

If there’s a challenge, whatever’s going on, there’s one resident in particular that I’ll sit with and I’ll go, “What we going to do about this? How are we going to get through this? Tell me what you think.” She’ll give me her input and I’ll look at, well how can I reasonably apply that? (P2)

Underpinning a respect for Anangu ways and the development of collaborative relationships was the need for effective communication, essential to providing meaningful services and navigating multiple accountabilities. Strategies workers used included taking the time to understand who to talk to and then genuinely listening.

A lot of... the work is actually just making contact and just talking with people, ... and then during conversations, or once people get to know you that’s when things probably come up ... and obviously the emphasis is on listening to the clients and what they want and not trying to put our interpretation onto things. (P8)

Working with interpreters or *malpa* was also important in ensuring an accurate understanding of Anangu needs. Workers described practical strategies like simplifying explanations and using pictures to support verbal communication. Taking time to find accessible language and concepts was critical to effective communication. One worker gave examples of how she had learned from the community to re-think her communication with Anangu about time:

So, keep going, keep exploring and keep digging until you can reach a common ground where the message is imparted and received and responding appropriately. So, for this chap for example, we’ve been supporting him through getting a wheelchair replaced. I had government on this side saying, “Oh he’ll have it within four weeks.” I’m saying [to him], “He’ll have it before Christmas.” ... and these are things that the community have strengthened me in my learning...calendarization doesn’t work. A key event works ... that they can relate to. (P2)

In addition to understanding and adapting to cultural expectations around communication, workers acknowledged potential additional challenges communicating with

A_nangu due to a range of disability-related factors such as intellectual or communication impairments. Participant 10 explained: “*some clients, they take a long time to understand ... because of disability ... we have little bit of communication barrier because of disability*”. Another worker reiterated the challenge in communicating with and supporting A_nangu with cognitive impairments:

I would love to have a specialist disability person on staff ... It’s difficult as it is because even people who aren’t cognitively impaired, their education levels are often so low that they ... struggle to understand that financial stuff. And so, then it’s another step up again if you’re talking about someone with a cognitive impairment. But, you know, that would be great to have someone who is a specialist disability worker to teach people how to do stuff with their finances. (P9)

Delivering flexible and creative services

Creativity and flexibility were noted as key traits or skills for workers supporting A_nangu with disabilities. Flexibility was required to work between multiple worlds and accountabilities but was also largely driven by the geographical and socioeconomic challenges of remote area work:

I think people need to be very adaptable. You can’t be rigid. You’ve got to have a very flexible approach and have 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. (P3)

Workers talked about the importance of “creating” a fit between otherwise incongruent government policies and the supports desired by A_nangu:

We have to do a report back to government on our service delivery under that program for example. So, our funding parameters say that you know we need to do A B, C and D ... that’s where we need to be creative in being responsive to the needs of that individual but being able to make the call as to which box we record that against. (P2)

Flexibility and creativity were evident in a range of worker activities, for example: modifying traditionally standardised assessments to ensure that they were relevant to the context, finding culturally appropriate ways to support people out of exploitative relationships, or identifying creative ways of communicating with A_nangu that respected avoidance relationships and cultural rules about sharing of particular knowledge. Some workers spoke of the need to be flexible within their teams so that if one multidisciplinary team member visited a community, they would make observations and implement simple interventions on behalf of another discipline. Or on occasions they would work closely with workers from other organisations who lived in communities. This was necessary given the geographic isolation and travel required, but also allowed workers to build on existing relationships and reduce the number of different people that A_nangu had to re-tell their story to. However, some workers noted that a small number of agencies chose not to collaborate and were rigid in the kinds of supports they would provide A_nangu. In these cases, workers often felt compelled to go above and beyond to provide the “missing” supports as explained by this worker:

We also organised incontinence products, got him funding because [name of organisation] didn’t see it as their business ... They have a policy of not getting involved

in money story... and you know, I would have to do it in my role because they weren't. (P11)

Some services identified value in employing family or community members to provide some culturally appropriate supports. However, one manager explained that employing Anangu in a culturally sensitive manner meant that she had to be flexible in managing her staffing budget and planning allocation of tasks and roles. This allowed Anangu the flexibility to retain employment and provide culturally relevant support while meeting various cultural responsibilities requiring a mobile lifestyle. Many times, being flexible and creative meant that workers had to “bend” the rules and work around systems. For example, one worker talked of a creative plan she developed to support someone to move to another regional centre where they had stronger cultural and language connections using respite as a guise.

Many participants lamented having to bend or break rules to enable them to provide meaningful supports to Anangu. They commented that if socioeconomic disadvantage were addressed in communities to meet basic needs, and if governments and services provided greater funding and flexibility, then they would be able to support Anangu without the additional, unacknowledged work and professional risk. Participants also recognised that often the work they did was beyond the stated expectations of their role or the services they were funded to provide. This meant that workers had to be extremely committed, viewing their role “as more than just a job”. It also came at a cost to workers. As one manager explained: “There’s loads of goodwill but people are so stretched”.

Critical reflection

Critical reflection and questioning of personal and professional cultural values, decision making, and cultural responsiveness were important strategies for navigating multiple expectations. Workers reflected on their culture and perspectives, for example, relating to time, food security, priorities in relation to physical and spiritual health. Participant 2 described how they would often “sit back and say, ‘By whose ideology am I thinking this through?’” Many workers also reflected that they were constantly learning and needed to remain flexible and open to new ideas. For example, Participant 2 explained:

I don't have all the answers. I'm learning like everyone else ... and I guess I don't have a rigidity around me as an individual in terms of professional capacity ... I'm on the learning path and we don't have the answers to everything ... if you had this vision of “I know it all”, then you're going to fail.

Another worker highlighted the importance of critiquing the perceived authority of health professionals to make decisions around living arrangements for Anangu under the banner of duty of care:

I think health professionals who visit will sort of ... see they have some sort of duty of care about making sure this person's life forever and a day is okay and nothing bad ever happens to them or they don't ever do anything bad. It's just unrealistic. And so, you know, it's not really a nurse's or a doctor's role to decide whether someone's able to live in a community or not. (P12)

Workers also reflected on the difficult decisions they had to make and the pressure they felt to balance legal, ethical and policy drivers with the often very different wants and needs of Anangu. Many felt torn between a strong desire to support Anangu to live the life they chose with legislative requirements, demands of their organisation or real or perceived safety concerns.

Discussion

The findings from this research illustrate the unique and often unacknowledged work in delivering culturally responsive and safe services to Anangu with disabilities in a remote context. These results highlight the key factors that workers must balance when navigating the expectations of the different parties that they are accountable to. These factors largely mirror the contextual factors that McEldowney and Connor (2011) identified in their revised cultural safety framework. The findings also highlight, as McEldowney and Connor (2011) have argued, the importance of understanding the “particular historical, geographical, physical, social, and politico/economic context” in which cultural factors occur (p. 345). Workers often had to balance the metropolitan-centric, neo-liberal policy and service values against the provision of meaningful supports to Anangu, whose lives were grounded in an entirely different cultural, social, economic, and geographic context.

Although interviews did not specifically focus on cultural safety, and workers did not use cultural safety language, much of the work they described reflected strategies understood as culturally responsive service delivery (e.g., respect for culture, self-awareness and reflection, and valuing perspectives of Anangu). Interestingly, many workers perceived that seeking cultural knowledge was important in the provision of services. This contrasts with the principles in many cultural safety frameworks, which have generally argued that gaining specific cultural knowledge is not important (Indigenous Allied Health Australia, 2019; Taylor & Thompson Guerin, 2019); rather, workers should be aware of their own values, respectful of the centrality of culture, and listen to the perspectives of service users.

The expectations workers were balancing also closely aligned with the various levels of accountability described by van der Tier et al. (2021) in their review of how social workers manage multiple, often competing, accountabilities in their work. In keeping with van der Tier et al.’s findings, participants spoke of the need to employ “street-level” strategies and creative approaches to work around bureaucratic administrative requirements. Workers identified a range of activities that went above and beyond the expectations of their role, “bent” the rules, and potentially, as van der Tier and colleagues described, undermined their legitimacy using creative approaches to make the supports delivered to Anangu “fit” bureaucratic requirements. It is critical to recognise that being culturally responsive requires a level of reflection, mental work, and flexibility not typical in traditional practice and that workers should be engaging in these practices as a core part of delivering culturally safe services. The findings in this study suggest that although workers are expected to deliver culturally safe services, they are often not supported to do so in the policies, practices, and funding arrangements of their employers and funding bodies. It is also important to acknowledge the additional

work done by Aboriginal colleagues and community members in supporting, mentoring, educating, and accommodating workers as they developed cultural knowledge, cultural responsiveness capabilities, and attempted to provide meaningful supports. The perceived additional and unacknowledged work performed by participants took its toll, with many references made to stress, burnout, and high staff turnover. This is particularly concerning, given the well-documented challenges of recruiting and retaining staff in remote areas (Gallego et al., 2015; Wakerman et al., 2019), and the fact that successful service provision relied on building long-term collaborative relationships. Workers, who were largely motivated by a desire to make a difference, were often willing to continue to work harder to achieve better outcomes for Anangu with disabilities. However, this work was generally not funded nor acknowledged, and would not be sustainable or equitable under a market-based funding model such as the NDIS. Others have argued that the collectivist nature of Indigenous culture is incompatible with the highly individualistic NDIS (Avery & First Peoples Disability Network, 2018; Stewart & Allan, 2013). The market-based approach of the NDIS, which emphasises choice and control for participants, means that workers delivering services to Anangu with disabilities will have to navigate the added tension of working within a system that emphasises accountability to service users, but which is largely incompatible with service users' values and practices.

Findings in this study also reiterate the importance of ensuring that responsibility for cultural safety is embedded at all levels of policy and practice. Expecting workers to be culturally responsive and “soften the edges” of a system that is inflexible and culturally unsafe is simply tinkering at the edges and shifting responsibility to already stretched workers. It does not acknowledge the deeply ingrained assumptions and values that underpin policies and organisations, nor the material and social inequalities that persist, meaning Anangu do not enter the service context with their basic needs being met or with a voice that is adequately privileged (Trounson et al., 2020). Systemic changes are required to address inequities and to create services that recognise and are flexible enough to work effectively within different geographic and cultural contexts. Cultural safety, including acknowledgement of the impact of remote context, must be embedded at legislation, policy, and organisational levels as well as “on the ground”. This requires that voices of Anangu are privileged in discussions of meaningful supports and service designs. It also requires the development of cultural responsiveness capabilities at organisational and practitioner levels (IAHA, 2019). van der Tier et al. (2021) identified that one of the challenges for workers was identifying ways to empower service users in practice. Given the power imbalances entrenched through colonisation, addressing the inequities experienced by Anangu with disabilities will require significant decolonising efforts. This is even more pertinent for Anangu with intellectual disabilities and other cognitive impairments, given that this group was identified as having unique communication and support challenges. Additionally, challenges associated with understanding and navigating services and systems may be even more pronounced for people with intellectual disabilities and thus they may require specialised support from workers to ensure culturally safe access to services. On the other hand, the connections and support provided through the strong kinship system

embedded in communities regardless of disability status may facilitate participation of Anangu with intellectual impairments.

Limitations

Due to the broader aims of this research, interviews with workers and Anangu did not explicitly focus on the concept of cultural safety, though both groups spoke extensively about cultural differences and providing meaningful or “proper-way” support to Anangu with disabilities. In addition, the perspectives of Anangu regarding “proper-way” support have not been presented directly in this article, making it difficult to confirm that workers were providing culturally-responsive supports. However, the views of Anangu about what makes and supports a good life has been presented in detail in a previous publication (Dew et al., 2020) and is generally reflected in the views presented by workers in this article.

Conclusion

Workers providing services to Anangu with disabilities from the geographically remote Ngaanyatjarra Pitjantjatjara Yankunytjatjara Lands of Central Australia reported navigating multiple factors and accountabilities in their work. These factors included organisational and administrative requirements, workers’ personal and professional values and history, and the perceived perspectives and needs of Anangu. To navigate these factors workers employed a range of strategies, including fostering cultural knowledge and collaborative relationships, delivering flexible and creative services, and critically reflecting on their practice. The unacknowledged, “street-level” work being done to create a fit between often incongruent values and priorities created significant challenges for workers. Expecting workers to take on the role of “sandpaper and polyfilla” to soften the hard edges of service systems and fill gaps does little to encourage the systemic change and critical reflection required to facilitate delivery of meaningful, culturally safe services to Anangu with disabilities.

Note

1. To protect participant anonymity we have chosen not to identify the type of service provided by each participant when presenting results

Acknowledgements

The authors would like to thank the Board of Directors and staff of the NPYWC and the Anangu who shared their stories throughout this research. We would also like to thank the service providers who shared their time and experiences with us.

Disclosure statement

No potential conflict of interest was reported by the author(s).

Funding

This work was supported by a grant from the Department of Family and Community Services, Research and Data Working Group, and an Australian Research Council – Indigenous Discovery Grant.

ORCID

Rebecca Barton  <http://orcid.org/0000-0001-5786-9864>

Angela Dew  <http://orcid.org/0000-0002-8800-5660>

Michelle Lincoln  <http://orcid.org/0000-0001-7536-5993>

John Gilroy  <http://orcid.org/0000-0002-7934-8485>

References

- Ariotti, L. (1999). Social construction of Anangu disability. *The Australian Journal of Rural Health*, 7(4), 216–222. <https://doi.org/10.1046/j.1440-1584.1999.00228.x>
- Australian Bureau of Statistics. (2018). *Estimates of Aboriginal and Torres Strait Islander Australians*. <https://www.abs.gov.au/statistics/people/aboriginal-and-torres-strait-islander-peoples/estimates-aboriginal-and-torres-strait-islander-australians/jun-2016>
- Avery, S., & First Peoples Disability Network. (2018). *Culture is inclusion: A narrative of Aboriginal and Torres Strait Islander people with disability*. First Peoples Disability Network.
- Biddle, N., Al-Yaman, F., Gourley, M., Gray, M., Bray, J. R., Brady, B., & Montaigne, M. (2014). *Indigenous Australians and the National Disability Insurance Scheme* (Vol. CAEPR Monograph No. 34). ANU Press.
- Braun, V., & Clarke, V. (2012). Thematic analysis. In H. Cooper (Ed.), *APA handbook of research methods in psychology* (1st ed., Vol. 2, pp. 57–71). American Psychological Association.
- Coleman, C., Man, N. W. Y., Gilroy, J., & Madden, R. (2018). Aboriginal and Torres Strait Islander disability prevalence: Making sense of multiple estimates and definitions. *Australian and New Zealand Journal of Public Health*, 42(6), 562–566. <https://doi.org/10.1111/1753-6405.12838>
- Dew, A., Barton, R., Gilroy, J., Ryall, L., Lincoln, M., Jensen, H., Flood, V., Taylor, K., & McCrae, K. (2020). Importance of Land, family and culture for a good life: Remote Aboriginal people with disability and carers. *Australian Journal of Social Issues*, 55(4), 418–422. <https://doi.org/10.1002/ajs4.96>
- Gallego, G., Dew, A., Bulkeley, K., Veitch, C., Lincoln, M., Bundy, A., & Brentnall, J. (2015). Factors affecting retention of allied health professionals working with people with disability in rural New South Wales, Australia: Discrete choice experiment questionnaire development. *Human Resources for Health*, 13(1), 11. <https://doi.org/10.1186/s12960-015-0013-7>
- Gilroy, J., Dew, A., Lincoln, M., Ryall, L., Jensen, H., Taylor, K., Barton, R., McCrae, K., & Flood, V. (2018). Indigenous persons with disability in remote Australia: Research methodology and Indigenous community control. *Disability & Society*, 33(7), 1025–1045. <https://doi.org/10.1080/09687599.2018.1478802>
- Gilroy, J., Donnelly, M., Colmar, S., & Parmenter, T. (2016). Twelve factors that can influence the participation of Aboriginal people in disability services. *Australian Indigenous Health Bulletin*, 1(16), 1–9.
- Indigenous Allied Health Australia [IAHA]. (2019). *Cultural responsiveness in action: An IAHA framework*. ACT.
- Mackean, T., Fisher, M., Friel, S., & Baum, F. (2020). A framework to assess cultural safety in Australian public policy. *Health Promotion International*, 35(2), 340–351. <https://doi.org/10.1093/heapro/daz011>

- McEldowney, R., & Connor, M. J. (2011). Cultural safety as an ethic of care: A praxiological process. *Journal of Transcultural Nursing*, 22(4), 342–349. <https://doi.org/10.1177/1043659611414139>
- Nowell, L. S., Norris, J. M., White, D. E., & Moules, N. J. (2017). Thematic analysis: Striving to meet the trustworthiness criteria. *International Journal of Qualitative Methods*, 16(1), 160940691773384. <https://doi.org/10.1177/1609406917733847>
- Ravindran, S., Brentnall, J., & Gilroy, J. (2017). Conceptualising disability: A critical comparison between Indigenous people in Australia and New South Wales disability service agencies. *Australian Journal of Social Issues*, 52(4), 367–387. <https://doi.org/10.1002/ajs4.25>
- Roy, M., & Balaratnasingam, S. (2014). Intellectual disability and Indigenous Australians: An overview. *Asia-Pacific Psychiatry*, 6(4), 363–372. <https://doi.org/10.1111/appy.12157>
- Stewart, J., & Allan, J. (2013). Building relationships with Aboriginal people: A cultural mapping toolbox. *Australian Social Work*, 66(1), 118–129. <https://doi.org/10.1080/0312407X.2012.708937>
- Stopher, K., & D'Antoine, H. (2009). *Aboriginal people with disability: Unique approaches to unique issues*. <http://www.disability.wa.gov.au/Global/Publications/About%20us/Count%20me%20in/Research/aboriginal-people-with-disability.pdf>
- Taylor, K., & Thompson Guerin, P. (2019). *Health care and Indigenous Australians: Cultural safety in practice* (3rd ed.). Red Globe Press.
- Trounson, J. S., Gibbs, J., Kostrz, K., McDonald, R., & Peters, A. (2020). A systematic literature review of Aboriginal and Torres Strait Islander engagement with disability services. *Disability & Society*. Advance online publication. <https://doi.org/10.1080/09687599.2020.1862640>
- van der Tier, M., Hermans, K., & Potting, M. (2021). Managing multiple accountability perspectives and expectations in practice. A scoping review of the use of accountability mechanisms by social workers. *European Journal of Social Work*, 24(3), 456–468. <https://doi.org/10.1080/13691457.2019.1709161>
- Wakerman, J., Humphreys, J., Russell, D., Guthridge, S., Bourke, L., Dunbar, T., Zhao, Y., Ramjan, M., Murakami-Gold, L., & Jones, M. P. (2019). Remote health workforce turnover and retention: What are the policy and practice priorities? *Human Resources for Health*, 17(1), 1–8. <https://doi.org/10.1186/s12960-019-0432-y>