

1-1-2008

## **Aboriginal ageing and disability issues in South West and Inner West Sydney**

Terri Farrelly  
*The Echidna Group*

Bronwyn Lumby  
*University of Wollongong, bcarlson@uow.edu.au*

Follow this and additional works at: <https://ro.uow.edu.au/artspapers>



Part of the [Arts and Humanities Commons](#), and the [Social and Behavioral Sciences Commons](#)

---

### **Recommended Citation**

Farrelly, Terri and Lumby, Bronwyn, Aboriginal ageing and disability issues in South West and Inner West Sydney 2008, 27-34.  
<https://ro.uow.edu.au/artspapers/1313>

# Aboriginal Ageing & Disability Issues in South West and Inner West Sydney

**DR TERRI FARRELLY & BRONWYN LUMBY**

*The Echidna Group – Indigenous Research & Development Consultancy*

## Introduction

The Department of Ageing, Disability & Home Care (DADHC) recently sought to conduct a needs analysis and develop resources that would provide the Sydney Metro South region with tools to assist in planning for service development activities, Home and Community Care (HACC) planning processes, and project development around access issues in Aboriginal communities. The Echidna Group Indigenous Research & Development Consultancy was externally contracted by Campbelltown City Council, and by Inner West Aboriginal Community Company, to complete the project objectives for the DADHC South West and Inner West Sydney Local Planning Areas. This article reports the results of community consultation activities in these regions which aimed to determine the needs and issues of Aboriginal people in regard to ageing and disability.

## Background

Australia, like many other western countries, has an ageing population. The proportion of the Australian population aged 65 years and over has risen steadily over the past two decades and is projected to rise further over the next 50 years. The major contributors to this trend are the large numbers of ageing 'baby boomers', increased life expectancy, and declining fertility rates (Australian Indigenous HealthInfoNet, 2007). The age structure of the Indigenous population differs notably from that of the total Australian population. More akin to patterns in developing countries, children and young people represent a much greater proportion of the Indigenous population, while there are relatively few older people (Australian HealthInfoNet, 2007). The lower proportion of older Indigenous people is attributed to the lower life expectancy of Indigenous Australians – approximately 15 to 20 years lower than that of the non-Indigenous population (Australian Bureau of Statistics (ABS), 2000, cited in Australian HealthInfoNet, 2007).

According to 2006 Census figures, there were 455,031 Indigenous Australians, representing 2.3% of the total Australian population (ABS 2007). Utilising these 2006 Census figures, it can be calculated that 17.1% of the Indigenous population is aged 45 years and over, compared to 38.8% of the non-Indigenous population (ABS 2007). Only 8.2% of the Indigenous population is aged 55 years and over, compared to 24.7% of the non-Indigenous population. Only 3.3% of the Indigenous population is aged 65 years and over, compared to 13.4% of the non-Indigenous population. Only 1.1% of the Indigenous population is aged 75 years and over, compared to 6.4% of the non-Indigenous population. These differences are attributed to

the lower life expectancies among the Indigenous population, with Indigenous males born during the period 1998 to 2000 having a life expectancy of 56 years; 21 years less than that for the non-Indigenous male population. Indigenous females have a life expectancy of 63 years; 20 years less than that for the non-Indigenous female population (ABS 2002c, cited in Australian Institute of Health and Welfare (AIHW) 2002). Indigenous people are at a higher risk of poor health due to factors such as poor nutrition, obesity, substance abuse, exposure to violence, inadequate housing and education, low income and unemployment.

As a result of such differences in health status and life expectancy for Indigenous Australians, the Aged Care Act 1997 acknowledges that planning for services for older Indigenous people needs to be calculated on the number of Indigenous people aged 50 years and over, instead of 70 years and over, as applicable to the non-Indigenous population (AIHW, 2002). The Home and Community Care (HACC) program also acknowledges these disadvantages by adjusting the age determination for Aboriginal people to 45 years, compared to 65 years for non-Aboriginal people.

Little is known about the level and types of disability prevalent within the Indigenous population (Disability Services Commission, 2006). There is evidence to suggest that the level of disability and handicap may be around twice the level experienced by the non-Indigenous population, possibly attributed to complex factors linked to social disadvantage and the effects of colonisation. As a result of data collected by the 2002 National Aboriginal and Torres Strait Islander Social Survey (NATSISS), the ABS and AIHW (2005) report that 36% of Indigenous people aged 15 years or over had a disability or a long term health condition, with 8% of these reporting a profound or severe core activity limitation, meaning they needed assistance with at least one activity of daily living. Indigenous people were 2.1 times more likely than non-Indigenous people to have a profound or severe core activity limitation, with the rate of limitation among Indigenous people aged 45-54 years as high as that found among non-Indigenous people aged 65 years and over. Indigenous people were found to be more likely to have disabilities of all types, and to have two or more disability types, than their non-Indigenous counterparts. Disability amongst the Indigenous population was strongly associated with fewer years of education, unemployment, low income, financial stress, being removed from the natural family, and having relatives removed from the natural family.

The Aboriginal Disability Network of NSW (2007) reports that despite gaining an increased profile, the needs of the vast majority of Aboriginal people with disability and their carers remain unmet, and very few Aboriginal people with disability

access any of the range of disability services available. In terms of Indigenous use of disability services, the NATSISS (ABS & AIHW, 2005) found that Indigenous service users reported a somewhat more frequent need for support than other service users, and were on average younger, with a median age of 25 years compared with 31 years for other service users. Indigenous service users were more likely to report having an informal carer than other service users, and more likely to report relatives other than their mother as primary carer, which may be a reflection of the extended kinship patterns in many Indigenous families. Nearly one-quarter of Indigenous people with a profound or severe core activity limitation stated that they could not get to, or had difficulty getting to, the places they needed to go.

The AIHW (2005, cited in ABS & AIHW, 2005) reports that as at 30 June 2004, Indigenous Australians make higher use of residential aged care services at relatively younger ages than their non-Indigenous counterparts. Indigenous people comprised 0.6% of all permanent residents in mainstream residential aged care services, and 0.7% of all people in respite care. Indigenous people comprised 4% of clients receiving mainstream Community Aged Care Packages, as well as there being 243 packages provided to Indigenous clients through 29 services operating under the Aboriginal and Torres Strait Islander Aged Care Strategy. Approximately 46% of Indigenous care recipients were under 65 years of age, compared with less than 8% of non-Indigenous care recipients. Approximately 20% of Indigenous care recipients were aged 75 years or over, compared with 74% of non-Indigenous care recipients. Indigenous clients comprised 2.4% of clients receiving HACC-funded services. Indigenous HACC clients also had a younger age profile than non-Indigenous clients, with 60% of Indigenous clients being under 65 years of age compared with 23% of non-Indigenous clients.

## Research Design

This needs analysis was conducted through the use of consultation activities with key stakeholders, and a review of the relevant literature. Consultation activities adhered to the ethical guidelines for Aboriginal health research stipulated by the National Health & Medical Research Council (2003; 2005). Consultation activities targeted key stakeholders in the South West and Inner West Sydney regions, with criteria for inclusion in any aspect of these consultation activities consisting of Indigeneity, being a resident in the South West and Inner West Sydney regions, and being aged 18 years or over. Key stakeholders could be those defined as aged or with disability, carers, service providers, consumers of aged and disability care services, or community members with vested interest. The use of semi-structured in-depth interviews, triangulated with the use of focus groups. A total of 43 interviews were conducted with participants from all of the fourteen Local Government Areas in the DADHC South West and Inner West Sydney Local Planning Areas, followed by fourteen focus groups located in each LGA, with a total of 77 participants. Thematic analysis conducted on data collected resulted in a set of categories which were further enhanced by a review of the relevant literature.

## Findings

### Data & Knowledge Issues

#### *Poor Knowledge of Prevalence*

A number of participants, notably those who provided Aboriginal health and wellbeing services, commented on the lack of public knowledge about prevalence of Aboriginal disability and related issues. This has also been noted by the Aboriginal Disability Network of NSW (2003) and the Disability Services Commission (2006), who report the lack of statistical data quantifying the prevalence of disability in Indigenous communities. It was stated by participants in focus groups that, in general, the identification, acknowledgement or recognition of individuals with a disability in Indigenous communities is typically minimal, and families are relatively unlikely to seek help from available support services. Explanations offered for this included differing cultural perceptions of disability and helping, and the likelihood that the focus within Indigenous communities is more often on survival rather than disability issues, despite the recognition that the poorer health status of the Indigenous population would result in a higher level of disability than that experienced in the general population.

### Help-Seeking Issues

#### *Poor Help-Seeking Knowledge and Skills*

As a result of past policies affecting Indigenous people, many Aboriginal people lack the knowledge and skills that can facilitate effective help-seeking. In the transmission between assimilation practices, which fractured many Indigenous helping and help-seeking channels, and the ideals of self-determination, failure to replace the forced dependence entrenched by the missions and reserves with any independent help-seeking knowledge and skills essential for successful access to western systems of assistance, has resulted in an inability for many to negotiate help in mainstream society, and a difficulty for many in re-establishing or re-connecting Indigenous channels. Given that the older members of the South West and Inner West Sydney Indigenous population experienced these policies and changes first hand, it is not surprising that difficulties related to help-seeking for aged care and disability needs are now evident.

Discussions with interview and focus group participants found that seeking help for ageing and disability needs was something that simply did not occur to many as an option. For those who had considered help-seeking, the lack of knowledge and skills regarding who and how to access help was described by several as a potential source of shame. This general lack of effective help-seeking skills that enable access to help resources also appears to result in an Aboriginal help-seeking behaviour that characteristically involves waiting until the situation reaches the crisis stage.

These sentiments are also noted extensively in the literature. A needs analysis conducted by Dance, Brown, Bammer & Sibthorpe (2000) targeting Aboriginal people aged 45 years and over in the ACT found that the desire to be independent, and feelings of shame, were common obstacles to help-seeking. Participants identified the need for education which targets potential clients, providing information about what services are available and how to access them as a means of

overcoming such obstacles.

Leipoldt (1998) conducted research into the reasons for an apparent low use of advocacy agencies in Perth by Aboriginal and Torres Strait Islander people who have a disability, in a context of high vulnerability. Nine Aboriginal people with disability were interviewed about their experiences with regard to their disabilities and any need for advocacy. The findings regarding barriers to accessing advocacy include a complete absence of participant awareness of advocacy or advocacy agencies, as well as Aboriginal 'shyness', poverty, effects of long-term discrimination, powerlessness, the wider Aboriginal background of abuse, lack of Aboriginal workers in advocacy agencies, and tensions between Aboriginal groups.

Participants also noted the fear, suspicion and mistrust experienced by many Aboriginal people in regard to strangers, including service providers entering their homes, or even enquiring about their lives and wellbeing. Consultations conducted by the Disability Services Commission (2006) with Aboriginal people with disabilities, their families and carers, and service providers across Western Australia found that some Aboriginal people feel that there is a stigma associated with being registered with a disability services agency. Consultations also found that many Aboriginal people are reluctant and even afraid to ask for information and assistance from agencies due to negative experiences with past government policies and practices. The Aboriginal Disability Network of NSW (2007) reports that many Aboriginal people are reluctant to identify as having a disability due to a fear of further discrimination related to their disability as well as their race. They also note that many parents of Aboriginal children with disability are reluctant to access services because of a retained fear of their children being removed by government authorities (Aboriginal Disability Network of NSW, 2003).

#### *Poor Knowledge of Available Services and How to Access Them*

Many participants were unaware of what services were available, and how they could access them. It should be noted that this included participants who were already currently accessing HACC-funded services such as Elders Groups. This indicates that being a current consumer of such services does not always result in further assistance in accessing other related services.

The majority of help services available for Aboriginal ageing and disability needs are 'formal' by their nature. There are procedures and protocols that must be followed in order to gain access, that to the uninitiated, unaccustomed, or those to which the service is not directly targeted, can be incredibly daunting. A number of participants described the pamphlets that advertise available services for aged care needs as being difficult to understand, causing them stress and compounding the lack of knowledge of available services and how to access them.

#### *Perceived and Experienced Cultural Inappropriateness of Services*

A number of participants described ageing and disability help services as being culturally inappropriate. For some participants this was based on a perception resulting from what they had heard or seen about the service and its service

delivery. For others, this was based on their actual experience of contact with the services.

The location of some of the services, and the facilities they utilised was described as one element of service delivery that was culturally inappropriate. For example, the location of Elders Groups and day care services in community health centres was described as *'putting people off'*. The style of helping adopted by ageing and disability help services was another element of service delivery described as being culturally inappropriate and a potential obstacle to access for Aboriginal community members. For example, one participant who actually worked for a HACC-funded service, explained that her mother needs assistance with domestic and personal care but refuses to access services because she perceives the manner that these services are provided as being somewhat akin to when *'... the welfare used to come into people's houses and inspect everything'*. Service delivery particular to ageing and disability care services was described as *'regimental'*, and *'like old times'*. While some of the issues indicated by participants may be disputed or questioned by others, the importance lies not in the details of whether some of these issues and stories are entirely correct in terms of the facts, but in the reality that these issues and stories are part of South West and Inner West Sydney Indigenous perceptions about ageing and disability issues, needs, service availability and service provision. It is these perceptions that can influence Indigenous help-seeking and access to available services.

### **Access Issues**

#### *Lack of Available Ageing and Disability Services*

Although the Home and Community Care (HACC) program offers a wide range of support services to assist the frail, aged and people with a disability, including their carers, to remain independent at home for as long as possible, including some Aboriginal-specific services, they are often limited by lack of funding or by agency rules and criteria about what they can and cannot provide. The current HACC-funded services which were consulted reported experiencing difficulty meeting the needs of all existing clients, let alone new clients requiring support.

The common complaint of all consultation participants related to a general lack of ageing and disability services in the South West and Inner West Sydney area. This is also evidenced in various consultation activities conducted by the Local Government Areas of both regions. The shortfall of services is common to findings of other studies into Aboriginal ageing and disability needs. For example, the Aboriginal Disability Network NSW (2003) noted the lack of support available to younger Aboriginal people with disability, particularly children, and parents of Aboriginal children with disability.

#### *Lack of Aboriginal-specific Ageing and Disability Services*

Participants described a lack of Aboriginal-specific ageing and disability help services in the South West and Inner West Sydney area, and only limited access to the Aboriginal-specific services that do exist. For example, it was reported that there was no Aboriginal-specific aged care facility in the area, and care provided by Aboriginal Home Care services was reported to be limited. In regard to Aboriginal-specific ageing and disability services, of interest are reports from several participants

regarding the difficulty faced by some people within the Inner West region who identify as Indigenous, yet have their identity either challenged or not accepted by other members of the Indigenous community when attempting to access Aboriginal-specific services.

Research conducted by Baldry, Green & Thorpe (2006) involving urban Aboriginal communities within the Sydney region found that the lack of Aboriginal-specific services was tantamount to institutionalised racism, ignoring the differing historical and political backgrounds of Indigenous people, and assuming that existing mainstream services are universally accessible to Aboriginal persons. The research also highlighted the issue of Aboriginal people in urban areas who do not necessarily have stereotypical physical features commonly recognisable as 'Aboriginal', resulting in the misconception of many fellow non-Indigenous community members that there are few, if any, Aboriginal people living in the area.

#### *Lack of Social Support*

The need for social support ranked highest among participants. In terms of aged members of the Indigenous community, this included the need for more social outings, cultural activities, interaction with the community such as speaking to youth in schools, and more meaningful activities in day care and Elders Groups. Participants who were Elders themselves reported being very detached from cultural activities and involvement with their communities. Many participants also indicated the need for support services for older Indigenous people who have drug dependent kin, and/or who are caring for grandchildren. A needs analysis conducted by Dance et al (2000) targeting Indigenous residents of the ACT aged 45 and over, found that many participants played a major role in rearing grandchildren, or other family members, as well as their own children. Of the 98 participants, 36 had current dependants.

In relation to social support, many participants who were health professionals reported concern at the rate of elder abuse occurring in the community – physical, emotional and financial.

In terms of Indigenous people with disabilities, the need for social support included the need for social activities that are not exclusively for people with disabilities, meaningful activities for those aged between 30–55 years, and one-on-one support for participation in sport and recreation.

#### *Lack of Education and Employment Opportunities*

In terms of disabled members of the Indigenous community, participants reported a lack of support for Aboriginal children with disability in regard to their education, and a lack of meaningful activities, both employment and leisure, for Aboriginal children and adults with disability. This situation has reportedly worsened since the closure of the Community Development Employment Program (CDEP) in the region.

#### *Lack of Respite and Other Carer Support Services*

In terms of caring for aged and disabled people in the Indigenous community, participants described a lack of respite services. A number of participants who worked in health and wellbeing services described their current situation of finding that carers were often not accompanying clients to appointments. These participants felt that this may be a reflection of the lack of

respite services, in that carers were using client's appointments with health and wellbeing services as an opportunity for a 'short break'. The same participants also reported a lack of family involvement in the care of Elders.

Consultations conducted by the Disability Services Commission (2006) with Aboriginal people with disabilities, their families and carers, and service providers across Western Australia found that many Aboriginal carers did not have sufficient support, and were unaware of existing available respite services or how to find them. The project found that many Aboriginal people, predominantly females, cared for their family member with a disability as well as supported or cared for others such as grandchildren or older parents. The project also found that Aboriginal people who were carers preferred to utilise help from other family members rather than bring in outside help for respite. However, it was also acknowledged that many carers did not have other family members available, leaving limited respite options.

#### *Lack of Transport Services*

Transport services also ranked highly among participants' needs, with there being one Aboriginal-specific transport service in the South West region, and none in the Inner West. Other Aboriginal organisations reported finding themselves frequently in the position of having to fill the gap, despite not being funded to provide such services. The costs associated with transport to medical appointments and social events, particularly outside of business hours, was also highlighted by participants, many of whom were questioning why there was a fee. One focus group reported difficulty in getting transport to attend funerals.

Consultations conducted by the Disability Services Commission (2006) with Aboriginal people with disabilities, their families and carers, and service providers across Western Australia found that many Aboriginal families do not have access to private use of a car, and the lack of transport limits opportunities for Aboriginal people with disabilities to participate in family and community activities. Much public transport is often not accessible by people with disabilities, as can be taxis, which are also expensive. The Aboriginal Disability Network of NSW (2007) reports that many of the communities visited during consultations experience little or no access to public transport, and often no public transport infrastructure. Participants identified a lack of transport as a major barrier to accessing services and both mainstream and Indigenous community activities.

#### *Lack of Home and Yard Maintenance Services*

Home and yard maintenance also ranked highly among participants' reported needs. Again, many of the participants who reported needing lawns and gardens maintained, and windows, gutters, stoves and fridges cleaned were already accessing other HACC-funded services such as day care or Elders Groups. The need for an Aboriginal lawn mowing and gardening service in both regions was emphasised by all focus groups.

#### *Lack of Health and Wellbeing Programs and Activities*

A number of participants reported the lack of necessary allied health services fundamental to people who are aged or have



a disability, such as counselling, podiatry, physiotherapy, hydrotherapy, and other rehabilitation services. It was also highlighted that due to the lack of Aboriginal-specific health services in the region, health education and promotion activities targeting Aboriginal community members who are aged or have a disability are rare. Participants gave examples of such desired and required health education activities, including nutrition, exercise, and falls prevention.

#### *Lack of Advocacy Services*

Participants who worked in health and welfare fields providing Aboriginal-specific services reported a lack of advocacy services for Aboriginal aged and disabled community members in the South West and Inner West Sydney regions, with many of these participants reporting that in their professional roles they often inadvertently 'get caught up' advocating for clients despite it often stretching outside of their role. Some participants described doing this because of their felt obligations to the Aboriginal community in their role providing Aboriginal-specific services.

Research conducted by Baldry, Green and Thorpe (2006, p.371) targeting Aboriginal communities in Sydney found that in regard to standing up for rights as a consumer of human services, Aboriginal community members commonly reported that they themselves, and others within their community, '*did not have the education, power, ability or confidence to argue their case and push the department to perform*'. During data collection for their ACT Indigenous Aged Care Needs Analysis, Dance et al (2000) found their role stretched to that of advocacy, providing advice about medical conditions, making appropriate referrals, and assisting with access to services. The authors suggest that an outreach service could be of value in improving the health and wellbeing of older Indigenous people, and cite the success of a similar model in New Zealand.

#### *Costs*

Participants reported the costs of transport, equipment and services to be obstacles to accessing what they need. Participants gave examples of costs for transport to shopping, for having groceries picked up, and for social events.

#### *Excluding Criteria*

Many participants reported perceptions of certain criteria that excluded people from being able to access services, particularly transport, examples being whether or not you live within certain geographical boundaries, and having a disability as well as working. Other participants had conflicting views of what costs were charged for particular services. These misinformed perceptions appear to act as major obstacles to accessing services.

#### *Physical Access*

Physical access to services continues to be an issue. A number of participants reported that many areas within their community were physically inaccessible to them, or difficult to access, making them unable to attend various activities, and impacting on their lifestyle. Examples were given of Elders Groups meetings having limited available venues, with some not having wheelchair access, thereby excluding some members from attendance.

#### *Homelessness*

Participants working in health and welfare fields reported having problems finding suitable homes for aged and disabled Aboriginal clients. Many clients were reported to be in current 'holding patterns' which consisted of moving from one relative or friend's residence to another while awaiting suitable housing. Other complaints involved clients who had surrendered their home to the Department of Housing under the promise that in return they would receive a more suitable residence, only to then find themselves homeless, and waiting for the allocation of suitable housing. Waiting periods were reported to be up to two years and still unresolved for some clients.

The Aboriginal Disability Network of NSW (2003, 2007) indicates that there is a serious lack of modified housing options available to Aboriginal people with disability, and report jurisdictional conflicts between Aboriginal housing providers in the provision of such accommodation. Aboriginal people with disability in NSW often live in inaccessible and poor standard housing with no, or irregular, maintenance. There is also a shortfall of housing stock, resulting in long waiting lists for public housing. They found that mainstream and Aboriginal housing authorities do not prioritise the availability of accessible housing in regional and remote areas, and disability does not appear to be high on the agenda, if included at all, in terms of entry criteria. As a result of these issues, overcrowding is a major issue for large and extended families. Many participants reported extreme frustration in dealing with the NSW Department of Housing particularly in regard to home modification and maintenance, due to a lack of knowledge of rights, and perceived and experienced discrimination.

#### **Service Delivery Issues**

##### *Poor Staff Manner*

Some participants reported having had negative experiences both with staff from Aboriginal-specific HACC-funded services and with staff subcontracted by these services, particularly relating to staff being '*rude*', '*disrespectful*', '*judgemental*', having an '*insensitive manner*', and '*lacking compassion*'. One participant described incidents of staff arriving at her home to provide care services at the wrong time, and entering her home without knocking. Participants stated that such experiences made them prefer to go without the services than have to encounter poor staff attitudes. Another participant described the rude manner of staff as 'shaming'.

##### *Poor Staff Skills*

One participant reported that staff of an Aboriginal-specific HACC-funded service did not have the skills necessary for her care, particularly relating to transferring from a wheelchair. Several participants complained of a poor quality of service provided by staff of Aboriginal-specific HACC-funded services.

##### *Poor Staff Cultural Awareness*

Many participants reported that many staff members providing home care services, both Aboriginal-specific and mainstream, are culturally incompetent. This appeared to apply particularly to staff of services subcontracted by Aboriginal-specific HACC-funded services to deliver services such as personal care and domestic assistance, with participants reporting that many of these staff members are often from non-English speaking

backgrounds. Focus group participants unanimously agreed that all staff of these services, including Aboriginal staff, should undertake cultural awareness training. Explanations for why Aboriginal staff should also undertake such training included the fact that some Aboriginal staff may have only become aware of their Indigenous heritage later in life and be unaware of historical and current factors affecting Indigenous people in the South West and Inner West regions, as well as the need to make Aboriginal staff aware of the issues faced by Indigenous people in the region who know little about their Indigenous heritage and may have difficulty being accepted in the local Indigenous community.

Baldry, Green and Thorpe (2006) found that common experiences of Aboriginal people in the Sydney region when accessing human services included receiving a lesser quality service due to racism and ignorance, noticing a subtle but clear and negative change in attitude once Aboriginal status was realised, false stereotyping which affected services received, and simply assuming the Aboriginal client should see the Aboriginal worker. Participants reported feeling that cultural awareness training was often 'taken begrudgingly by workers' resulting in little attitudinal change (Baldry, Green & Thorpe, 2006 p. 370).

#### *Confidentiality Concerns*

While the majority of participants agreed with the commonly held view that Indigenous people prefer to access Indigenous-specific services, it was noted that this is not always the case. For Indigenous people accessing their local Indigenous-specific organisation, it is highly likely that the particular organisation is staffed by people who are well known, if not related or closely connected to them in some way. This can present particular confidentiality concerns in certain circumstances. For this reason, participants emphasised that it is important that Indigenous people have a level of choice available in terms of service providers.

#### *High Staff Turnover*

Participants working in health and welfare fields providing Aboriginal-specific services reported a high level of staff turnover, particularly among Aboriginal workers in ageing and disability support services. This has also been reported by the Aboriginal Disability Network of NSW (2003), which indicates there is high staff turnover among Aboriginal workers who provide direct support to Aboriginal people with disability due to the extent of the unmet need prevalent within communities.

#### *Manner and Cultural Awareness is More Important Than Indigeneity*

The majority of participants indicated that they had no specific preference for home care services to be provided by either Indigenous or non-Indigenous staff members, as long as they were respectful, considerate, culturally aware and sensitive. All participants agreed that it was the manner of the staff member in their service delivery that was more important than whether or not they were of Indigenous descent. However, a number of participants indicated that they knew of other Indigenous members of the community who would access services only if they were provided by an Indigenous person. Baldry, Green and Thorpe (2006 p.368) found that a common

perception among Aboriginal clients of human services is that an Aboriginal worker is more likely to make the effort to direct them to appropriate services according to need, and that they '*... have an understanding, they know how to communicate with Koori clients and they get things done. They're also more informal and talk a different language*'.

A needs analysis conducted in the ACT targeting Indigenous seniors found that in terms of residential aged care services, 32% of participants would prefer Indigenous-run services, and 50% expressed a preference for an arrangement whereby an existing mainstream service would 'cluster' Indigenous people together in a section of the facility (Dance et al 2000). Just over half (54%) of participants did not have a preference for an Indigenous or non-Indigenous carer, and the majority of the remaining participants (43%) expressed a preference for an Indigenous carer. The authors state there was a general agreement among participants that the essential qualities were properly trained staff, respectful manners and ways of addressing clients and ongoing monitoring of service provision. The majority of female participants expressed a preference for a female carer to provide personal care, while the majority of men stated they did not mind if the carer providing personal care was male or female. Of those participants expressing a preference for a non-Indigenous service, reasons cited were related to confidentiality, and fairness.

#### *Communication Problems*

Many participants reported communication problems between service staff, between services and sub-contracted services, and between services and clients. Participants who worked in health and wellbeing services reported difficulty in communication with carers due to some carers not accompanying clients to appointments, and this was felt to be possibly due to the lack of respite available for carers.

#### *Poor Quality of Service Provision*

A number of participants reported feeling that the quality of service provision by the Aboriginal Home Care service was poor, inconsistent, inefficient, and not effectively meeting the needs of the South West and Inner West Aboriginal communities.

#### *Lengthy Delays Receiving Services*

Several participants offered stories of their experiences with Aboriginal-specific HACC-funded services that included lengthy delays in receiving services, leaving the individuals involved with no services at all. These delays reportedly extended to as long as 12 months for one particular client, and to as far as three years in the Campbelltown region. One particular case reported by health professionals in the Campbelltown region involved a client suffering from cancer. A number of health professionals were involved in trying to organise basic cleaning services through the Aboriginal Home Care service. After approximately three years of this process, the Aboriginal Home Care service reportedly contacted the client to report that services were finally able to commence, only to find that the client had unfortunately passed away.

#### *Factionalism*

Factionalism was reported to be affecting communication and support between several Aboriginal organisations and groups

in the regions, impacting on both service provision and access to services.

### *Culturally Inappropriate Helping Styles*

Some participants spoke of the helping styles adopted by Aboriginal-specific HACC-funded services, and the services they subcontract, as being culturally inappropriate. One main issue appeared to be time – staff members were described as having to work to a time-limited schedule and are typically unable to spend additional time with a client if they felt it was necessary or appropriate. This also appeared to be related to the issue of flexibility of service provision, with some participants describing service provision as rigid and inflexible, unable to adapt according to clients' needs.

There is very little information available regarding Indigenous perceptions of disability, and regard for people with disabilities (Disability Services Commission, 2006). Prior to colonisation, it seems that perceptions of disability differed to Western perceptions, with disabled individuals treated and responded to in the same way as others within the group. Having a disability was not seen as something that defined an individual as being separate or different to the rest of the group. For example, the Disability Services Commission (2006) reports that the Ngaanyatjarra, Pitjantjatjara and Yankunytjatjara people had no general word for disability to separately identify people with impairments from others within the group. Individuals were cared for within the extended family kinship system, and assumed the same social obligations, responsibilities and roles as would be expected of others. It appears that it was this engagement with family and fulfilment of social roles that influenced an individual's perception of their 'ability', and those with impairments were otherwise unaware of the extent to which their disability served as a handicap (Disability Services Commission, 2006).

Ariotti (1997) conducted research into how the Anangu peoples in ten remote communities in the cross border region of South Australia, Western Australia and the Northern Territory perceive disability. The research targeted Aboriginal people with disabilities, their families and community members, the workers of the Disability Support Project and the Commonwealth Rehabilitation Service. A total of 53 Aboriginal individuals were interviewed about their perceived disability. The participants outlined many specific characteristics of disability, all of which are the associated realities that combine in the ongoing construction of disability. Ariotti states that this construction is occurring in the evolving and often tragic historical context of colonisation. For the Anangu, Ariotti concludes this means that dealing with disability is primarily an issue of regaining and retaining control of the care of their family members who have severe disabilities. Ariotti also concludes this means that the Anangu control the type and provision of services offered by other agencies.

Consultations conducted by the Disability Services Commission (2006) with Aboriginal people with disabilities, their families and carers, and service providers across Western Australia found that Aboriginal people continue to be less familiar with the term 'disability' and the context of which is it is understood in Western culture, and this is evidenced in a number of aspects:

- Some Aboriginal cultures maintain various cultural and

mythological beliefs about the reasons for a disability occurring, such as a birth defect being the result of the mother's actions during pregnancy (for example, the mother treading on a goanna's back whilst pregnant), however such beliefs generally do not result in any form of discrimination against the mother or child;

- Many Aboriginal people consider both health and disability-related conditions to be 'disabilities' – for example, diabetes may be considered by many as a disability because of the restrictions it may cause to daily activities;
- Many Aboriginal people consider Aboriginal families to be more accepting and supportive of disabled individuals than non-Aboriginal families, as individuals continue to be included within their extended families, assuming their social roles, responsibilities and obligations where possible; and
- Disabilities are not emphasised in Aboriginal community life, which means that Aboriginal families may not readily identify an individual's disability, or the potential for assistance from services.

In their review of the literature on disability services for Aboriginal and Torres Strait Islander peoples, O'Neill, Kirov and Thomson (2004) summarise the main features as being:

- Individuals with a disability not being excluded from or stigmatised in their community;
- The belief that some disabilities may be 'pay-back' for a past wrongdoing, while others may be perceived as something 'special';
- Independence may not be regarded as a major issue;
- Disability may be perceived as a family or community problem rather than just an issue for the individual concerned;
- An individual with a severe disability may be regarded as being the responsibility of 'welfare'; and
- An individual may be identified and named after their disability (eg. 'one eye').

The Aboriginal Disability Network NSW (2003, 2007) reports that Aboriginal issues are inappropriately included in mainstream disability programs. They emphasise the inappropriateness of current mainstream disability services which fail to take into account the social as well as health perspectives of disability, and lack a holistic approach to service delivery. The impact of living with disability as an Aboriginal person relates to the whole of life of the individual. It is not enough to assume that an Aboriginal person with disability simply requires support for one facet of their life.

Despite the preference and apparent trend for Aboriginal people with disability being cared for by extended family, it needs to be acknowledged that this situation can often be difficult for many families, due to low income, alcohol misuse, family breakdown, inconsistencies in care, family allegiances affecting access to particular services, and carer's lack of knowledge regarding how to care and what services are available (O'Neill, Kirov & Thomson, 2004).

### **Funding Issues**

#### *Funds Need to be Distributed More Evenly*

Participants reported that while some Aboriginal organisations/groups were receiving no HACC or DADHC funding and were struggling to continue to provide services, others were receiving relatively strong funding. This gave some participants



the perception that DADHC was 'taking sides' in terms of factionalism, by supporting one faction while neglecting another.

### *Many Aboriginal Organisations/Groups Are Already Providing Support Services Without HACC or DADHC Funding*

Consultations with Aboriginal organisations and groups in the South West and Inner West Sydney regions found that many are already providing support services that comply with HACC service types, without HACC or DADHC funding. These services most popularly included social support, advocacy, and home and yard maintenance.

### *Organisations/Groups Need Additional Funds to Provide Quality Services*

Many participants, both staff of Aboriginal-specific HACC-funded services and community members, reported that Aboriginal organisations and groups, whether they did or did not currently receive HACC or DADHC funding, required additional funding in order to provide quality services to clients. This included the need to utilise a suitable venue or improve an existing venue, conduct appropriate activities, gain transport, enable clients to engage in meaningful pursuits, provide outings and events. The Aboriginal Disability Network of NSW (2003) notes that Aboriginal disability services are under-funded and under-resourced, greatly limiting their ability to meet the needs within Aboriginal communities.

## **Conclusion**

These findings are being utilised by DADHC to develop strategic responses that are specific to the South West and Inner West Sydney Aboriginal communities. While many of the needs and issues identified in consultation activities with members of Aboriginal communities within the South West and Inner West Sydney regions apply to the unique situation of these areas, the majority of issues have also been identified in various other consultation activities across Australia. Of importance, and interest in terms of literature and evidence base, is how such needs and issues are addressed, both in locally-specific and wider contexts.

## **References**

Aboriginal Disability Network of NSW (2007) *Telling it like it is: A report on community consultations with Aboriginal people with disability and their associates throughout NSW, 2004-2005*. Strawberry Hills, NSW: Aboriginal Disability Network of NSW. Retrieved January 3, 2008, from: [http://www.pwd.org.au/adnsw/news/telling\\_it\\_like\\_it\\_is.doc](http://www.pwd.org.au/adnsw/news/telling_it_like_it_is.doc)

Aboriginal Disability Network of NSW (2003) First state conference November 18–20, 2002 Gibba Gunya Stone Quarry Lodge, Picton NSW. Retrieved January 5, 2008 from: [http://www.pwd.org.au/adnsw/news/conference\\_report.doc](http://www.pwd.org.au/adnsw/news/conference_report.doc)

Ariotti LJ (1997) *'The newly planted tree': an exploration of Anangu perceptions of disability*. Unpublished Master of Science thesis, Flinders University of South Australia, Adelaide, South Australia.

Australian Bureau of Statistics (2007) Indigenous Status by Age Australia Count of persons based on usual place of residence Cat. No. 2068.0 2006 Census Tables, Retrieved April 22, 2008 from: <http://www.censusdata.abs.gov.au/ABSNavigation/prenav/ViewData?breadcrumb=TLPD&method=Place%20of%20Usual%20Residence&subaction=-1&issue=2006&producttype=Census%20Tables&documentproductno=0&textversion=false&documenttype=Details&collection=Census&javascript=true&topic=Indigenous%20Population%20Size%20%26%20Distribution&action=404&productlabel=Indigenous%20Status%20by%20Age&order=1&period=2006&abname=Details&areacode=0&navmapdisplayed=true&>

Australian Bureau of Statistics & Australian Institute of Health & Welfare (2005) *The health and welfare of Australia's Aboriginal and Torres Strait Islander peoples*. Canberra: ABS & AIHW

Australian Indigenous HealthInfoNet (2007) Population sub-groups: Ageing. Retrieved November 7, 2007, from: [http://www.healthinfonet.ecu.edu.au/html/html\\_population/population\\_subgroups\\_ageing.htm#what](http://www.healthinfonet.ecu.edu.au/html/html_population/population_subgroups_ageing.htm#what)

Australian Institute of Health and Welfare (2002) *Older Australia at a glance*. Canberra: Australian Institute of Health and Welfare

Baldry, E., Green, S. & Thorpe, K. (2006) Urban Australian Aboriginal peoples' experience of human services. *International Social Work* 49 (3) 364-375

Dance, P., Brown, R., Bammer, G. & Sibthorpe, B. (2000) *Needs for residential aged care and other services by the older Indigenous population in the ACT and region*. Canberra: National Centre for Epidemiology and Population Health, The Australian National University. Retrieved January 7, 2008 from: [http://nceph.anu.edu.au/Publications/Indig\\_docs/Residential\\_Aged\\_Care\\_Document.pdf](http://nceph.anu.edu.au/Publications/Indig_docs/Residential_Aged_Care_Document.pdf)

Disability Services Commission (2006) *Aboriginal people with disabilities: Getting services right*. West Perth: Government of Western Australia. Retrieved January 9, 2008 from: [http://www.disability.wa.gov.au/dscwr/\\_assets/main/guidelines/documents/pdf/getting\\_services\\_right\\_\(id\\_3565\\_ver\\_1.0.0\).pdf](http://www.disability.wa.gov.au/dscwr/_assets/main/guidelines/documents/pdf/getting_services_right_(id_3565_ver_1.0.0).pdf)

Leipoldt EA (1998) *Aboriginal people with disability and their use of advocacy: a phenomenological approach*. Bachelor of Social Science (Honours) thesis, Edith Cowan University, Perth, Western Australia.

National Health & Medical Research Council (2003). Values and ethics: *Guidelines for ethical conduct in Aboriginal and Torres Strait Islander health research*. National Health & Medical Research Council: Canberra.

National Health & Medical Research Council (2005). *Keeping research on track: A guide for Aboriginal and Torres Strait Islander peoples about health research ethics*. Australian Government: Canberra.

O'Neill, M., Kirov, E. & Thomson, N. (2004) A review of the literature on disability services for Aboriginal and Torres Strait Islander peoples. *Australian Indigenous Health Bulletin* 4 (4)

### **Continued from page 18**

their very essence. Aboriginal people have been adapting and changing and learning for somewhere between fifty and eighty thousand years. These are the world's most resilient people. Let us celebrate this strength and knowledge!

Our true humanity demands that we respect the right of Aboriginal people to be themselves, that we share a pride in this Culture and that we recognise it is the shades of human

difference and creativity that give our species the best chance of survival.

We need to believe in the common good. Instead of a crude intervention into the lives of some children we need to take action as a society – community by community, family by family – recognising that every Australian child is deserving of our very best effort.

Yes, equality is still a hopeful dream, but if we work at it, we may be closer to it than any other nation on earth.