

# **Exploring Community-Based Aged Care with Aboriginal Elders in three Regional and Remote Australian Communities: A qualitative study**

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## **Abstract:**

While a small body of literature focuses on various facets of aged care services delivered to Aboriginal and Torres Strait Islander Elders, very little is known about the support needs and preferences of Indigenous Elders who 'return to country'. This article addresses this gap. It explores the support needs of Indigenous Elders who return to their communities after having lived elsewhere for prolonged periods of time. It provides an overview of the key themes emerging from group sessions and semi-structured interviews with 11 Aboriginal Elders and 12 representatives of regional health and social care organisations conducted between 2012 and 2013. The article argues that the quest of Elders to strengthen kinship systems should not be seen as a barrier but as an opportunity to develop aged care services that resonate with the needs of Indigenous Elders and with their kinship network. The findings presented in the article are structured around the themes of empowerment and choice; community-based kinship care; and enhancing program flexibility. The article argues that it is crucial for Aboriginal community care services to be grounded in Indigenous culture. To address the wider socio-cultural project of Aboriginal Elders (i.e. to re-connect with their families, strengthen the kinship system and, re-create their cultural roles) when designing aged care services not only ensures that services are relevant to Indigenous Elders, it also ensures that services are culturally safe and address the psychosocial needs of Elders returning to country as well as their families. The article lends further weight to research that reports that a mainstream approach to the aged care of Indigenous Elder is likely to produce poor care outcomes.

## **Key Words:**

Aboriginal Elders, community aged care, co-design, stolen generation, socio-emotional wellbeing, cultural safety

## **Introduction**

While a small body of literature focuses on various facets of aged care services delivered to Aboriginal and Torres Strait Islander Elders, very little is known about the support needs and preferences of Indigenous Elders who ‘return to country’. This article addresses this gap. It explores the support needs of Indigenous Elders who return to their communities after having lived elsewhere for prolonged periods of time. The article argues that the support needs of those Elders returning to their communities - and particularly those who formed part of the ‘Stolen Generation’ - are importantly shaped by colonial policies and particularly those in effect between 1910 and 1972 that forcibly removed many of them from their families, communities and country. It is crucial to address the wider socio-cultural project of Aboriginal Elders (i.e. to re-connect with their families, strengthen the kinship system and, to some extent, re-create their cultural roles) when designing aged care services if aged care support is to be experienced as relevant and effective by Indigenous Elders. A failure to do so tends to perpetuate the experience of government services as an inflexible imposition and extension of a colonial mindset that drives a cultural wedge between Aboriginal and non-Aboriginal Australia. Yet, practitioners and policy makers who would like to develop approaches that are of greater socio-cultural significance to Aboriginal Elders ‘returning to country’ find only scant academic literature that could assist them in that task. This article addresses this gap in the literature. It provides an overview of the key themes emerging from an ongoing discussion with Indigenous Elders located in three regional and remote Australian communities, outlining five key implications for policy and practice.

## **Aged Care in Rural and Remote Locations:**

At a macro level, ageing in most inland rural areas is strongly affected by geographic isolation, economic challenges, demographic shifts, and

environmental change (Duftey-Jone & Connell, 2016). The limited availability of basic services including health, transport, recreation, and personal support tends to result in higher prices for basic goods and services, including appropriate nutrition (Davies & Bartlett, 2008; Thomas, Wakerman, & Humphreys, 2015). In particular, palliative and residential aged care and specialist health and mental health services are in limited supply (Bernoth, Dietsch, & Davies, 2012). In terms of the delivery of health and social care services, the retention, training and skills development, administration and management, inadequate support networks, and flexibility in program planning and service delivery were identified as a challenge as early as the 1990s (Howe, 1991). Most of these issues have persisted. In addition, the transfer of care and particularly mental health care from rural/remote locations to metropolitan service providers has been identified as fragmented and in need of improvement (Taylor, Edwards, Kelly, & Fielke, 2009). For older people in rural locations, these structural factors translate into social isolation, reduced mobility, more chronic disease and co-morbidities, and limited access to community and health services. Older people in regional/rural settings tend to receive around half of the assistance with cleaning, showering and dressing, shopping and food preparation compared to their counterparts in urban areas (Ottmann, Millicer, & Bates, 2015). Several researchers have pointed out that clients' distance from health and social care organisations, the cost or absence of transport, in conjunction with a limited pool of qualified staff and the absence of services and community infrastructure (McBain-Rigg & Veitch, 2011) create powerful structural barriers.

### **Cultural Factors affecting the Delivery of Aged Care Services for Indigenous Elders:**

A number of researchers have identified cultural issues that result in the provision of aged care services that fail to resonate with the needs and preferences of Indigenous Elders. These include, limited adaptation of service providers to local conditions, cultural disjuncture, a lack of communication and collaboration across the aged, primary, and acute care sectors potentially leading to conditions where service

providers work in isolation and fail to share scarce resources resulting in or exacerbating existing service gaps (LoGiudice et al., 2012; Stewart, Lohar, & Higgins, 2011). Also, it has been pointed out that inflexible organisational structures, adherence to a culturally inappropriate mainstream model of care, vestiges of racism, a refusal to acknowledge trauma, and a reluctance to relinquish control over funding and decisional authority generate poor care outcomes for Aboriginal Elders (Herring, Spangaro, Lauw, & McNamara, 2013; Stewart et al., 2011). Overall, there is a consensus emerging that a culturally insensitive and inflexible aged care menu that fails to cede control to Indigenous Elders and fails to take into account the wider kinship and social context and the widespread trauma experienced by many Indigenous people generally fails to translate into quality care outcomes (AIHW, 2013; LoGiudice et al., 2012; Smith, Grundy, & Nelson, 2010a; Stoneman, Atkinson, Davey, & Marley, 2014).

### **Community Aged Care Best Practice Examples:**

There is some evidence that culturally appropriate, well-designed community aged care services may facilitate considerable improvements in care outcomes (AIHW, 2013; LoGiudice et al., 2012; Smith, Grundy, et al., 2010a; Stoneman et al., 2014). This literature suggests that service provision should be holistic and family- (rather than individual-) focused, evidence-based and clinically robust, culturally competent and safe adapting to the needs and preferences of the client (and not to the service provider). Researchers who conducted successful Aboriginal aged care pilots agree that services should be based on genuine community engagement, ideally involve community-based advocates, should involve Indigenous communities in the management and delivery of services, and that services should be more integrated supporting the families as a whole (Casey, 2014; LoGiudice et al., 2012; Milroy, Dugeon, & Walker, 2014; Smith, Flicker, et al., 2010; Smith, Grundy, et al., 2010a).

### **Mental Health and Socio-emotional Wellbeing:**

Mental health concerns are common among Aboriginal Australians. The 2012-2013 Australian Aboriginal and Torres Strait Islander Health

Survey indicates that Aboriginal and Torres Strait Islander people aged 18 and over were 2.7 times more likely to experience high or very high levels of psychological distress than non-Indigenous Australians with around 30% of respondents experiencing compromised socio-emotional wellness (ABS, 2013). According to the 2014-15 National Aboriginal and Torres Strait Islander Social Survey, approximately half (49.7%) of Indigenous adults living with an ongoing mental health issue directly experienced removal from their families or the removal of a close relative and 44.1% experience racial discrimination (ABS, 2016). Factors that contribute to compromised socio-emotional wellbeing for Indigenous Australians include discrimination and racism, grief and loss, child removal and unresolved trauma, life stress, social exclusion, economic and social disadvantage, incarceration, child removal by care and protection orders, violence, family violence, substance use, and physical health problems (Herring et al., 2013; McMillan, Kampers, Traynor, & Dewing, 2010; Zurbrick et al., 2014). Researchers have identified a number of factors that are likely to enhance the socio-emotional wellness, such as (re-) connection to country, spirituality and ancestry, kinship and self-determination, community governance, and cultural continuity (Gee, Dugeon, Schultz, Hart, & Kelly, 2014). Bearing these factors in mind, there is an embryonic consensus emerging that healing in the case of Elders who experienced removal from their families requires re-connection with family, culture, and community. However, they also point out that re-connection is often fraught with difficulties as Elders attempt to come to terms with a background of denial and denigration of Aboriginality and that good support services ought to be in place to assist Elders on this journey (Peeters, Hamann, & Kelly, 2014). Service providers may have a role to play in assisting Elders to come to terms with the varying levels of loss they experienced and assist them and their communities to deal with continuous grief and loss if that support is offered in a culturally safe way (Isaacs, Pyett, Oakley-Brown, Gruis, & Waples-Crowe, 2010; Milroy et al., 2014). Yet, authors agree that cultural safety has only superficially been absorbed by service providers (Herring et al., 2013; Isaacs, Maybery, & Gruis, 2012, 2013; McMillan et al., 2010). In addition, the authors report that service providers should encourage

the recording of oral history and the dissemination of cultural lore (Milroy et al., 2014). There is consensus among researchers that Elders returning to country and particularly ‘Stolen Generation’ people may want support on their reconnection journey (Casey, 2014; Dugeon, Wright, Paradiies, Garvey, & Walker, 2014; Milroy et al., 2014; Peeters et al., 2014; Peeters & Kelly, 1999).

## **Policy Context**

The research underpinning this article was implemented within the context of a significant policy reform process that aimed to afford greater choice, flexibility and independence to service users (DSS, 2014). Influenced by the philosophy of consumer-directed care implemented in the United States of America and in England over the last two decades, the aged care reform aimed to make care arrangements more individualised, involving service users more directly in decisions that affect their care. Based on the ideology that markets are better at allocating resources, the reform attempted to create a quasi-market for aged care services, expecting that this would generate more choice, flexibility, and independence for ‘consumers’. The reform gave rise to a set of governmental guidelines that, among other things, excluded the use of aged care packages as a source of general income. (Aged Care Act 1997, 2015; DSS, 2017). It is also important to point out that the aged care reform significantly re-shaped vocational training, such as the Certificates in aged care.

## **Methodology**

A co-design process was employed to sketch the contours of an aged care approach that is relevant to Indigenous Elders. Co-design has become synonymous with innovative approaches to public service delivery in European Union countries as well as in Australia (Alford, 2009; Dunston, Lee, Boud, Brodie, & Chiarella, 2009; Hunter & Ritchie, 2007; Loeffler, Parrado, Bovaird, & Van Ryzin, 2008; Needham, 2008). Co-design was the appropriate methodology because it has the capacity to bring together individuals, communities, and organisations in a process to collaboratively develop new approaches with the aim to improve public services (Ottmann, Allen, Laragy, & Feldman, 2011).

Historically, co-design is rooted in a vast body of thought that aims to empower ordinary citizens by involving them in decisions that directly affect their lives.

The research question that guided the co-design process was:

What are the culturally appropriate support needs of Aboriginal Elders?

### **Methods:**

To gather robust data, the research team engaged in an ongoing discussion structured around three group meetings and semi-structured interviews with Aboriginal Elders, staff employed by a regional domiciliary aged care organisation, and representatives of external service providers. Group meetings were conducted in regional, rural, and remote communities. Aboriginal Elders also participated in semi-structured, face-to-face interviews. Group meetings and interviews took place between November 2012 and February 2013. Interviews were conducted between November 2012 and September 2013. Field notes were kept to record occurrences and participant responses.

### **Sampling:**

A purposive sampling strategy was employed. In order to participate in this project, individuals had to be eligible for a community aged care package administered by the participating aged care service provider agencies. When the study was conducted, aged care packages consisted of Commonwealth Aged Care Package (CACPs) and Linkage packages (low care), Extended Aged Care at Home (EACH) (high care), and Extended Aged Care at Home Dementia (EACH-D) (high care with dementia supplement). All except for one participant caring for a person assisted by an EACH package, were assessed to receive CACPs packages.

### **Profile of Participants:**

A total of 11 Aboriginal clients, two care coordinators, one manager, and nine representatives of regional health and social care organisations participated in the group meetings and interviews. Eight of the clients were female and three male. Four of the participating agency staff were

female and one male. The majority of clients were aged 67-74 with the exception of one participant aged 59 and one aged 85. Their mean age was 67.8 years. Elders belonged to three different kinship groups. Clients lived in a small regional centre and three small remote communities situated between 2 and 5 hours from the regional centre. Clients received aged care services in their own home. However, some of the clients had to travel regularly to the regional centre or the closest major city to receive medical care. Clients collectively attended two sessions of approximately 3.5 hours and care managers and the manager attended two sessions of a similar duration. External providers were interviewed once.

### **Procedure:**

Clients of a participating community aged care organisation were given the project documentation and a Plain Language Statement. If they expressed interest in the project to their case managers, they were asked for permission to forward their contact details to the research team. Subsequently, a researcher contacted interested Elders to invite them to the group sessions.

Participants attending the three group sessions were provided with a project overview and the Plain Language Statement. The researchers ascertained that the information was absorbed and participants were asked to sign a consent form during the interview sessions. Two participants declined consent and were excluded from the project. During the initial group session, participants were asked to describe assistance or services that would be important to them and the key challenges they faced in terms of everyday living arrangements. Two subsequent group sessions focused on socio-cultural themes that emerged during the first group session. Group sessions lasted approximately 3.5 hours. Responses were systematically recorded on a large piece of paper or white board. All Elders participating in the group discussions also participated in semi-structured interviews. Semi-structured interviews were approximately 50 minutes in duration. Interview questions homed in on support services or assistance that would be important to them.

### **Data Analysis:**

The group discussions and around half of the interviews (some participants preferred not to be tape recorded) were voice recorded and later transcribed. A thematic analysis making use of an inductive and deductive approach (Fereday & Muir-Cochrane, 2006) was used to identify the key themes. The themes were refined and sub-themes identified and entered onto a spread-sheet.

To ensure the trustworthiness of the findings (Guba, 1981), a team of three researchers analysed the data. Differences in interpretation were resolved using a peer mitigation process. Furthermore, participants were given an opportunity to collectively comment on the identified themes, issues, and proposed solutions during subsequent group sessions. Their comments were annotated and integrated into the analysis.

The project received the approval of Deakin University's Human Ethics Committee (2012-211).

### **Findings & Discussion**

All of the Indigenous Elders in this study had spent decades away from their communities – mainly in larger urban areas on the east and south coast of Australia. Upon their 'return to country' they found their communities much changed, with different kinship groups living in close proximity to each other. Since their return to their communities, many of the participants assumed positions of responsibility within Aboriginal management committees and became strong advocates in matters of healthcare, land management and native title. At the time the group discussions took place, participating Elders had been receiving domiciliary aged care support for an average of 9 years. With the exception of one individual, they received minimal direct care services. On average, they received less than half the amount of age care services (i.e. home care, personal care, respite or shopping assistance) than non-Aboriginal people in rural locations (Ottmann et al., 2015). All with the exception of two participants used less than one third of the resources contained within their aged care packages. To some extent, this is due to the fact that participating Elders were on average around 10 years younger than their non-Aboriginal peers in rural areas (Ottmann et al.,

2015). The main health concerns reported by participants were arthritis, diabetes, and cardio-vascular issues. In addition, several elders reported unresolved grief and loss issues and support needs of a very different nature than the conventional home and personal care services offered by mainstream aged care providers. It also emerged that participants were much less informed about their aged care entitlements than their non-Aboriginal peers (Ottmann et al., 2015).

### **Information, Empowerment, and Choice:**

During the initial group meeting, it became quickly obvious that participants knew little about the domiciliary aged care system and the types of goods and services that could be funded under the guidelines that were in place at the time. Moreover, they were unaware of the fact that, most of them only spent a small fraction of their aged care package. Participants were keen to learn more about their entitlements as they felt that this empowered them to use more of their package and increased their choices:

“It is great having you explain all about it like that. I have never heard the package thing in those terms before.” [P02]

“I’m much more likely to use my package if I know information like that”. [P02]

“Case managers should tell us what people can have and ask us what we want. Some days I want cleaning and some days I want something else, but I didn’t know I could choose”. [P01]

“They don’t ask us what we want, [they] just tell us”. [P03]

Lack of transparency and lack involvement in decision making processes, as one Elder (P04) explained, increased the Elders’ distrust of government agencies and compounded their sense of disempowerment. Another Elder argued that shared decisional authority would lead to a sense of empowerment and help Elders to assume more easily the role of deserving clients of a modern welfare system rather than the recipients of charity and handouts:

“... giving people choices gives them a sense of ownership and pride: that’s what’s missing these days.” [P07]

This knowledge gap and sense of disempowerment was largely the result of deeply felt distrust that separated agency staff and Indigenous clients. In fact, an aged care services manager [S01] explained that he preferred not to inform Indigenous clients about the potential scope of services as this could open the “floodgates” to “unreasonable” demands that would be difficult to manage. Clearly, this approach has very little in common with the successful Indigenous aged care models based on collaborative service delivery and shared control developed over the last decade. There is a consensus that community control is a key ingredient of aged care services that resonate with Indigenous Elders (LoGiudice et al., 2012; Smith, Flicker, et al., 2010; Smith, Grundy, et al., 2010a; Smith, Grundy, & Nelson, 2010b). Indeed, the issue of empowerment resonates well with the wider political agenda of Aboriginal Australians for greater political self-determination, cultural recognition, and ownership over land and resources. It is, hence, not surprising that participants took a keen interest in knowing more about and having more control over their domiciliary care packages. While the current aged care reform underpinned by the ideology of Consumer-Directed Care (CDC) can - at least in theory - facilitate greater client control, CDC facilitates individual rather than communal control. As will emerge in the following paragraphs, this tension is limiting the relevance for Indigenous Elders of the aged care model currently rolled out in Australia.

### **Community-Based Kinship Care:**

The participants in this project highlighted the fact that ‘Aboriginal culture’ is very diverse. Some families were intensely engaged in a cultural and political project to reinvigorate Aboriginal culture based on kinship, family and cultural obligations (see also Smith, Grundy, et al., 2010a). Others, and particularly those without extended family networks in the region, preferred to be indirectly involved in this project.

As a result, for most participants, aged care is the responsibility of the extended family; or as one Elder put it:

“Most people look after their own” [P 04].

Elders who lived in close proximity to the extended family generally received support from family members, who pooled resources to provide transport, home or personal care, and other assistance. These Elders had very little in terms of conventional home or personal care needs. As a result, conventional (home and personal care, meals service) domiciliary aged care services were irrelevant to the majority of participants. However, this more traditional provision of care depended on the resources available to the extended family. Hence, a more holistic, family-focused approach is required to make services relevant to these Elders and their families (see also LoGiudice et al., 2012).

Because the Indigenous aged care system envisaged by the participants in the above examples largely draws on the resources of the extended family, support services should holistically focus on the kinship network as a whole and strengthen under-resourced elements within it (see also LoGiudice et al., 2012). The need for this goes beyond a project to re-invigorate Aboriginal culture, however. In more remote communities, crucial public as well as commercial services, such as public transport or taxis, are simply not available. In such cases, the resources of the extended family (i.e. the family car) are crucial for the health and wellbeing of Elders. For example, if the family car broke down and the family did not have the money to repair it, the Elder could not be taken to a GP appointment - many families live in remote areas not covered by public transport. Should families be unable to support their Elders, Elders may be forced to leave their communities to 'finish up' (pass away) in a place where they are not supported and surrounded by family or face hardship (McBain-Rigg & Veitch, 2011, p. see also ). In order to facilitate a kinship or community-focused approach to social services, an integration of aged care and other social services funding streams would be desirable. Indeed, recent research suggests that an integrated community care program combining several funding streams developed in direct partnership with Indigenous stakeholders and controlled by the community can result in a shift from a service-led to needs-led service provision (LoGiudice et al., 2012).

It should be needless to say that such an approach requires fundamental changes to funding guidelines and particularly rules around income

subsidisation. Within the context of kinship care, current guidelines undermine the utility of community aged care services for Indigenous Elders.

### **Grief & Loss:**

Some of the needs of Aboriginal Elders are shaped by their socio-cultural and historical context. Grief and mental health issues were an important part of participants' lives. Their stories were steeped in loss - loss of family and loved ones and the loss of country, culture, language, identity, and community. This resulted, as some Elders (P01, P03, P04) explained, in unresolved grief and loss issues.

“Grief plays a big part in Aboriginal life.” [P01]

“Grief is the reason for the problems nowadays, unresolved grief.” [P04]

Yet as the following quote suggests, such psycho-social needs require a more holistic and culturally sensitive approach to service provision:

“Having the time to sit and yarn is good medicine for our old people, to sit and have a yarn when they are lonely. It helps them with their grief, and is more important than having the floors done”. [P01]

These statements illustrate the centrality of grief and loss issues. In the case of our participants, although recorded on occasions, they were rarely addressed - let alone addressed in a culturally appropriate fashion.

Psycho-social and psychological needs associated with grief and bereavement of most of the above-featured Elders is inextricably linked with the issues faced by members of their extended kinship group and the fragmentation of their communities (ABS, 2013, 2016; Zurbrick et al., 2014). The statements of our participants consistently indicated that they would like to address grief issues in a collective manner involving the wider community. For example, one participant [P04] reported that grief and loss issues should be seen within the context of the wider family and, particularly, the weakening of kinship ties. He argued that the strengthening of kinship ties should be at the centre of therapeutic approaches. For this Elder, recording the foundation stories of his

community and taking younger people back to the ‘old country’ to reignite their interest in the traditional lore and to strengthen family ties was key to dealing with grief and loss. Indeed, recent research highlights the mismatch between mental health services and the needs of Aboriginal men, particularly (Isaacs et al., 2012), and indicates that the healing of trauma caused by the removal of individuals from communities should involve re-connection with family, culture, and community (see, for example, Peeters et al., 2014).

For most Aboriginal Elders who participated in this project, it was tremendously important to reconnect with and re-claim their cultural lives, to meet their kinship roles and responsibilities (such as attending funerals or other ceremonies), and to transmit their knowledge of culture and traditions to the next generation. For participants, this re-claiming of Aboriginal culture was at the core of a ‘healing process’ that slowly emerged from their testimonies. Particularly, participant who formed part of the ‘stolen generation’ wanted to reconnect with family members they had lost contact with during childhood due to their removal from their families. Given these considerable psychosocial needs, one participant explained that:

“Our people want flexibility. Because their needs are different ...”  
[P01]

Examples of culturally appropriate programs addressing grief and loss issues with Indigenous Elders are available. The existence of such programs should become common knowledge among service providers working with Indigenous Elders (see also Isaacs et al., 2012, 2013; Milroy et al., 2014; Peeters et al., 2014).

However, participants indicated that the cultural understanding that could render aged care services culturally appropriate was often missing. Or as the above-mentioned Aboriginal Elder put it:

“It’s good you’re doin’ this [explore culturally appropriate services] because [name of care agency manager] doesn’t really understand our people”. [P01]

Indeed, several participants (P01, P04, P09, P11) reported considerable cultural misalignment when describing aged care staff and management as lacking in cultural understanding:

“Staff need to be mindful of Aboriginal culture and family values”. [P01]

There is general agreement among researchers that culturally safe services are based on the clients’ culture (and not that of the service provider), directly involve Indigenous people in their design, and redress power imbalances between clients and service providers by means of community control over services (Smith, Grundy, et al., 2010a). While Consumer-Directed Care potentially increases the control of individuals over services, a lack of awareness of culturally safe practices among service provider staff alongside the lack of trust that comes with conventional service-led approaches effectively truncates the empowerment of Indigenous communities that is potentially available through CDC.

### **Enhancing Program Flexibility:**

The quality of home and personal care, represented a key point of contention and most participants regarded these services as being of poor quality. When exploring further the issue, participants mentioned the lack of an effective complaints pathways, disrespectful workers, difficulties having their preferences acknowledged, workers leaving early or arriving late, and inflexible service delivery among other issues. With two exceptions, participants rejected the ‘canon’ of home and personal care, gardening, and meals conventionally supplied by aged care organisations. They largely regarded such services as irrelevant since members of the extended family volunteered to provide them. As a result, with the exception of one participant, Elders received very few services. Rather than spending their aged care resources on standard items, participants explained, they would rather use some of their package on items such as a funeral plan to reduce the burden on their families, culturally safe grief and loss counselling, or reconnecting with siblings they had not seen since they were forcibly removed from their families.

Seven of the ten participants expressed a preference for services to be delivered by Aboriginal people, preferably from their own kinship group (see also LoGiudice et al., 2012; Smith, Flicker, et al., 2010; Smith, Grundy, et al., 2010a). This, they explained, would render services more culturally safe, relevant, and would do away with issues associated with the management of direct care workers (P09, P03).

“[It] is important to me and my people because we understand each other. If we have a fight about something, then we can sort it out easier.” [P04]

Two other Elders (P05, P06) expressed satisfaction with the personal care services delivered by Aboriginal staff. They commented on the person-centred approach that underpinned their approach and the excellent relationship between the Indigenous care workers and the care recipient. However, the employment of Indigenous staff is often made difficult by the fact that they are over-represented in the criminal justice system (they make up 28% of Australia’s prison population but only 3% of Australia’s society). As a result, many Indigenous people have criminal records. This leads to widespread discrimination by potential employers who regard a criminal conviction to be a contravention of the inherent requirements of aged care support workers (see, for example, HREOC, 2004).

Many examples of poor care services were provided. For example, two Elders (P01 and P09) reported that when asked to sweep the wooden floor boards, care workers, responded that they are not allowed to sweep and would only vacuum the floors. Yet, one of the Elder (P09) did not own a vacuum cleaner. When she asked a case manager to look into this, she was reportedly told to resolve the issue herself. Another Elder (ATIS02) reported that she lodged a complaint with a case manager because her care worker was working less than half of the contracted hours. She was told to report to another case manager. Instead, she decided to terminate the care arrangement and do the floors herself. She stated that homecare workers were of little use to her as they

“... never asked me what I wanted or how I liked things done”.  
[P02]

Another Elder (P01) who received monthly gardening and three-weekly homecare services echoed the sentiment that homecare was not particularly effective. She stated that she would prefer garden waste removal and window cleaning instead of dusting and vacuum cleaning because ...

“it’s a bit of a waste having them come as often as they do, because they aren’t allowed to do hardly anything anyway”. [P01]

As a result, direct care services were regarded by two thirds of the participants as irrelevant and several clients expressed the preference to either do homecare tasks themselves, ask family members to do them, or employ local indigenous people. The proposition to employ members of the extended family as care workers should be seen in the context of sub-standard care services (see, for instance, Ottmann, Allen, & Feldman, 2013).

However, two Elders [P03, P04] did not view favourably the employment of family members, as this was essentially monetising a relationship that these Elders regarded as the responsibility of the extended family under the kinship system. In other words, paying members of the extended family was seen to undermine their socio-cultural project to re-invigorate Aboriginal culture. They stated that their project to reconstruct an Elder care system based on ‘traditional’ values was still very much in progress as “the young people don’t look after their Elders anymore” [P03, P04].

The participants interviewed for this project were very clear about their individual and collective needs. For most of these participants, ‘conventional’ aged care services held little value. Their accounts illustrate the extent to which the mode of domiciliary aged care delivery they experienced was at odds with their wider socio-cultural project to connect with an Aboriginal culture based on traditional kinship systems. For most of the participants, conventional aged care services created a cultural disjuncture that did not support them in their quest to strengthen Aboriginal culture (see also, McBain-Rigg & Veitch, 2011; Stewart et al., 2011), a project that also strengthens family-based aged care available to Elders. It is difficult to over-emphasise the importance

that this quest has for many Aboriginal Elders ‘returning to country’. Because it largely screened out participants’ socio-historical and cultural context, conventional aged care was largely perceived as irrelevant (see also Bell, Lindeman, & Reid, 2014; LoGiudice et al., 2012; Smith, Grundy, et al., 2010a). A more culturally appropriate approach would regard kinship systems as an opportunity to provide aged care services that grounded in Indigenous culture – not as an obstacle. Participants made it clear that aged care services have to take into account (i.e. designed around, delivered into, and to some extent controlled by) this context in order to be relevant and culturally appropriate.

Consumer-Directed Care (CDC) can, under ideal conditions (i.e. equilibrium of demand and supply, access to sufficient information) address issues associated with poor quality and inflexible care practices. However, in rural and remote communities there is rarely an equilibrium of demand and supply. Indeed, in the communities under study, basic public infrastructure such as transport was not reliably available and support services tended to be limited - if available at all - offering clients very little choice (see, for instance, Spall, McDonald, & Zetlin, 2005). In such contexts, the potential of CDC to result in more choice and control for clients rarely materialises – even assuming sufficient access to information. What is more, the current individual–focused operational framework of CDC creates powerful barriers for the establishment of care arrangements grounded in Aboriginal culture (i.e. family-focused and family controlled) that would allow for the allocation of resources to where they are needed in the family support structure of Indigenous Elders. In fact, CDC can lead to a monetisation of relationships, which undermines the development of a communal care system based on kinship responsibilities. More importantly still, CDC is unlikely to overcome a culture of racism, stereotyping and distrust that assigns Aboriginal Elders, despite their standing in the wider community, the role of un-deserving welfare parasites whose access to resources ought to be restricted. However, such vestiges of racism, albeit often barely visible and often subconsciously reproduced, are still ingrained in the relationships between Aboriginal and non-Aboriginal Australia. The insidious presence of often microscopic particles of racial prejudice still

infiltrates administrative power and informs a wide range of decisions creating formidable barriers to social justice.

One central theme clearly emerged from our conversations with participants: holistic, family-focused and community controlled aged care services that resonate with Indigenous Elders can only be developed with their input and that of their kinship networks. Culturally safe services require a transfer of power and control from aged care staff to Indigenous Elders and their communities (see also Casey, 2014; LoGiudice et al., 2012; Smith, Flicker, Lautenschlager, Atkinson, & LoGiudice, 2008; Smith, Grundy, et al., 2010a; Stewart et al., 2011) and the development of a relationship of mutual trust and respect (Isaacs et al., 2013). Such a transfer of power can take many forms including aspects of authentic co-design, a process that has been endorsed widely as key to better policy making. However, authentic co-design is built on the premise of shared control and decision making requiring a fundamental change of culture from service providers (Stewart et al., 2011).

### **Limitations:**

Irrespective of how rigorously executed, all research has limitations and the research underpinning this article is no exception. As mentioned above, the Aboriginal Elders involved in the research constituted a heterogeneous group. Hence, it is unlikely that our sample of 11 participants allowed us to provide an exhaustive account of all issues of importance to Aboriginal Elders in the region under study. Nevertheless, the research canvassed a range of core issues that are of key importance to participants. In order to mitigate the limiting influence of the sample size, the researchers consulted widely with Indigenous Elders/leaders and representatives of health and social care organisations providing services to Indigenous Elders in the region. Nevertheless, the above-mentioned findings should not be transferred to contexts beyond the communities in which the data was gathered. As mentioned above, Aboriginal culture is extremely diverse and so are the life histories of older Indigenous people.

Due to the limited scope of this article, a range of issues commonly encountered in rural and remote locations, such as a lack of collaboration between service providers, the problem of geographical distance between clients and service providers, the limited availability of services, and the increased cost of goods and services were not discussed. They are discussed extensively in the above-reviewed literature.

## **Conclusion**

This article provided an outline of an ongoing conversation structured around group and one-on-one discussions with 11 Aboriginal Elders who ‘returned’ to three communities in regional and remote Australia, as well as representatives of regional health and social care organisations. The article lends further weight to research that reports that a mainstream approach to the aged care of Indigenous Elder is likely to produce poor care outcomes for the majority of clients. To some extent, the sub-optimal care outcomes described in this article are the result of a cultural disjuncture and the tension between Elders’ quest to reconnect with a kinship system that is communal in focus and a ‘conventional’ mode of service delivery that is individually focused and rigidly structured around a canon of home and personal care. This tension led to the situation where Aboriginal Elders were unable to receive culturally safe assistance and have their psycho-social support needs met. Instead, they received mainstream services the majority of respondents did not really need. In light of the above, it is not surprising that the majority of Indigenous Elders participating in this research regarded ‘conventional’ services as irrelevant.

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