

**ACT Department of Disability, Housing &
Community Services:**

**Feasibility Study for Respite Care for Aboriginal
& Torres Strait Islander Peoples**

Prepared by:



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Introduction

Background

In 2001, the Australian Capital Territory (ACT) Government made a commitment to develop a comprehensive policy for carers. In December 2003, following extensive consultation with the community, the ACT Government released the *Caring for Carers Policy* (Policy) with the aim to better acknowledge and support carers in the ACT.

In August 2004, the ACT Government launched the *Caring for Carers – A plan for action 2004/2007* (Action Plan) outlining 34 actions for the ACT Government to progress over three years in order to achieve the objectives of the Policy.

The Action Plan outlines strategies and actions to implement the seven principles in the Policy:

- i. carers have the right to decide whether to take on or continue the role of care and are supported in their choices;
- ii. the health and well being of carers is supported through services and programs that are flexible and responsive to individual needs and circumstances;
- iii. resources are available to provide timely and adequate assistance to carers;
- iv. affordable services of a high standard are available to people who need care, complementing the role of the carer;
- v. the critical contribution of carers is recognised, valued and promoted in the community;
- vi. the carer and the person receiving care are regarded as a partnership, in which each person has rights and responsibilities; and
- vii. organisations welcome and support carer participation at all levels of decision making, with respect for the rights and choices of people receiving care.

The Action Plan reflects the key messages from consultations with carers and the people receiving care. These messages included:

- the need for public recognition for the role and contribution made by unpaid, informal carers;
- assurance that the person being cared for is provided with quality, adequate and accessible support; and
- that carers be regarded as partners with Government.

The Action Plan included a commitment to table an annual report of progress in the Legislative Assembly during November each year, commencing in 2005.

The First Progress Report covered a wide variety of initiatives including a new website to enhance communication and networking, a training kit for professionals and other service providers, research on the needs of young

carers and culturally appropriate support services for Aboriginal and Torres Strait Islander carers.

The Second Progress Report provided an overview of the key initiatives that had been undertaken across ACT Government during the period 1 July 2005 to 30 June 2006. The Action Plan built and extended the work progressed from the First Progress Report and took stock of all the initiatives that were in operation aimed to improve the lives of carers in the community.

Actions addressed a range of measures the majority of which were undertaken in partnership both across government departments and between government departments and peak community organisations. These measures were in areas of support, practical skill development, family-friendly workplaces, education, housing, information and resources targeting carers, the care recipients, professionals and service providers.

Of the 34 actions prioritised in the Action Plan the only one that had not been completed was a feasibility study on respite models for Aboriginal and Torres Strait Islander peoples.

The action from the *Caring for Carers in the ACT – A plan for action 2004-2007* to be completed was Strategy 3, Action 3B:

- a. Conduct a feasibility study to develop a new model of respite care that better recognises and supports Aboriginal and Torres Strait Islander peoples' preference for kinship and family care. The feasibility study will include:
 - i. scoping possible models in consultation with Aboriginal and Torres Strait Islander carers;
 - ii. researching similar models in other jurisdictions and sectors;
 - iii. identifying likely problems with the model; and
 - iv. identifying structures and safeguards needed to support the model in consultation with relevant government and community agencies who could potentially fund and deliver services.

The feasibility study needed to:

- a. analyse existing respite care and kinship and family care supports for Aboriginal and Torres Strait Islander peoples in the ACT;
- b. scope models of respite care and kinship and family care supports nationally for Aboriginal and Torres Strait Islander peoples;
- c. consult with key stakeholders including Aboriginal and Torres Strait Islander carers and elders, community organisations and government agencies; and
- d. develop recommendations including model/s of respite care that better recognises and supports Aboriginal and Torres Strait Islander peoples' preference for kinship and family care.

In 2008, *The Echidna Group – Indigenous Research and Development Consultancy* were contracted by the ACT Government to conduct the above described feasibility study activities. This report documents these activities and their findings, including the recommended model for Aboriginal and Torres Strait Islander respite care and associated recommendations.

Methods

The aim of this research project was to undertake a feasibility study to develop a model of respite care that better recognises and supports Aboriginal and Torres Strait Islander peoples' preference for kinship and family care.

The objectives of the study were as follows:

- To analyse existing respite care and kinship and family care supports for Aboriginal and Torres Strait Islander peoples in the ACT;
- To scope models of respite care and kinship and family care supports nationally for Aboriginal and Torres Strait Islander peoples;
- To consult with key stakeholders including Aboriginal and Torres Strait Islander carers and Elders, community organisations and government agencies; and
- To develop recommendations, including model/s of respite care that better recognises and supports Aboriginal and Torres Strait Islander peoples' preference for kinship and family care.

Two sources of data were sought for this study: a review of the literature, and consultations with key stakeholders.

Literature was located through databases searches conducted in Google Scholar, Australian Indigenous Health *InfoNet*, Australian Family & Society Abstracts Database (FAMILY), FAMILY-ATSI, Aboriginal & Torres Strait Islander Health Bibliography (ATSIHealth), Health & Society, AIATSIS, RURAL, Meditext, and Journals@Ovid Full Text databases. Literature was also located within various hard copy sources, notably public and private collections of reports relating to various Indigenous issues. The following keywords/phrases were used in the context of Australian Indigenous settings: Indigenous, Aboriginal, Torres Strait Islander, respite, care*, age*, disability, kinship, cultural awareness, culturally appropriate, culture*.

Key ACT stakeholders targeted for consultation activities included:

- Aboriginal and Torres Strait Islander persons with disability;
- Aboriginal and Torres Strait Islander carers;
- Aboriginal and Torres Strait Islander community members;
- Aboriginal organisations and groups;
- Indigenous-specific disability support services;
- Other Indigenous-specific services commonly utilising kinship care in service provision; and
- Mainstream disability support services.

Participation in consultation activities was entirely voluntary, and all participants gave informed verbal consent prior to participation. No personal information was sought or reported in this study, including any identifiable information regarding individuals or families that other members of the community may recognise. The identities of all participants remain strictly confidential.

Consultation activities were conducted by Indigenous consultants from *The Echidna Group – Indigenous Research & Development Consultancy*.

Consultation activities consisted of the use of semi-structured in-depth interviews, triangulated with available literature. A total of 9 organisations/groups and 25 individual community members participated in consultation activities. Indigenous consultants also attended relevant meetings and discussion sessions, to familiarise people with the study, generate general discussion, and recruit interview participants. Data from interviews were recorded by note taking as opposed to audio-recording as it was felt that this would help ensure that participants felt confident to speak freely.

The consultation guide utilised for interviews is included in Appendix A. This guide was utilised by the interviewing consultant only as a prompt where necessary. Questions were based around the broader topic areas of:

- The current situation – How do things work now?
- What works – What aspects of the current system work well?
- What is needed – How can things work better?
- What important principles should guide any delivery of respite care for Aboriginal and Torres Strait Islander peoples in the ACT?

Evidence from the Literature

Aboriginal & Torres Strait Islander Care Recipients

The term 'care recipient' refers to a person with one or more disabilities, or aged 60 years or over, who requires formal or informal help or supervision with at least one everyday activity, not including assistance from the use of aids (Australian Capital Territory (ACT) Government Department of Disability, Housing & Community Services, 2003).

Aboriginal and Torres Strait Islander peoples typically experience higher rates of disability and long-term health conditions and hospitalisation than their non-Indigenous counterparts (Australian Bureau of Statistics (ABS) & Australian Institute of Health and Welfare (AIHW), 2008). In the 2006 Census of Population and Housing, a total of 19,600 Aboriginal and Torres Strait Islander peoples (4%) identified as needing assistance with core activities of self-care (eating, washing, dressing or toileting), physical mobility or communication, some or all of the time - a level twice as high as that among the non-Indigenous population (ABS & AIHW 2008). Among those needing assistance, the median age for Aboriginal and Torres Strait Islander males was 41 years, and for females 49 years, compared to 61 years for non-Indigenous males and 75 years for non-Indigenous females. The proportion of Aboriginal and Torres Strait Islander peoples identified as needing assistance with core activities ranged from 3% of the population in very remote parts of Australia, to 5% of those living in major cities and inner regional areas.

The 2006 Census (ABS & AIHW 2008) found that in regards to those Aboriginal and Torres Strait Islander peoples identifying as needing assistance with core activities:

- 90% (17,700) were living in private dwellings, while the remaining 1,900 lived in non-private dwellings (primarily nursing homes, retiree or aged accommodation, hospitals and hostels for the disabled);
- They were less likely to have completed school to at least Year 10 than Indigenous people not needing assistance with core activities, regardless of age;
- of those aged 15-64 years (12,100 or 4%), 12% were employed, 3% were unemployed and looking for work, and 80% were not in the labour force;
- Just under half (49%) reported weekly income in the range of \$150-\$249, with median weekly income for males \$218 and \$221 for females;
- Median weekly incomes were lower than the corresponding incomes for those not needing assistance across all age groups;
- They were more likely than those not needing assistance to be living in a low resource household (44% compared with 38%); and
- They were twice as likely as non-Indigenous people who needed assistance to be living in a low resource household.

In regards to education, 6% (13,600) of Aboriginal and Torres Strait Islander peoples aged 15 years or over (excluding those still at school) who provided information on both their highest level of schooling and whether or not they needed assistance with core activities, needed assistance. The ABS & AIHW (2008) surmise that it is likely that a need for assistance with core activities in childhood contributes to lower levels of educational attainment, and that lower levels of schooling, accompanied by other risk factors, increase the likelihood of a person requiring assistance with core activities in their adulthood. Aboriginal and Torres Strait Islander peoples were considerably less likely than non-Indigenous people to have completed year 12 regardless of whether or not they needed assistance with core activities.

In regards to weekly income, the median individual weekly income was lower for Aboriginal and Torres Strait Islander peoples than non-Indigenous people (\$220 per week compared with \$240 per week), however this difference in median incomes was much smaller than that between Indigenous and non-Indigenous people not needing assistance (\$291 per week compared with \$499 per week). Aboriginal and Torres Strait Islander peoples overall were almost five times as likely as their non-Indigenous counterparts to be living in a low resource household (39% compared with 8%) (ABS & AIHW 2008).

Data from the 2002 National Aboriginal and Torres Strait Islander Social Survey (NATSISS) show that Aboriginal and Torres Strait Islander people with a profound/severe core activity limitation had been involved in social activities in the previous three months, and had access to support at times of crisis at rates similar to those without core activity limitation, however were less likely to be in a registered or de facto marriage (ABS & AIHW 2008). The NATSISS also found that disability amongst the Aboriginal and Torres Strait Islander 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 2006 Census found that approximately 10,300 Aboriginal and Torres Strait Islander peoples (58% of those who needed assistance in private dwellings) reported living in a household in which there was at least one identified carer (i.e. a person who provided unpaid care, help or assistance to another person because of their disability, long-term illness or problems related to old age).

In the ACT specifically, the 2006 Census data found that:

- The total population of the ACT was 324,035, with 3,873 of these identifying as Aboriginal and Torres Strait Islander (1,931 males and 1,942 females);
- Of the non-Indigenous ACT population, 106,006 people were aged 45 years and over, representing 34.7% of the total non-Indigenous population for the Territory. Of the Aboriginal and Torres Strait Islander ACT population, 577 were aged 45 years and over, representing 14.9% of the total Aboriginal and Torres Strait Islander population for the Territory;
- A total of 151 Aboriginal and Torres Strait Islander peoples reported having a profound or severe disability, defined as needing help or

assistance in one or more of the three core activity areas of self-care, mobility and communication because of a disability, long term health condition (lasting six months or more) or old age, representing 3.9% of the total ACT Indigenous population;

- The median age for Aboriginal and Torres Strait Islander people in the ACT was 21, compared to 34 for their non-Indigenous counterparts;
- Aboriginal and Torres Strait Islander peoples in the ACT recorded lower median individual weekly income (\$514) and median household weekly income (\$1,221) figures than their non-Indigenous counterparts (\$724 and \$1,513 respectively);
- The average Aboriginal and Torres Strait Islander household size in the ACT was 3.0, compared to an average non-Indigenous household size of 2.6;
- The Aboriginal and Torres Strait Islander median housing loan repayment was \$1,517 a month, compared to a non-Indigenous median housing loan repayment of \$1,500 a month; and
- The Aboriginal and Torres Strait Islander median rent was \$210 per week, compared to a non-Indigenous median rent of \$260 per week (ABS 2007).

It is believed that data relating to Aboriginal and Torres Strait Islander disability may be underestimating the true rates, due to a lack of use of definitions of disability meaningful in the Aboriginal and Torres Strait Islander context in the majority of data collections such as the Census (ABS 2001, cited in ACT Government Department of Disability, Housing & Community Services, 2003).

Aboriginal & Torres Strait Islander Carers

The term 'carer' refers to a person of any age, who provides unpaid help or supervision with everyday activities to any person with a disability or long-term health condition, or to any person aged 60 years and over, on an ongoing basis or at least for six months (ACT Government Department of Disability, Housing & Community Services, 2003). The term 'unpaid' does not exclude those carers receiving a pension, carer payment, carer allowance or financial support from a partner, relative or friend. It does however exclude those who are directly employed to provide care, and receive a wage or salary (ACT Government, 2003). The majority of carers are female relatives of the care recipient (Cardona, Chalmers & Neilson, 2005).

The ABS (2004, cited in Allen Consulting Group, 2008) report that in the general Australian population in 2003:

- More than half of all primary carers had been in their role of carer for between five and 24 years
- Six percent of primary carers had been in that role for 25 years or more
- Almost half of all primary carers spent 40 hours or more per week in care-related activities
- The three most frequently reported reasons for primary carers adopting their role were family responsibility (58%), the ability to provide better care (40%) and emotional obligation (35%).

The 2006 Census found that there were 11,600 Aboriginal and Torres Strait Islander male carers and 20,000 Aboriginal and Torres Strait Islander female carers across Australia, with Aboriginal and Torres Strait Islander peoples more likely to be caring for another person with disability, long-term illness or problems related to old age than their non-Indigenous counterparts (ABS & AIHW 2008). The median age of Aboriginal and Torres Strait Islander carers was 37 years, compared to a non-Indigenous median age of 49 years, reflecting the higher birth rates at younger ages and the earlier onset of many chronic diseases.

The ABS & AIHW (2008) note the opportunity and financial costs associated with the caring role, with carers of working age often finding it difficult to work in full-time paid employment. However, non-Indigenous carers were around one-and-a-half times more likely to be employed than were Aboriginal and Torres Strait Islander carers. Rates of participation in the labour force (either employed, unemployed or looking for work) were similar to those for non-caregivers (54% compared with 58%). Both Indigenous and non-Indigenous carers were more likely than non-caregivers to be employed on a part-time basis. Both Aboriginal and Torres Strait Islander male and female carers had a lower median weekly income than their non-Indigenous counterparts, with the Aboriginal and Torres Strait Islander male rate being only 42% of that available to non-Indigenous males (\$248 compared with \$589). Aboriginal and Torres Strait Islander carers were four times as likely as non-Indigenous carers to be living in a low resource household. Approximately 2,100 Aboriginal and Torres Strait Islander carers reported needing help with core activities themselves, at a rate between one-and-a-half and three times that of non-Indigenous carers. (ABS & AIHW 2008).

In the ACT specifically, the 2006 Census found a total of 25,936 carers in the ACT general population (ABS 2007 cited in Allen Consulting Group, 2008). A total of 318 Aboriginal and Torres Strait Islander people reported providing unpaid assistance to a person with a disability, representing 8.2% of the total ACT Aboriginal and Torres Strait Islander population (ABS 2007). A further 171 Aboriginal and Torres Strait Islander peoples failed to record any response regarding unpaid assistance. It is believed that data relating to Aboriginal and Torres Strait Islander carers may also be underestimates of the true rates, due to a lack of use of definitions of disability meaningful in the Aboriginal and Torres Strait Islander context in the majority of data collections such as the Census (ABS 2001, cited in ACT Government Department of Disability, Housing & Community Services, 2003).

Research reported by Carers NSW Inc (2002, cited in South Australia (SA) Carers, 2004) found that for the population as a whole, carers had high rates of poor mental or emotional health, the majority of whom reported this has worsened as a direct result of being a carer, with common effects being sadness, depression, anxiety, excessive worry, distress, frustration, boredom, stress and exhaustion. Research findings have also shown that many carers delay their own health care, have worse physical health than non-carers, rate their health as fair or poor, and reported physical health problems directly related to providing care. Other research found that in 1998, 51% of all carers

in the general population received no help, and 30% of all carers received no services (ABS 1998, cited in SA Carers 2004).

Aboriginal & Torres Strait Islander Use of Disability Services

The Aboriginal Disability Network of NSW (2007) reports that despite gaining an increased profile, the needs of the vast majority of Aboriginal and Torres Strait Islander peoples with disability and their carers remain unmet, and very few with disability access any of the range of disability services available. In terms of Aboriginal and Torres Strait Islander use of disability services, the NATSISS (ABS & AIHW, 2005) found the following:

- Aboriginal and Torres Strait Islander services users reported a somewhat more frequent need for support than other services users;
- The most common disability group reported among Aboriginal and Torres Strait Islander service users was intellectual disability (45%) followed by physical disability (19%), acquired brain injury (7%) and psychiatric disability (7%).
- Aboriginal and Torres Strait Islander service users were on average younger than other service users, with a median age of 25 years compared with 31 years for other service users;
- Aboriginal and Torres Strait Islander 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 Aboriginal and Torres Strait Islander families;
- Nearly one-quarter (23%) of Aboriginal and Torres Strait Islander 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; and
- 35% of Aboriginal and Torres Strait Islander service users reported always needing help, and 46% reported sometimes needing help with activities of daily living.

In 2005-06, there were 7,182 Aboriginal and Torres Strait Islander users of Commonwealth State Territory Disability Agreement-funded services, comprising 3.3% of all users, a rate which had changed little from the previous three years (AIHW 2007). In keeping with the younger age structure of the Aboriginal and Torres Strait Islander population, service users were more likely to be in younger age groups (0-19 years) than non-Indigenous users, and less likely to be in the older age groups (40-44 years and older), with an Aboriginal and Torres Strait Islander median age of 24.7 compared with non-Indigenous median age of 31.5 for service use. Aboriginal and Torres Strait Islander service users exhibited a higher mean number of reported disability groups for all disability types, indicating that Aboriginal and Torres Strait Islander service users may experience more complex disabilities than non-Indigenous service users (AIHW 2007). Patterns of service use were similar for both Aboriginal and Torres Strait Islander and non-Indigenous users, with community support services accounting for the majority of service provision for both groups, followed by employment, accommodation, community access, and respite services. However, Aboriginal and Torres Strait Islander

service users were more likely than their non-Indigenous counterparts to access respite (20% compared with 13%), accommodation (20% compared with 18%) and community support (53% compared with 42%) services. However, the AIHW (2007) cautions that differences in service access rates may be reflective of differing availability of services (particularly in regional, remote and very remote areas) rather than indicative of differing needs.

A needs analysis targeting 98 Aboriginal and Torres Strait Islander residents of the ACT aged 45 years and over, found that 11% were currently accessing Home and Community Care (HACC) services, and 10% expressed dissatisfaction with HACC services (Dance, Brown, Bammer & Sibthorpe, 2000).

The SA Carers (2004) note that findings such as those noted above do not take into account the greater degree of disadvantage experienced by many Aboriginal and Torres Strait Islander peoples, and the low access rate to health and welfare-related services, suggesting that such problems and issues would be greatly compounded for Aboriginal and Torres Strait Islander carers.

Disability Policy and Service Approaches

Australia, in keeping with global trends, is influenced by a strong human rights focus underpinning international contemporary disability policies, based on the perception that "...all people with a disability should be able to take advantage of the same opportunities open to the rest of society" (National Disability Administrators, 2004, p.8).

Current disability policies and service approaches are based on the preference for the provision of care for people at home and within the community, as opposed to within nursing homes and other care institutions, resulting in separate acute residential care and community care funding arrangements. This shift has occurred in response to policy research highlighting this preference (Shaver & Fine 1995, cited in Cardona et al, 2005), as well as popular belief in small government, and the perception that families have an obligation to care for their own members (de Vaus 1996, cited in Cardona et al, 2005). The official recognition of the preference for the care of people at home and in the community in Australia can be pinpointed to the introduction of the *Home and Community Care (HACC) Act* in 1985 by the Federal Government, consolidating four community care funding bodies into a single program (Cardona et al, 2005). The HACC Program also introduced a broader range of types of support to people living in the community, including transport, home modifications and respite care, with a focus on those living outside family settings and living alone, as well as specific programs to support informal caregivers. The HACC Program was also accompanied with the introduction of the Community Aged Care Packages, providing low-level care for older people within their homes.

Despite the introduction of such services, the shift towards community care has increased the reliance on family social, financial and emotional resources for informal care-giving (Cardona et al, 2005). Until recently, the role of carer

was not recognised as anything outside of the natural responsibilities and obligated duties that family members had towards each other, particularly relevant to women who were traditionally viewed as being responsible for the provision of informal care within the home (Shaver & Fine, 1995, cited in Cardona et al 2005). The new policy approach of separating acute residential care and community care funding arrangements has resulted in a long-term budget emphasis on institutional care, estimated to cost approximately 12.4 times more than community care provided through HACC services (de Vaus 1996, cited in Cardona et al, 2005). Community care costs less simply because of its reliance on family resources to provide care in the home. Unfortunately, the person with high-level needs wishing to remain at home has limited options – either choose high-level institutional care and have all needs met, or choose to remain at home, which will require family support to supplement community care, which itself will not provide support for accommodation and possibly not meet all other needs (McCallum et al, 2001, cited in Cardona et al, 2005). This is because the community care system must prioritise service provision to those people who have no family or other informal carers to provide support such as help at home, maintenance and community transport.

Community care, aside from presuming the availability, willingness and ability of family to provide support, has been criticised as being under-funded, resulting in HACC services becoming a crisis care system as opposed to a preventative care system (de Vaus, 1996, cited in Cardona et al, 2005). This in turn increases pressure on friends and family as carers to provide the support needed for an individual to remain at home rather than access institutional care, who subsequently have limited access to essential services that can ease caring responsibilities and enable them to address their own wellbeing and improve their own quality of life. Such criticisms have highlighted the need for further research to address the issue of how to suitably prioritise resources without penalising caregivers for opting to provide support to a person who wishes to remain at home rather than access institutional care.

The community care system also relies on individuals self-identifying as carers in order for them to be able to seek what assistance may be available from community care services (Allen Consulting Group, 2008). This self-identification as a carer may not happen for three reasons. Firstly, a carer may not view themselves as performing any sort of duties that are not simply part of the responsibilities and obligations as a family member or friend. Secondly, a carer may not be aware of 'carer' as a term defining those in their circumstances, and therefore the password enabling access to relevant policy, services and other support. Thirdly, an individual may not feel that the concept of 'carer', in terms of its definition and what it encompasses, accurately describes their situation and role – particularly when their pre-existing role of 'parent' or 'partner' provides a much stronger identity (Allen Consulting Group, 2008).

General Care Recipient and Carer Issues

The term 'carer' as a formal definition of what had previously been a private family relationship first emerged approximately 30 years ago as a means to describe the roles, responsibilities and rights inherent to the 'social contract' between a carer, care recipient, and community care services (Cardona et al, 2005). However, this 'social contract' has been criticised for failing to adequately support such rights and assistance from community services.

The following key issues relating to carers and care recipients have been identified from the literature:

Roles

- Research suggests that while a large proportion of people providing care do not recognise themselves as 'carers', others have difficulty coming to terms with the fact that they have adopted such a role (Bittman et al, 2004, cited in Cardona et al 2005).
- Such difficulties have been attributed to the term 'carer' generally referring to attendance to physical care, therefore 'caring for' someone fails to account for the emotional relationship – the 'caring about' (Parker 2000, cited in Cardona et al, 2005).
- Such difficulties have also been attributed to the reluctance of people to accept a term that is associated with notions of 'burden and dependency' (Wilson 1998, cited in Cardona et al 2005).
- The other concurrent roles held by carers, such as spouse, child, or parent, can make it impossible for them to move out of the caring role if the situation becomes unsatisfactory – an issue that does not affect voluntary or paid carers, for whom the care is the only, or at least over-riding element of their relationship with the care recipient (SA Carers 2004).
- Carers regularly experience difficulty co-managing work and/or study obligations and caring, which generally leads to the caring role having to win over – resulting in loss of income, loss of employment, poor academic performance, or withdrawal from education (ACT Government 2003).

Resources

- Despite a desire to do so, some people are not in a position to provide assistance or receive assistance from their family – this is particularly the case for those with low incomes, chronic health problems, psychological and emotional issues, and limited social and family networks (Millward 1998, cited in Cardona et al 2005).
- Carers are typically either invisible to service providers, or are considered as a 'resource' or 'partner in care', leaving many feeling "...exploited, disregarded and resentful" (SA Carers, 2001, p.1).
- Care recipient's needs, and therefore caring itself, often changes over time in terms of amount and type required (ACT Government, 2003). This means that episodic support is required for particular transition or crisis periods in addition to the regular support required (Allen Consulting Group, 2008).

- Current generic service delivery approaches fail to account for the diversity of carers and their needs (Allen Consulting Group, 2008).
- The level of financial support required by carers also varies, depending on the level of care they provide, and their ability to participate in the workforce (Allen Consulting Group, 2008).

Results

- Many carers develop health conditions directly resulting from caring activities, such as physical tasks (particularly heavy lifting), and lack of sleep.
- Research has shown that carers often experience mental health issues (stress, anxiety, depression), relationship difficulties, and a lack of time for leisure activities and social interaction (ACT Government, 2003).
- Care recipients who receive care through family and social networks may have little power to exert control over aspects of their own lives, may experience changes in relationship dynamics which can result in feelings of frustration, inadequacy, burden, guilt, and may ultimately result in relationship breakdown, and may be vulnerable to abuse (ACT Government, 2003).
- While caring often requires a high level of involvement in the care recipient's physical health, carers who are not part of a traditional parent, spouse or child relationship with the care recipient are often excluded from important decisions or not fully informed (Allen Consulting Group, 2008).

Respite Care

Respite care is care that is provided by someone other than the carer, in order to allow the carer a break from their caring responsibilities, and to allow the care recipient the opportunity for socialising with people other than their usual carers.

The majority of respite is provided on an informal basis, by friends and relatives of the care recipient and/or their carers (Respite Working Group, 2000, cited in Standing Committee on Social Issues, 2000). Formal respite is also provided by government and non-government agencies. While their modes of delivery vary greatly, they can generally be described as falling into the following categories:

- In-home respite – where support is provided to the care recipient in their own home;
- Out-of-home daytime and recreational respite – where care recipients are supported outside their home during the day; and
- Residential overnight respite – where overnight supported accommodation is provided to the care recipient in a facility outside of their home (Standing Committee on Social Issues, 2000).

Formal respite care typically occurs on the following terms: regular planned, occasional planned, occasional unplanned, and emergency out-of-hours. It is delivered by a wide range of service providers, and funded through a variety of funding programs.

In-home respite is typically provided by the HACC program, either through specific Home Care services or through non-government organisations who receive HACC funding. In-home and Out-of-home daytime and recreational respite may also be provided on a voluntary basis by host family support organisations and peer support networks who may receive limited funding from various programs.

Residential overnight respite services are generally funded by state and territory disability service programs, incorporating both government and non-government providers (Standing Committee on Social Issues, 2000).

Respite care has been shown to be the most effective means of meeting the needs of care recipients for whom accommodation within their home is appropriate as long as additional support is available to maintain these arrangements (Standing Committee on Social Issues, 2000). Benefits of respite care reported in the literature include:

- Socialising and improved health for the care recipient, and a break for the carer (Warren et al, 2003, cited in McGrath, Patton, McGrath, Olgivie, Rayner & Holewa, 2006);
- Strengthened and replenished relationships between carer recipients and carers, resulting from being able to take a break from each other's company (Standing Committee on Social Issues, 2000);
- Prevention of carer burnout, extension of caregiving abilities, conservation of family and community economic resources, avoidance of institutionalisation, and ability for care recipient to remain living in the community (Zelewsky & Deitrick, 1987, cited in McGrath et al, 2006); and
- Increased development of social networks and independent living skills for the care recipient, facilitated by experiencing challenges outside of the usual carer/family environment (Standing Committee on Social Issues, 2000).

It is widely acknowledged that respite is a highly cost-effective means of supporting people with disability, as well as their carers. However, evidence indicates that the level of respite available in all forms is not adequate to meet current needs. Numerous carers require a level of assistance that can only be adequately provided by residential overnight respite, as the availability of in-home and out-of-home daytime and recreational respite will be insufficient in terms of preventing deterioration of the situation to crisis levels (Standing Committee on Social Issues, 2000).

Consultations conducted by the Standing Committee on Social Issues in NSW found that many carers reported significant barriers to accessing residential overnight respite, with bookings needing to be made well in advance, preventing any real opportunity for spontaneous access, and even this fails to be a guarantee of a place in respite care, with carers often turned down at the last minute. Carers also reported concerns regarding the quality of respite care, and problems related to gaining respite for children once they reach the age of 16 or 18 in areas where there is little respite available for adults.

The Respite Working Group (2000, cited in Standing Committee on Social Issues, 2000), established by the NSW Government, made the following recommendations regarding respite care:

- Properly define respite, to ensure it is a flexible support response customised to meet individual care recipient and carers' needs, provided only to people who have a carer, and provided only as planned support, not emergency or crisis care or long-term support accommodation – these should be funded as separate services;
- Establish better assessment, service planning, quality control and monitoring, and carer involvement systems;
- Develop a clear policy framework to ensure equitable distribution of services;
- Enable comprehensive data collection on use of respite services;
- Increase coordination between Commonwealth and State programs in regards to funding of respite services, to improve equity of access, flexibility and cohesion of service systems; and
- Address the needs of groups in the community disadvantaged by limited access to respite and other supports, including Aboriginal and Torres Strait Islander peoples, people living in remote areas, and people from non-English speaking backgrounds.

Recent consultations conducted with carers in the ACT found that respite care ranked highest amongst support required by carers to assist them in their role (Allen Consulting Group, 2008). It was reported that respite used by carers most typically involved time out of the home for the care recipient, providing the carer with a break from their caring responsibilities.

Aboriginal & Torres Strait Islander Perceptions of Disability

Little is known about the perceptions of disability prior to and in the early period of colonisation (National Disability Administrators, 2004). Contemporary studies however indicate that Aboriginal peoples, in general, are relatively not familiar with the term 'disability' and the way in which it is conceptualised in Western culture.

Prior to colonisation, it seems that perceptions of disability differed to Western perceptions, with disabled individuals treated and responded to the same 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 family 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.

Susman (1994, cited in National Disability Administrators, 2004) notes that contemporary Anangu people have attempted to make sense of the western concept of disability by adapting an existing word, *nyumpu*, meaning 'crippled' or 'maimed'. However, many object to its use, as it labels and stigmatises a person, not about their actual impairment, but rather about their perceived social status within the community.

A study conducted by Elliot (1984, cited in National Disability Administrators, 2004) of people living in Darwin, Katherine, Bamyili and Ngukurr in the Top End of the NT found that disability appeared to only become an issue if it resulted in a handicap. Other international studies have also found that in cultural groups that value sociability above productivity amongst its members, disability does not hinder an individual's participation in everyday activities (Whyte & Ingstad, 1995, Armstrong & Fitzgerald, 1996, cited in National Disability Administrators, 2004). This was also found in a study conducted by Senior (2000, cited in National Disability Administrators, 2004), who noted that in the communities targeted, an Aboriginal or Torres Strait Islander individual's ability to fulfil their role within the family and engage and participate within the family unit determined their perceived level of ability, or disability – people with disabilities were generally unaware of how much they were limited by their condition. Maher (1998, cited in O'Neill et al, 2004) found in a NT study that physical impairments that were highly visible were more likely to be seen as disabilities, while restrictions related to ageing and degenerative changes were more likely to be seen as a natural result of the ageing process.

Consultations conducted by the Disability Services Commission (2006) with Aboriginal people with disabilities, their families and carers, and services providers across Western Australia found that Aboriginal people continue to be less familiar with the term 'disability' and the context of which 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 terms of mental illness and intellectual disabilities, the same level of acceptance within the Aboriginal community appears to apply, whereby such conditions are viewed simply as characteristics of that individual – 'that's just the way he is' - as described by Vicary and Westerman (2004) in their research into depression in Aboriginal communities.

Research conducted in more urban Aboriginal communities of NSW, Victoria and WA (Gething et al 1994, Gething 1995, Gething 1997, Smeaton 1996, Smeaton 1998, Victorian Aboriginal Community Services Association 2000, Danelluti 2000, O'Neill 1994, Commonwealth Rehabilitation Service, 1994 cited in O'Neill, Kirov & Thomson, 2004), with relatively limited scope, has highlighted the following features:

- In general, disability incurs no discrimination, exclusion or stigmatisation within the Aboriginal community, but does within the wider community;
- Some disabilities may be perceived as a 'pay-back' for a past wrongdoing, while others may be perceived as something 'special';
- Disability may be viewed more as a family or community problem, rather than a personal one for the affected individual;
- Individuals with severe disabilities may be considered to be the responsibility of 'welfare';
- Individuals may be identified and even named after their disability (e.g. an individual who lost an eye may be referred to as 'one eye'); and
- Shame, in terms of an individual being singled out from the group, may factor for some individuals with a disability, particularly in relation to being identified as having a disability.

It also appears that many contemporary Aboriginal perceptions of disability include health-related conditions, such as those related to chronic diseases, for example renal failure, are perceived as a disability because of the restrictions such conditions pose to everyday activities (Disability Services Commission, 2006). Taking into account the disproportionately high rates of such conditions and the disproportionately high levels of disease and other health and wellbeing conditions evident in the Indigenous population, it stands to reason that in some communities, disability could affect a high number of its members. Certainly, from this perspective, disability would affect the

majority of Aboriginal families in some manner or form (Hepburn & Twining, 2005). This also means that within many Aboriginal families and communities, disability is not viewed as such an unusual occurrence (Gething, 1994, cited in Aboriginal Disability Network of NSW, 2007). Such a conceptualisation can result in confusion given the current division of responsibilities in Australia that sees disability and health service provision as separate entities (O'Neill et al 2004).

Aboriginal & Torres Strait Islander Perceptions of Caring

Within all cultures, 'care' is fundamental to human existence – each person requires some level of care at some point during their life, requiring a dependence on others to provide it (Fine, 2003, cited in SA Carers, 2004). However, how care is expressed is culturally determined, and varies greatly. Conceptualisations of the role of 'carer' differ among cultural groups – definitions and constructs that are western-based have been found to be difficult to 'translate' (Ethnic Disability Advocacy Centre, 2003, cited in Cardona et al, 2005) due to the differing cultural meanings and understandings related to family and community dynamics, reverence for parents and elders, other family roles which may have to run concurrently with that of carer, disability and responsibility towards those who are disabled (Cardona et al, 2005).

In many Aboriginal and Torres Strait Islander languages the word 'carer' may not exist in the same way it does in the western context. For example, there is no Anangu word to describe a carer of a person with a disability, and the idea that an individual needs to be cared for holds negative connotations, implying they are deficient in some way (SA Carers, 2004). Instead, caring words that describe the supportive roles are used, which reinforce the value of the care recipient as a member of the community. Hepburn and Twining (2005, p.27) found that the term 'carer' was a difficult concept for many Indigenous people to get their heads around, as caring was viewed as '*...just what you do, look after your own, black common sense*'.

Ariotti's (1997) research found that for the Anangu, the care of an individual with a disability was the responsibility of the broader extended family, rather than a community issue, and outsiders would not interfere with such personal family business.

The Aboriginal 'Community'

The term 'the Aboriginal community' appears frequently in health and disability literature, notably in guidelines, policies and strategies relevant to Aboriginal and Torres Strait Islander peoples. 'Community' as a concept in general, typically "...invokes notions of an idealised unity of purpose and action among social groups who are perceived to share a common culture" (Peters-Little, 2000). As a concept relating to Aboriginal people, 'community' certainly invokes these notions, however a perceived synonymous relationship

between 'community' and 'culture' typically lends itself to the definition of the Aboriginal community by Aboriginal culture.

Up until the 1970's, assimilation policies which sought to assimilate Aboriginal people into white society enforced segregation laws which kept them isolated on missions and reserves. Such 'institutions' were typically comprised of people who had been involuntarily displaced from their lands and forced to commune with others from differing cultures and languages. A change in policy, adopting the ideals of self-management and self-determination resulted in the granting of such missions and reserves a 'freedom' of sorts, with limited autonomy, forcing them to become 'communities' in name, despite the lack of voluntary association amongst members (Tatz, 2001). Any cohesiveness that was evident in such 'communities' was "...institutional and imposed, not cultural, spiritual or linguistic" (Tatz, 2001, p. 36). The characteristics and dynamics common to a 'community' were not investigated, and Aboriginal notions of 'community' were certainly not taken into consideration (Tatz, 2001). As Hunter (1993, p. 260) states, "...it was geographic and demographic considerations, rather than social ones, that determined definition". When the artificial infrastructure, comprised of Aboriginal Affairs legislation, authoritarian laws and regulation, and 'mission evangelism', was removed, often nothing was substituted in its place, resulting in a 'structural vacuum', "...an absence of an overarching or binding philosophy (however bad or misguided), a lack of system, without goals beyond mere survival" (Tatz, 2001, p. 36).

While ongoing fights for citizenship, land rights, and equality fill a small part of this vacuum, the general outcome for such 'communities' has been disorder. Despite this, the romanticised notion of 'the Aboriginal community' is readily put forward as the culturally appropriate and democratic medium by which funds for health and welfare programs and service delivery can be distributed, readily endorsed by government guidelines, strategies and policies (Peters-Little, 2000). However, in reality, this notion is complicated by defined groups or factions within the 'community' competing for resources (Hunter, 1993). Regardless, in order to access such funds, one must play the 'community game', and as Smith (1989, cited in Peters-Little, 2000) notes, Aboriginal people have become so adept at playing the 'community game' that many have begun to believe it.

Peters-Little (2000) lists the popularised notions of the 'Aboriginal community', which make the following assumptions: that members are caring and generous in all matters; that disadvantage and adversity is inevitable, and even acceptable; that materialistic values are unnecessary; that independence and individuality is rejected if not in the common interest of the larger population; that external assistance is revoked and solutions only exist within the community; and that there is a communal sharing of socio-economic and cultural opinions, experiences and expectations. Such romantic views have been referred to as the type of views one can afford to have when they themselves don't have to live in the 'community' (Peters-Little, 2000).

While some of the family groupings within a typical Aboriginal 'community' may be aligned, others may be long-standing antagonists, often resulting in factionalism (Eckermann, Dowd, Martin, Nixon, Gray & Chong, 1992). Factionalism is characteristic of many Aboriginal communities (Tatz, 2001). Influence and prestige within the faction or community is based on reputation, and also by dominating community-controlled organisations (Eckermann et al, 1992). In Alberta, Canada, recent successes have been achieved in addressing what has been termed 'lateral violence' (The Koori Mail, 2007). Lateral violence refers to the way "...people in positions of powerlessness covertly or overtly direct their dissatisfaction inward toward each other, toward themselves, and toward those less powerful than themselves" (The Koori Mail, 2007, p. 9).

Kinship

Western society is strongly individualistic, while Aboriginal society emphasises membership of a group and the obligations and responsibilities of individuals to meet the expectations of others (Bourke & Edwards, 1994). For many Aboriginal people the family and community are of central significance, and group interests and needs are a fundamental part of an individual's identity and self-fulfilment (Lynn, Thorpe & Miles, 1998). Personal identity and self-esteem is expressed in places of belonging, and one's place within the extended family, rather than individualistic characteristics or achievements (Quinn, 2000).

Traditional Aboriginal society functioned by means of 'kinship' networks, which formed the basis of social relationships and maintained social order (Healy, Hassan & McKenna, 1985). 'Kinship' is a term coined by non-Aboriginal anthropologists to conceptualise the complex relationships within Aboriginal cultural groups, however is largely inappropriate as it stems from a white construction of extended family (NSW Office of the Children's Guardian, 2003). A definition of Aboriginal kinship relationships that has been credited with being closer to an appropriate description is that used by Billingsley (1992, cited in NSW Office of the Children's Guardian, 2003) who states that they are 'relationships of appropriation' and include 'unions without blood ties or marital ties'.

The kinship network enabled obligations to be met without confusion, prescribing rules about what must and must not be done (Healy et al, 1985), ensuring the passing on of Aboriginal knowledge (Franks & Curr, 1996). The kinship system has continued to evolve and adapt as part of Aboriginal culture, with Aboriginal families in urban and rural areas still exhibiting kinship structures that provide psychological and physical support and security (Bourke & Edwards, 1994).

Amongst a particular kinship group, the kinship network determines the roles, responsibilities and relationships of the individuals within that group. However, several important issues must be highlighted here. The existence and function of kinship networks varies greatly both between and within communities. Not all members of the community are members of the one

network. There may in fact be many networks within a community, or there may be none. The exact nature of the protocols and the extent to which they apply, to roles, responsibilities and relationships, also varies greatly.

Franks and Curr (1996, pp. 37-40) state:

Kinship relationships can be likened to the most intricate tapestry you can imagine...The sharing of the responsibilities and obligations ensures that functional Aboriginal culture survives; that it is successful is demonstrated in the fact that it has survived and functioned for tens of thousands of years...Each person is supported and guided throughout every aspect of life, from birth to death and in turn guides and supports others in accordance to their particular kinship role...Aboriginal society has no hierarchical structure; it can be thought of an intricate, interconnected system of relationship, with each person having responsibility and obligation for someone else within this system. In an essentially oral tradition this ensured that cultural values and tradition were passed on throughout the generations with minimal variation. The viability is maintained by a system of checks and balances. Each person within the kinship network has a specific role of guardianship and supervision for another designated person within the system.

A key feature of kinship networks is the relationships of classificatory kin, "...whole classes of people identified by an Aboriginal person as his or her 'brothers', 'fathers', 'sisters', 'mothers'..." (Gray et al, 1991, p. 82). Put simply, in contrast to Western societies, where the relationships and their inherent roles and responsibilities change as an individual moves out from their immediate family to the wider community, Aboriginal societies extend the relationships held within the immediate family out onto the larger group (Bourke & Edwards, 1994). A basic principle of the classificatory system of kinship is the '*equivalence of same-sex siblings*' which dictates that people of the same sex and same sibling line are equivalent in relationship and terms of reference. Bourke & Edwards (1994, pp. 104-105) provide the following example:

Thus two brothers are considered to be equivalent. If one has a child, that child views not only his biological father as father but applies the same term to the father's brother. The same principle applies to two sisters with both being mothers to any child either one bears. As a father's brother is also identified as father, the latter's children will be brothers and sisters rather than cousins...Thus a person has several fathers, several mothers, and many brothers and sisters. A mother's brother, being on the same sibling line but of the other sex, is identified as an uncle. A father's sister is an aunt.

Reser (1991, pp. 257-258) refers to the 'relatedness' for the Aboriginal individual that comes from such kinship networks, stating "...there has been little discussion of what these networks *mean* in terms of emotional well-being, or of how they *function* in terms of social support, experienced connectedness and identity, and with respect to coping and adjustment". 'Relatedness' is important in all cultures (Pilisuk & Parks, 1986, cited in Reser, 1991), however

few compare to the “emotional and ontological intensity of particular relationships and interdependencies” characteristic of many Aboriginal cultures (Reser, 1991, p. 258).

Kinship & Caring

There is a paucity of literature on the needs and experiences of Aboriginal and Torres Strait Islander carers. Throughout Australia, the majority of Aboriginal and Torres Strait Islander peoples with disability are cared for within their extended family or kinship network (O'Neill et al, 2004). Aboriginal Elders, particularly women, are likely to share their households with more people, often of two or more generations, entailing extra obligations and responsibilities, but with the benefits of additional family support (Bourke & Edwards, 1994). Hepburn and Twining (2005) found that in the Aboriginal and Torres Strait Islander communities studied, carers were present in all age groups, however the majority were the elders of families (particularly women), with caring seen as part of their responsibilities that come with that role. Many elders were caring for grandchildren. Research conducted in the ACT found that many Aboriginal and Torres Strait Islander peoples play a major role in rearing grandchildren, or other family members, as well as their own children (Dance et al, 2000). It should be noted that as a result of past government policies, many Aboriginal and Torres Strait Islander peoples may not be living in situations that enable them the extended family and kinship networks that can assist with the caring role. Hepburn and Twining (2005) found that some Aboriginal and Torres Strait Islander carers reported that failing to assume the role of carer can result in being shunned or marginalised by other members of the community, who see this as a failure to meet the cultural responsibilities and obligations to the care recipient.

Research into the care of terminally ill members of Aboriginal communities in the NT found that the traditional value of caring for one's own family was paramount (McGrath 2008). Care recipients stressed a strong desire to be cared for by their own family members. However it was also noted that not all family members are able to provide such care. This was often due to a lack of material and financial resources such as equipment and even basic household items like a refrigerator or a washing machine, or low income, posing practical obstacles to caring. The interruptions to works and study were also emphasised. Kinship rules were reported to define who was in the right relationship to provide care to a dying person. Caring was described as difficult and challenging work, not suited to certain individuals. In light of this, respite care was reported to be a necessity, however for many this required relocation of the care recipient to another geographical location far from their family, community and land. Family meetings were highlighted as an important means of addressing the care of an individual and ensuring the appropriate family members had been consulted.

As stated earlier, in the non-Indigenous community, carers who are not friends or relatives of the care recipient (typically volunteers or paid carers), generally only have one role in relation to the care recipient – that of carer. This enables them the advantage of being able to end their role as carer if the

situation becomes unsatisfactory. However, in an Aboriginal or Torres Strait Islander community, these boundaries are not always so clear-cut. Aboriginal and Torres Strait Islander carers who are volunteers or paid carers of Aboriginal and Torres Strait Islander care recipients may still have other roles in relation to that care recipient, resulting from kinship networks, and therefore may not be afforded this same advantage. For example, Aboriginal and Torres Strait Islander workers commonly report that the boundaries between work and after hours are not always clear cut, and they are frequently expected and feel obliged to provide additional support outside of their normal duties (SA Carers, 2004; Hepburn & Twining 2005).

The fear of 'pay-back' in the event of a care recipient's condition deteriorating whilst under their care can make potential Aboriginal and Torres Strait Islander carers reluctant to assume such a role (SA Carers, 2004). On a similar thread, respite can be viewed as a failure on behalf of the carer to adequately meet their responsibilities to that person, and community.

The proportion of Aboriginal and Torres Strait Islander people with profound or severe impairments requiring high-level assistance in activities of daily living is higher than that of non-Indigenous people (Senior, 1998, cited in O'Neill et al, 2004). Paired with this burden is the fact that Aboriginal and Torres Strait Islander carers typically provide care within a cultural context that is in conflict with current service provision and policies (SA Carers 2004). The higher levels of socioeconomic and health disadvantage in the Aboriginal and Torres Strait Islander population means that the impact of caring is much greater on Aboriginal and Torres Strait Islander carers and communities than applicable for non-Indigenous carers and communities (SA Carers 2004). Many carers may themselves have health problems. Monahan and Twining (2007) found that Aboriginal and Torres Strait Islander carers may experience depression, grief and loss, isolation, guilt, anger, anxiety, worry, financial hardship, lack of access to carer entitlements, poor health and wellbeing, and a lack of general support. Caring often occurs in very complex situations, including mental illness, chronic illness, substance abuse, family violence, suicide, and premature death.

Not all extended families and kinship networks have the ability to provide optimum care for an individual with a disability (Woenne-Green 1995, cited in National Disability Administrators, 2004). A Perth-based study of the needs of urban Aboriginal aged peoples noted that "...the myth that Aboriginal people are being cared for by their families can lead to their needs being overlooked" (Stokes 1988, cited in O'Neill et al, 2004, p.5). A further study by O'Neill (1994, cited in O'Neill et al 2004) highlighted the following reasons why some families are unable to care for a disabled member:

- Low income and resources mean that adequate care is unable to be provided, and the additional expenses of caring for a member with a disability can disadvantage the other members of the family group;
- Individuals with a disability can be at risk of exploitation or abuse in environments of alcohol misuse and family breakdown;
- The high incidence of grief and stress evident in many communities can lead to inconsistencies in care;

- Family allegiances and factionalism can make accessing services difficult; and
- Many Aboriginal and Torres Strait Islander peoples are unaware of how to provide care, and what services and support are available to assist them to do so.

Aboriginal & Torres Strait Islander Access to Respite Care

There is relatively limited literature available regarding Aboriginal and Torres Strait Islander utilisation of respite care services. A recent study conducted by McGrath et al (2006) which aimed to develop an Aboriginal and Torres Strait Islander model for palliative care, explored access to respite care by Aboriginal and Torres Strait Islander terminally ill peoples and their carers in the Northern Territory. Their findings highlight the serious lack of Aboriginal and Torres Strait Islander respite services, particularly within rural and regional areas, and the negative impact this has on the ability of carers to satisfactorily fulfil their role, and the wellbeing on the care recipients and their families. A lack of local respite services was reported to be causing many rural and regional terminally ill care recipients to have to relocate to metropolitan areas, moving away from their family, community and land, subsequently obstructing wishes for death to occur in their local community. Other obstacles identified included beliefs about families looking after their members themselves, limited resources, and availability of staff in local areas (McGrath et al, 2006).

Current Models

Current Aboriginal & Torres Strait Islander Respite Models Across Australia

The Commonwealth State/Territory Disability Agreement (CSTDA) provides the framework for planning, policy setting and management of disability support services in Australia (National Disability Administrators, 2004). It covers specialist disability services including accommodation support, community support, community access, employment, advocacy, information, and respite. While such a national agreement produces some uniformity in the development and delivery of disability support services, substantial differences still exist in the methods by which each State and Territory addresses these aspects, reflecting historical factors about the way disability services have developed in different jurisdictions, and contemporary differences in the ways agencies responsible for the delivery of disability services are structured.

In a number of jurisdictions, an example of which is South Australia, there are two main types of services available to carers (SA Carers, 2004). The first type consists a wide variety of services delivered by agencies with a primary focus on the care recipient. The level of assistance available to carers from such services relies greatly on the particular sector involved. The second type consists of services delivered by agencies specifically for carers, most of which are funded by the HACC program (SA Carers, 2004). The ACT have developed a specific policy supporting carers, the *Caring for Carers Policy*, and a recent review has found that since 2004, there have been 62 carer-related initiatives in the ACT, in the areas of information and awareness-raising, respite, in-home support, community supports and income support (Allen Consulting Group, 2008).

Across Australia, the following formal respite services are available to Aboriginal and Torres Strait Islander peoples:

- Aboriginal-specific services such as Aboriginal Home Care, with Aboriginal and Torres Strait Islander workers;
- Mainstream services with Aboriginal and Torres Strait Islander workers; and
- Mainstream services with non-Indigenous workers.

However, the availability and accessibility of such services varies greatly depending on geographical location. Regional and remote areas typically experience a greatly reduced choice of service provision. In areas where the Aboriginal and Torres Strait Islander population is higher, access to Aboriginal-specific services may be greater, however in other areas with lower Aboriginal and Torres Strait Islander populations, there may be no Aboriginal-specific services available at all.

The limited number of Aboriginal-specific services can also mean that such services are overwhelmed with clients yet under-resourced to provide services

to them. The Aboriginal Disability Network of NSW (2007) notes that while Aboriginal Home Care services are the most likely to interact with Aboriginal people with disability, their focus is narrow in that they generally only provide some in-home supports, and are not a holistic service. As a result of demand, many Aboriginal Home Care services are put under pressure to perform duties that are beyond their funding, expertise and experience.

A review of the literature was unable to locate any Aboriginal and Torres Strait Islander models of respite care in any particular state or territory, however, there is evidence of activity in a number of regions towards creating more culturally appropriate models of disability service provision, including respite care.

The National Disability Administrators (2004) initiated a project they titled *Sharing Stories* in recognition of the need to bridge gaps in service provision for Aboriginal and Torres Strait Islander peoples with disability and their carers living in rural and remote areas of Australia. The aim of the research project was to guide the development of a more effective national response to service planning, development, funding and delivery for communities supporting people with disability and their carers. The project consisted of an in-depth study of nine organisations from NSW, the NT, Queensland, SA and WA credited with showing elements of 'good practice' in the provision of one or more types of disability support services. Based on evidence in the literature, the services were examined in relation to the following six areas felt to contribute to 'good practice' in delivering disability services to Aboriginal and Torres Strait Islander peoples:

- Community participation – in decision-making relating to service delivery;
- Appropriate service delivery – involving both physical and cultural aspects;
- Cultural protection – to ensure that services are accessible and effective;
- Partnerships – at local, regional, jurisdictional and national levels;
- Capacity building – of individuals, communities and organisations; and
- Sustainability – in terms of resourcing, governance and management, and monitoring and evaluation (National Disability Administrators, 2004)

Research was recently conducted into the needs of Western Australian Aboriginal people with disability, commencing with the initial establishment of an *Access for Aboriginal People Steering Committee* by the Disability Services Commission in 2001 to oversee the development of culturally responsive disability policy and services for Aboriginal people (Murphy, Stopher & Thomson, 2004). In light of the paucity of information regarding the needs and issues experienced by WA Aboriginal people with disabilities and their families and how to respond to them, the Steering Committee encouraged the development of the Aboriginal Disability Action Research (IDAR) Project by the Disability Services Commission under the Edith Cowan University – Industry Collaboration Scheme, conducted in 2004. The extensive literature review and state-wide consultation process resulted in numerous initiatives and policies relating to disability service provision for Aboriginal peoples in WA

In 2003, a project was conducted in Port Augusta, SA, to develop a model of support for Indigenous carers of children with disabilities (Warmington, Haynes, Chong & Schneider, 2005). The project focused on the development of an effective partnership between the Carers Association and the Council of Aboriginal Elders, and identified nine elements vital to the process:

1. Respect of the Elders' role;
2. Taking time and holding fast to the agreed approach despite pressures for a quick fix;
3. Establishing ethical practices;
4. Developing, nurturing and sustaining close relationships;
5. Mutual respect and trust;
6. Understanding cultural protocols;
7. Social action and community involvement associated with primary health care;
8. Establishing an agreed approach and working protocols; and
9. Ensuring simple acts of witnessing along the pathways of partnership (Warmington et al, 2005).

A series of community consultations were conducted from March 2004 to July 2005 by the Aboriginal Disability Network of NSW (2007), targeting Aboriginal people with disability and their associates living in 32 communities in north, western, central and south coast NSW. Approximately 300 Aboriginal people with disability and their associates attended these consultations, plus an additional 100 Aboriginal people with disability were interviewed in their own homes. The study highlighted many issues experienced by Aboriginal and Torres Strait Islander peoples with disability and carers, particularly relating to access to services and support.

A needs analysis was conducted by Dance et al (2000), from the National Centre for Epidemiology and Population Health, Australian National University, surveying 98 older Indigenous residents aged 45 years and older of the ACT and surrounding region. The study resulted in a number of recommendations made to the Department of Health & Aged Care – ACT Branch particularly aimed at addressing Aboriginal and Torres Strait Islander access to services and support.

Aboriginal & Torres Strait Islander Models from other Sectors

The development of Aboriginal and Torres Strait Islander models for disciplines and services from other sectors can be of relevance in terms of informing the development of an Aboriginal and Torres Strait Islander respite care model. Two such models were located and are reviewed below:

Aboriginal & Torres Strait Islander Child Protection & Out-of-Home Care

Aboriginal and Torres Strait Islander children are significantly over-represented in child protection and out-of-home care statistics in Australia (Australian Foster Care Association, 2006). In response to this, the Australian Government and all states and territories have adopted the Aboriginal Child

Placement Principle, either in legislation or policy (Australian Foster Care Association, 2006). The purpose of the Principle is to enhance and preserve Aboriginal children's sense of identity as Aboriginal, by ensuring that Aboriginal children and young people are maintained within their own biological family, extended family, local Aboriginal community, wider Aboriginal community, and their Aboriginal culture. The Principle outlines the preferred order of placement for an Aboriginal or Torres Strait Islander child who has been removed from their birth family, the order being the child's extended family, the child's Aboriginal or Torres Strait Islander community, or other Aboriginal or Torres Strait Islander people. It is only in the instance that an appropriate placement can not be found from any of these three groups that the child be placed with a non-Indigenous carer (Richardson et al 205, cited in Higgins, Bromfield & Richardson, 2005).

The Aboriginal Child Placement Principle forms the basis of what has become commonly referred to as the 'kinship care' model. However, as mentioned previously, it should be noted that the word 'kinship' holds no meaning in traditional Aboriginal society (NSW Office of the Children's Guardian, 2003). It stems from a white construction of extended family, and does not appropriately define the distinct cultural practices of Aboriginal people. Kinship relationships have been more appropriately defined as 'relationships of appropriation', which include 'unions without blood ties or marital ties' (Billingsley, 1992, cited in NSW Office of the Children's Guardian, 2003), however this definition still fails to account for the different types of relationships that can be held and how these may shape Aboriginal children's placements (NSW Office of the Children's Guardian).

The following issues have been identified in the literature relevant to the kinship care model:

Resources

- The over-representation of Aboriginal and Torres Strait Islander children in out-of-home care has meant there are more children in care than there are carers, resulting in some Aboriginal and Torres Strait Islander children having to be placed with non-Indigenous carers (Higgins et al, 2005).
- Many Aboriginal and Torres Strait Islander peoples are already acting as informal (unpaid) carers to relatives children and are unable to take on the role of paid carer for additional children (Higgins et al, 2005).
- Socioeconomic disadvantage makes many potential Aboriginal and Torres Strait Islander carers unable to take up such a role – factors include low income, overcrowded and inadequate housing, and limited access to support and resources.
- One of the largest groups of kinship carers are grandparents, who report a lack of recognition and support (Council on the Ageing National Seniors, 2003, cited in Bromfield & Osborn, 2007).
- Aboriginal and Torres Strait Islander carers need to be provided with quality training that includes how to access carer support and advocacy services to assist them (Higgins & Butler, 2007).

- Australian research has shown that kinship care placements receive less, or even no, monitoring, training and support (Bromfield & Osborn, 2007). Aboriginal and Torres Strait Islander carers need effective support systems, including financial, practical and emotional support (Higgins et al, 2005). Out-of-home care agencies report being understaffed and under-resourced and unable to provide carers with adequate services and support (Bromfield & Osborn 2007).

Cultural Competence

- The Aboriginal Child Placement Principle does not ensure culturally appropriate practice in facilitating that placement. For example, assessment procedures have been criticised as being culturally inappropriate as they can employ criteria that are inconsistent with Aboriginal and Torres Strait Islander child rearing practices, which themselves can be incorrectly viewed as a risk to the child's safety and wellbeing.
- Both non-Indigenous and Indigenous staff of out-of-home care agencies need training to increase their level of cultural competence (Bromfield & Osborn, 2007).
- The model fails to accommodate traditional child rearing practices, particularly in terms of shared care arrangements (Higgins et al, 2005).

Effectiveness

- Aboriginal and Torres Strait Islander carers may be difficult to recruit, due to past experience with government policies and welfare practices making many reluctant to become involved with the out-of-home care system (Higgins et al, 2005).
- Many Aboriginal and Torres Strait Islander families may be reluctant to care for a child because of the repercussions this may hold for them in terms of community scrutiny, traditional law, and harassment and even 'pay-back' from the birth family (Higgins et al, 2005).
- Sometimes families may request that the Aboriginal Child Placement Principle not be adhered to, and that the child be placed with non-Indigenous carers – this creates a tension in deciding between their wishes, and what would be in the child's best interest (Higgins et al, 2005).
- There is a need for research that investigates child outcomes for those placed in accordance with the Aboriginal Child Placement Principle and those placed in non-Indigenous placements (Bromfield & Osborn, 2007)

Aboriginal Palliative Care – 'The Living Model'

The National Health and Medical Research Council recently funded a two-year research project in the NT to develop an innovative model for Aboriginal palliative care (McGrath 2008). Prior to this, there was scant literature available on the palliative care needs of Aboriginal and Torres Strait Islander peoples, and palliative care services were typically based on western understandings and perceptions of health, illness, death and dying (McGrath & Holewa, 2006).

In 2004, the National Palliative Care Program (NPCP) put forward a holistic notion of palliative care as applicable to Aboriginal and Torres Strait Islander peoples:

Palliative care is the care provided to a person whose disease is terminal and not responsive to curative treatment. It recognises the special needs of a person with a life threatening illness. These needs may be cultural, spiritual, emotional, psychological, social and/or physical. A holistic approach to palliative care also recognises the support needed by the person's family and, for many Indigenous Australians, their community as well (NPCP, 2004, cited in McGrath & Holewa, 2006 p. 182).

McGrath and Holewa (2006, p.12) describe the resulting Aboriginal palliative care model – ‘the living model’ – as:

...one of advocacy to be used by those at the coalface of Indigenous care, to ensure appropriate resources to carry out their important work. It is not a static model to be imposed on services or communities, but rather a living and flexible model to assist with service delivery and health policy.

The model is underpinned by seven principles, the articulation of which has been developed through extensive consultation with Aboriginal peoples and health professionals through the NT, and reviewed and affirmed by a diversity of national audiences (McGrath & Holewa, 2006). These principles are:

- Cultural safety;
- Equity;
- Autonomy;
- Trust;
- Humane, non-judgemental care;
- Seamless continuity of care;
- Emphasis on living; and
- Respect.

The model is encompassed by ‘advocacy for resources and infrastructure’, and ‘cultural awareness’. At the centre of the model is the patient and extended family. Surrounding them is cultural safety. Encompassing this is community participation, personal advocacy, choice, and empowerment. This is overlaid by the following, overlapping components:

- Respect/support Indigenous grief practices;
- Use of Indigenous workers;
- Effective communication/respect of language;
- Address psychosocial and practical problems;
- Build services in the communities;
- Encourage family meetings;
- Education – consumer and professional (cultural, cancer and palliative care);
- Address relocation issues – focus on staying at home;
- Understanding/support cultural practices;
- Culturally appropriate health care facilities;
- Cancer and escort support; and
- Provision of respite (McGrath & Holewa, 2006).

Evidence from the Consultations

Current Issues Regarding Aboriginal & Torres Strait Islander Access to Respite Care in the ACT

Consultation activities conducted for the purpose of this study found issues voiced by participants as current concerns in the ACT region for Aboriginal and Torres Strait Islander peoples regarding respite care were synonymous with those identified in the literature.

Poor Help-Seeking Knowledge & Skills

As a result of past policies and practices, many Aboriginal and Torres Strait Islander peoples lack the knowledge and skills that can facilitate effective help-seeking. In the transmission between assimilation practices, which fractured many traditional 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 Aboriginal and Torres Strait Islander channels.

Consultation with participants found that seeking help with caring, in terms of respite care, was something that simply did not occur to many Aboriginal and Torres Strait Islander carers as an option. Reasons for this were cited as being due to carers not realising they were actually classes as a carer and fitting such criteria, and a lack of knowledge of respite care as a service and support option. For those that do consider help-seeking, the lack of knowledge and skills regarding who and how to access help was described as a potential source of shame.

This general lack of effective help-seeking skills that enable access to respite care also appears to result in an Aboriginal help-seeking behaviour that characteristically involves waiting until the situation reaches the crisis stage.

Poor Knowledge of Available Services & How to Access Them

Participants reported being unaware of what respite services are available, and how they can access them. This can even include those who are already accessing other disability support services, indicating 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 and Torres Strait Islander people with disability and carers 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 targeting, can be incredibly daunting. This is compounded by an

inappropriateness of western conceptualisations of disability and caring in Aboriginal and Torres Strait Islander contexts.

Advocacy

Participants reported a lack of advocacy services available to assist Aboriginal and Torres Strait Islander peoples with disability and carers in accessing respite care, and addressing the issues that may be impacting on the caring role (e.g. housing, income, etc.).

Eligibility

Another issue relates to members of the community, and other health professionals in a position to provide key information, being largely misinformed and having perceptions of certain criteria that excluded people from being able to access particular services. Many participants in this study had varying perceptions of what they believed to be criteria for being eligible to access respite services.

Lack of Available Respite & Carer Support 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 consulted with reported experiencing difficulty meeting the needs of all existing clients, let alone new clients requiring support.

Attitudes towards Mainstream Services

Many participants reported a preference for Aboriginal-specific services, and even a reluctance to access mainstream services. Reasons for this were based around perceived and experienced levels of cultural competence of these services, historical contact, and fear that asking for respite may invite scrutiny, or be seen as a sign of not coping, and could even result in the removal of a child with a disability.

Consultations conducted by the Disability Services Commission (2006) with Aboriginal people with disabilities, their families and carers, and service providers across Western Australian 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) report 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 that their children will be removed by government authorities (Aboriginal Disability Network of NSW, 2003). Dance et al (2000) also found a recurring theme of distrust of mainstream services

directly related to experiences resulting from the policies of forced removal of children. O'Neill et al (2004) highlight the fear of abuse, shame, and of being exploited. Other obstacles include previous negative contact with services, experienced either personally or by others in the community, shame at not being able to cope and at having to ask for help, and perceived and experienced cultural competence, racism, and discrimination.

Inappropriate Approaches

A large number of participants commented on the failure of respite services to accommodate Aboriginal and Torres Strait Islander ways, particularly referring to the individualistic approach that fails to recognise the importance of including family and kinship networks. Current respite service provision was reported to also fail to accommodate the Aboriginal and Torres Strait Islander preference for in-home care as opposed to being taken to an unfamiliar, and often mainstream-oriented location. Some participants indicated that this was due to a lack of Aboriginal and Torres Strait Islander involvement and input into the development, implementation, monitoring and evaluation of service delivery.

Lack of Aboriginal-Specific Respite Services

Participants reported a lack of Aboriginal-specific respite care services, and a lack of Aboriginal and Torres Strait Islander peoples working in mainstream respite services. While many participants reported a preference for Aboriginal-specific services, or at least Aboriginal and Torres Strait Islander workers, others reported that Aboriginal and Torres Strait Islander peoples in the ACT needed choice between both Aboriginal-specific and mainstream services and workers, as some members of the community would prefer mainstream services.

Cultural Inappropriateness

The cultural inappropriateness of respite care service provision, and the cultural incompetence of staff was unanimously noted by all participants as an obstacle to Aboriginal and Torres Strait Islander access to respite care services.

Lack of Resources for Carers

Many participants commented on the lack of resources for carers, including:

- Lack of financial assistance. This also impacted on the ability of other members of the family and kinship network to provide respite care.
- Lack of skills regarding care provision, and the inability to attend courses that provide such skills because this would require time away from their caring responsibilities. Also, the lack of caring skills of other members of the family and kinship network made respite involving these members difficult.
- Lack of aids and equipment
- Lack of support in general – as one participant stated: *“I know of very little support available. Sink or swim situation.”*

Housing

Inadequate housing was reported by some participants as an issue exacerbating Aboriginal and Torres Strait Islander carer stress, and making it difficult for other members of the family and kinship network to assist with respite care. Housing was reported to be structurally inadequate in terms of size and condition. Overcrowding was also reported as an issue affecting carers.

An Aboriginal & Torres Strait Islander Respite Model for the ACT

The following Aboriginal and Torres Strait Islander model for respite care in the ACT is a culmination of the review of the literature, and the issues and needs identified by participants consulted with during this study. It has largely been adapted from the model for Aboriginal palliative care developed by McGrath and Holewa (2006). In keeping with the Aboriginal palliative care model, the following Aboriginal and Torres Strait Islander respite care model is a generic model which:

...stands as a base line of information to be applied by service providers to their own unique circumstances. As every service is different, there will be great variation in the detail of the specifically developed model for each service. There may be great diversity on such issues as needs, obstacles, resources, geography, populations and service aims. Such diversity will be reflected in a different configuration of factors underpinning the model development for each service. The commonality between the varied service models will be the myriad of essential factors posited by the generic model. Thus, the view is of a 'Living Model' – the generic model providing a firm foundation which can be applied to the needs of the plethora of services involved in providing Indigenous palliative care. (McGrath & Holewa, 2006, p.21)

The model is depicted diagrammatically below. In the centre of the diagram are the care recipient, the carer, and the family and kinship network, depicted together in a circle to denote their partnership and need to be considered as a joint force. Overlapping this central circle, and overlapping each other, are a series of elliptical shapes which represent the components of the model.

These are as follows:

- Advocacy;
- Community Participation;
- Cultural Competence;
- Choice of Respite Care;
- Respect & Support for Aboriginal & Torres Strait Islander Cultural Perspectives & Practices;
- Indigenous Organisations and Workers;
- Information & Awareness;
- Effective Communication;
- Increase Respite Service Availability & Accessibility;
- Education – Consumer & Professional;
- Community-Centred, Family Inclusive Approach;
- Flexibility;
- Partnerships, Support & Cultural Mentoring; and
- Responsive Respite Services.

Encompassing both the centre circle, and the overlapping elliptical shapes is a large circle, which contains the principles that overlay the entire respite care model. These are as follows:

- Cultural Safety;
- Equity;
- Autonomy;
- Trust;
- Humane, non-judgemental care & support;
- A Holistic Approach;
- Respect; and
- Diversity.



Principles

The principles of the model are described as follows:

Cultural Safety

In their model for Aboriginal palliative care, McGrath and Holewa (2006, p.17) define the principle of 'cultural safety' as:

...an outcome that enables safe service to be defined by those who receive the service. In essence, it is based on a respect for Indigenous culture as understood and expressed by Indigenous people. It necessitates the bracketing of imposed assumptions by those outside of the culture.

Eckermann et al (1992, p.168) define cultural safety as:

...to be recognised within the healthcare system and to be assured that the system reflects something of you – of your culture, your language, your customs, attitudes, beliefs and preferred ways of doing things.

Of relevance, the National Disability Administrators (2004, p.7) also note the importance of ensuring what they term 'cultural protection', which requires "...an understanding of the experience, expectations and aspirations of those people receiving the service and a respect for the diversity they offer". They detail cultural protection as being about ensuring a consumer has the ability to make choices that are optimal for their cultural and general wellbeing; and learning from consumers how best to work to standards that reflect the specific characteristics of their community.

Cultural protection involves respecting, securing and appreciating the diversity of Aboriginal and/or Torres Strait Islander cultural backgrounds and how people identify themselves within the broader Aboriginal and/or Torres Strait Islander community. It means acquiring and utilising an understanding of people's experiences, expectations and aspirations in a manner that is sensitive to their historical legacy, geographical location, language, knowledge, customs and beliefs, law and lore, community protocols and ways of being together in family and kinship groups (National Disability Administrators, 2004, p.21)

Equity

The principle of equity encompasses "...the democratic right of equal access to services" (McGrath & Holewa, 2006, p.182).

In terms of the Aboriginal and Torres Strait Islander respite care model, equity applies to addressing issues such as:

- The disproportionately higher rates of disability amongst Aboriginal and Torres Strait Islander peoples compared to their non-Indigenous counterparts;
- The socioeconomic disadvantage experienced by Aboriginal and Torres Strait Islander peoples with disability and carers;
- The availability and accessibility of disability and carer support services;
- The availability and accessibility of culturally appropriate respite care; and
- The disproportionately lower rates of employment of Aboriginal and Torres Strait Islander peoples compared to their non-Indigenous counterparts, and the need to increase such employment in disability and carer support services;

Autonomy

The principle of autonomy encompasses notions of self-determination and empowerment. It is about the importance of ensuring that both Aboriginal and Torres Strait Islander peoples with disability and carers have the opportunity and ability to take control of their own respite care solutions and support (McGrath & Holewa, 2006). Autonomy is not always an individualistic notion, but rather may be inclusive of family and community networks.

Autonomy includes:

- The right to make fully informed, fundamental choices regarding respite care;
- The right to access services which can implement and support such choices;
- The right to access culturally appropriate information and be made aware of available services and support;
- The ability to make choices based on Aboriginal and Torres Strait Islander perceptions of disability and caring; and
- The importance of advocacy in enabling and facilitating the ability of those with disability and carers to make choices and have those choices implemented.

Trust

The importance of trust needs to be considered in the historical context of colonisation, and the past experiences Aboriginal and Torres Strait Islander peoples have had in dealing with government agencies (McGrath & Holewa, 2006). Such a contact history has resulted in three significant oppressive processes: forced relocation from traditional lands; the taking of children; and the lack of rights and decision-making power (National Palliative Care Program, 2004, cited in McGrath & Holewa, 2006). It can be argued that these processes are still in effect today. The result of these processes is a lack of trust in government agencies and mainstream service provision.

In terms of the Aboriginal and Torres Strait Islander respite care model, trust includes:

- Transparency of all aspects of service provision, including assessment and other decision-making mechanisms;
- Engaging with and building relationships with the Aboriginal community;
- Establishing a '...continuing and face-to-face presence' (McGrath & Holewa, 2006, p.184) within the Aboriginal community;
- Honouring service provision agreements, and other statements of intent;
- Ensuring confidentiality; and
- Consulting with community members, and 'asking permission' when appropriate.

Humane, Non-Judgemental Care & Support

The principle of humane, non-judgemental care and support incorporates the need for Aboriginal and Torres Strait Islander peoples with disability and their carers to be able to access care and support that is humane, compassionate, and responsive rather than judgemental (McGrath & Holewa, 2006).

This principle includes the availability of care and support that:

- Is respectful of cultural perceptions of disability and caring;
- Is respectful of lifestyle choices;
- Is respectful of cultural protocols and customs; and
- Does not pass judgement on the need for respite, both for the care recipient and the carer.

An Holistic Approach

Eckermann et al (1992, p.174) state:

Health to Aboriginal people is a multi-dimensional concept that embraces all aspects of living and stresses the importance of survival in harmony with the environment.

The National Aboriginal and Islander Health Organisation (NAIHO) (1982, cited in Eckermann et al, 1992, p.174) define health as:

Not just the physical well-being of the individual but the social, emotional and cultural well being of the whole community. This is a whole-of-life view and it also includes the cyclical concept of life. Health care services should strive to achieve the state where every individual is able to achieve their full potential as human beings, and thus bring about the total well-being of their community...

This is also in keeping with the philosophy, policies and practices of primary health care, as outlined in the Alma Ata Declaration (1978, cited in Eckermann et al, 1992, p.175):

...health, which is a state of complete, physical, mental and social well-being, and not merely the absence of disease or infirmity, is a fundamental right and...the attainment of the highest possible level of health is a most important world-wide social goal whose realization requires the action of many other social and economic sectors in addition to the health sector.

An holistic approach requires respite care to operate in collaboration with other services and other sectors, to ensure that the physical, social, emotional and cultural well-being needs of the Aboriginal or Torres Strait Islander individual with disability, their carer, their family and community are met, and in a seamless manner. In this respect, Aboriginal and Torres Strait Islander respite care services should be perceived as a collaborative discipline, involving input from a multidisciplinary team. It is not enough to assume that an Aboriginal or Torres Strait Islander person with disability or a carer simply requires support for one facet of their life.

Respect

In terms of the Aboriginal and Torres Strait Islander respite care model, the principle of respect encompasses the following:

- Respect for cultural perceptions of disability and caring;
- Respect for cultural protocols and customs;
- Respectful terms of address e.g. 'aunty', 'uncle';
- The appropriate use of male and female respite carers;
- Consulting with the care recipient, carer and family;
- Respectful personal manner of respite carers; and
- Allowing a time-rich, circuitous process that may be required in assessment and consultation activities with the care recipient, carer, family and community (Lynn et al, 1998).

Diversity

The principle of diversity acknowledges that there is no single Aboriginal or Torres Strait Islander culture. There is vast diversity amongst the multitude of Aboriginal and Torres Strait Islander cultural groups across Australia, including within the ACT, and such heterogeneity can then also be applied to the level within such groups i.e. there is diversity within a group.

Such diversity results from a variety of cultural, historical, geographic, social, health and economic contexts. Diversity means that cultural protocols, perceptions and attitudes towards disability and caring can differ greatly, as can kinship networks. This means that a uniform approach to respite care for Aboriginal and Torres Strait Islander peoples in the ACT can not be applied across the territory – rather, the approach needs to be about flexibility, enabling incorporation of and appropriate response to such diversity.

Components

The components of the model are described as follows:

Advocacy

Respite care for Aboriginal and Torres Strait Islander peoples in the ACT needs to incorporate elements of advocacy into service provision.

Advocacy provides:

- Knowledge of how to use both mainstream and Aboriginal-specific service systems;
- Direct information and action;
- Brokerage role with other services;
- Use of authority and power in situations where an Indigenous person may feel intimidated, oppressed or suspicious;
- The ability to walk the care recipient and/or carer through the respite system, and make connections within that system, and gain the information needed to make informed choices regarding services provided by that system (Aboriginal Disability Network of NSW 2007);
- Support and representation, to ensure appropriate access to services; and
- A holistic approach to respite care, as it can facilitate collaboration between multiple disciplines and sectors.

Community Participation

Community participation has been recognised as an important means to increasing the effectiveness of services, and facilitating community empowerment (National Disability Administrators, 2004). The nature of community participation is reliant on:

- How the community is defined;
- The characteristics of the service;
- The levels at which it is allowed to occur;
- Use of western and/or Indigenous ways of participating, and decision-making processes;

- The willingness and commitment of the service to encourage and facilitate community participation; and
- The level to which the community has been able to choose the model of community participation (National Disability Administrators, 2004).

The National Disability Administrators (2004) give examples of different levels of community participation. High levels of community participation can involve the use of Indigenous management committees or steering groups. Intermediate levels may involve advisory or consultative groups. Low levels include general public consultation activities.

Community participation should occur at the broader national and territory policy levels, while also occurring at the local, individual service delivery levels, including the setting of priorities, decision-making, planning and implementation of respite care. Care recipients and carers should also have the opportunity to participate in quality assurance and improvement systems (ACT Government, 2003).

Relevant to Aboriginal and Torres Strait Islander respite care, community participation should occur through the establishment of the following:

- i. One or more Aboriginal and Torres Strait Islander Management Committees or Steering Groups, who should hold more decision-making power than an Advisory Committee, comprised of Aboriginal and Torres Strait Islander community members with a vested interest in disability, carer and respite care issues.
- ii. Aboriginal and Torres Strait Islander representation on existing management boards and committees. Representation should ensure there are at least two Aboriginal and/or Torres Strait Islander members appointed, to reduce the stress associated with community representation, and provide members with training and mentorship to assist them in their role (National Disability Administrators, 2004). Membership should be elected by the Aboriginal and Torres Strait Islander community. Roles and responsibilities should be clearly defined, as should mechanisms for information transfer between the committee and the ACT Aboriginal and Torres Strait Islander community.
- iii. Mechanisms that can allow the participation of Aboriginal and Torres Strait Islander community members, particularly those who have disability or are carers, in the setting of priorities, decision-making, planning, implementation, monitoring and evaluation of respite service provision.

Cultural Competence

A number of key terms are evident in the literature describing concepts akin to cultural safety the principle described above. These terms include 'cultural appropriateness', and 'cultural competence'. These terms are often used, but rarely defined. Yet they need to be differentiated here from 'cultural safety'.

As described previously, Eckermann et al (1992, p.168) define cultural safety as:

...to be recognised within the healthcare system and to be assured that the system reflects something of you – of your culture, your language, your customs, attitudes, beliefs and preferred ways of doing things.

Thomas (2002) defines cultural appropriateness as:

...the delivery of programmes and services so that they are consistent with the communication styles, meaning systems and social network of clients, or programme participants, and other stakeholders.

King, Sims and Osher (n.d.) define cultural competence as

...a set of congruent behaviours, attitudes and policies that come together in a system, agency or among professionals and enables that system, agency, or those professionals to work effectively in cross-cultural situations (Cross et al, 1989; Isaacs & Benjamin, 1991). Operationally defined, cultural competence is the integration and transformation of knowledge about individuals and groups of people into specific standards, policies, practices, and attitudes used in appropriate cultural settings to increase the quality of services, thereby producing better outcomes (Davis 1997).

Durie (2001) notes that cultural safety focuses more on the experience of the Indigenous client accessing the service, whereas cultural competency focuses on the attributes of the service provider and service provision.

Included in Appendix B are the 'Principles of Culturally Appropriate Service Delivery'. It is through the implementation of strategies addressing these principles that service provision, and service providers, can work towards increasing cultural competency. These principles cover four levels of cultural competency, as identified by the National Health & Medical Research Council (2006):

- Systemic – effective policies and procedures, mechanisms for monitoring and sufficient resources;
- Organisational – commitment from management to a process of diversity management at all staffing levels, with cultural competency valued as integral to core business and therefore supported and evaluated;
- Professional – cultural competence is an important component in education and professional development, and also results in specific professions developing cultural competence standards to guide the working lives of individuals; and
- Individual – knowledge, attitudes and behaviours defining culturally competent behaviour are maximised and made more effective by a supportive health organisation and wider health system (NHMRC, 2006).

In turn, these levels have been adopted by the concept of 'cultural respect', detailed in the Australian Health Ministers' Advisory Council's (AHMAC) (2004) document *The Cultural Respect Framework*, which aims to service as a guiding principle for jurisdictions both in policy construction and service delivery, assisting them to develop their own initiatives to strengthen relationships between Aboriginal and Torres Strait Islander peoples and the

health care system. Cultural respect is defined as “Recognition, protection and continued advancement of the inherent rights, cultures and traditions of Aboriginal and Torres Strait Islander peoples”, noting that cultural respect can only be achieved when health service providers create an environment in which cultural differences are respected, and Indigenous peoples can feel culturally safe (AHMAC, 2004, p. 6).

Perhaps the most familiar strategy listed in the *Principles of Culturally Appropriate Service Delivery* (Appendix B) is Cultural Competence Training, and while very important as it addresses the attitudes and behaviour of staff, it will not achieve cultural competence of an organisation or service provision on its own.

The Echidna Group – Indigenous Research & Development Consultancy advocate for Cultural Competency that is delivered by Aboriginal or Torres Strait Islander consultants, developed in consultation with local Aboriginal and Torres Strait Islander peoples, mandatory for all staff, including Aboriginal and Torres Strait Islander and non-Indigenous staff, and incorporating the following learning objectives and content.

Learning objectives should be as follows:

- Greater appreciation of the role of history and racism on contemporary Indigenous society;
- Increased knowledge of Indigenous cultures;
- Dispelling of myths and misconceptions;
- Self-reflection on own cultural values, beliefs and attitudes and how they impact on interaction with people from other cultures;
- Increased understanding of white race privilege;
- Anti-racism and anti-discrimination strategies;
- Skills in cross-cultural communication;
- Skills and strategies to enable better working relationships with Indigenous colleagues;
- Skills and strategies to enable better service provision for Indigenous clients; and
- Positive changes in attitudes towards Indigenous peoples and cultures, and confidence in working effectively with Indigenous colleagues and clients.

Content can be divided into two modules. The first module should consist of general content, suitable for all staff regardless of role or geographical location of service. The content of this general module should include:

- Indigenous history in Australia – pre-colonisation;
- Indigenous history in Australia – post-colonisation;
- Impact of government legislation on Indigenous peoples;
- Influence of colonisation and government legislation on the current situation of Indigenous peoples today;
- Overview of current national Indigenous demographics and other relevant statistics;
- Contemporary Indigenous issues;
- Overview of Indigenous cultures and protocols;
- Common myths and misconceptions;

- Anti-racism training;
- Strategies for positive cross-cultural communication and interaction; and
- Strategies for increasing cultural safety in the workplace.

The second module should consist of more specialised content, customised to specifically suit particular staff roles, and provide information on the cultural groups in the geographical location in which those staff work. This module would build off the foundations laid in the general module, delivered prior to specialised modules. The content for these specialised modules should include:

- Demographics and other relevant statistics pertaining to the local Indigenous community;
- Aspects of local Indigenous history, and impact on contemporary situation;
- Information on Indigenous cultures and protocols applicable in local community;
- Local- and role-specific myths and misconceptions;
- Information on working partnerships with Indigenous groups, and the importance of consulting with these communities in order to provide appropriate services;
- Strategies for engaging the Indigenous communities of the local region, and establishing working relationships and partnerships;
- Cultural understandings pertaining to particular roles and locations, in terms of more specific effects of colonisation and government legislation, particular service delivery issues, communication and interaction, contemporary issues, etc.;
- Role-specific examples of best practice;
- Learning and practicing appropriate behaviours and strategies;
- Strategies for culturally appropriate service delivery; and
- Opportunities to apply newly gained knowledge and skills in practice situations

Choice of Respite Care

As noted previously, findings from the literature and consultation activities indicate that Aboriginal and Torres Strait Islander peoples with disability and carers have a preference for kinship care, and for Aboriginal-specific services. However, it was also highlighted that this does not apply to everyone as a rule, and there are certain situations that can make these preferences inaccessible. For example, accessing Aboriginal-specific services can hold confidentiality risks for many Aboriginal people – Aboriginal-specific services tend to be staffed by members of the Aboriginal community. This can pose kinship-related problems, making it inappropriate for some workers to provide care for certain members of the community. Factionalism may also serve as an obstacle for some members of the community. This reinforces the need for choice between Aboriginal-specific and mainstream services.

The ACT Government (2003) recognise that carers have the right to decide whether to take on or continue the role of care and are supported in their choices. Choice in regards to respite care needs to be available to both Aboriginal and Torres Strait Islander peoples with disability and carers, and needs to encompass the realms of kinship care, Aboriginal-specific services, and mainstream services.

The component of choice is closely linked with the need for comprehensive, accurate and culturally appropriate information, for advocacy, and cultural competence. To have real choice, care recipients and carers need to have information about respite care options that are available to them. They need open access to the assistance they may require in considering and negotiating such options, gaining access, and planning and monitoring respite care.

In terms of kinship care for respite, choice needs to be enabled by the provision of adequate support and resources to identified members of the kinship network so that they can feasibly provide optimum respite care, including:

- Financial assistance;
- Housing and accommodation;
- Equipment;
- Education and training;
- Information; and
- Advocacy.

In terms of Aboriginal-specific respite care, choice needs to be enabled by the following factors:

- The establishment of Aboriginal-specific respite services;
- Funding of Aboriginal organisations and groups to provide respite services; and
- Employment of more Aboriginal and Torres Strait Islander peoples in mainstream services in Indigenous-identified positions.

In terms of mainstream respite care, choice needs to be enabled by the following factors:

- Employment of more Aboriginal and Torres Strait Islander peoples in mainstream services, both in Indigenous-identified, and non-identified positions; and
- Improved and continuous striving for cultural competence, of staff and service provision.

There should also be ample choice available for Aboriginal and Torres Strait Islander peoples with disability and carers regarding whether respite is conducted in-home, or out-of-home.

Respect & Support for Aboriginal & Torres Strait Islander Cultural Perspectives & Practices

This component encompasses respect and support for the following:

- Worldviews
- Perceptions of disability and caring
- Cultural protocols and practices
- Methods for community participation and decision-making
- Lifestyle choices

In terms of respite care, this may include respecting and supporting:

- A care recipient's desire to stay within a particular geographical location;
- A care recipient and carer's desire to utilise other family and kinship network members for respite care;
- A holistic perspective of disability;
- Cultural protocols relating to the care of an individual (e.g. male or female carers, cutting of hair);
- Desire to use traditional medicines and therapies;
- The importance of building relationships;
- Culturally appropriate methods of communication;
- Respectful terms of address (e.g. 'aunty', 'uncle');
- A community-centred, family inclusive approach to care provision;
- The need for a time-rich, circuitous approach, particularly when attempting to undertake assessments, and plan care needs;
- Appropriate consultation with and involvement of the care recipient, carer and members of the family and kinship network; and
- Aboriginal and Torres Strait Islander staff who may experience conflicting obligations to community and employer.

Indigenous Organisations & Workers

This component encompasses:

- The establishment of new, and adequate support of existing Aboriginal-specific respite care services;
- Funding of Aboriginal organisations and groups to provide respite services;
- The establishment of partnerships between Aboriginal organisations and groups, and mainstream services; and

- Employment of more Aboriginal and Torres Strait Islander peoples in mainstream services in Indigenous-identified positions, and in non-identified positions.

The establishment of new and adequate support of existing Aboriginal-specific respite care services requires a level of resourcing that can ensure optimal service provision and sustainability. Sustainability requires adequate and appropriate funding, management and governance, effective accountability mechanisms, and a trained and supported workforce (National Disability Administrators, 2004).

Many Aboriginal organisations and groups report already providing certain disability services to Aboriginal and Torres Strait Islander community members, despite not being specifically funded to do so. Through the implementation of capacity building with interested organisations and groups to assist them in building the infrastructure, governance and management systems, skills and tools required, such organisations and groups can be funded to provide respite services.

Partnerships between Aboriginal organisations and groups, and mainstream services, can assist in the delivery of culturally appropriate respite care. Partnerships can result in the use of Aboriginal organisations and groups as brokerage services, mentors for mainstream service providers, or as funded respite care service providers. The Centre for Development and Innovation in Health (Legge et al, 1996, cited in National Disability Administrators, 2004) identify three types of partnerships in considering strategies for good practice in primary health care, which have applicability in the disability sector:

- i. Collaborative local network (usually informal) relationships at the local or community level;
- ii. Vertical networking – partnerships between service providers at various levels of the disability service system; and
- iii. Intersectoral collaboration – partnerships between service providers within various sectors, both locally and central.

The employment of Indigenous staff in disability services has been found to be difficult due to the following challenges:

- Use of inappropriate recruitment and retention methods;
- Difficulty recruiting and retaining staff outside of urban areas;
- Perceived and experienced racism and discrimination;
- Inadequate provision of education and training;
- Lack of mentoring and support mechanisms for Indigenous staff;
- Lack of mentoring and support mechanisms for non-Indigenous managers of mainstream services;
- Cultural incompetence of mainstream service;
- Poor awareness or perception of the employment positions available;
- Location and transport issues;
- Preference for employment in Aboriginal organisations;
- Conflict between expectations of the community and those of the employer; and
- Failure of employing organisations to build relationships with Indigenous communities.

Increasing the employment of Aboriginal and Torres Strait Islander workers in mainstream respite services requires the following:

- Determining methods for enabling Aboriginal control over the identification of community employment priorities and expectations, the development of initiatives to address these priorities and expectations, and the implementation and evaluation of these initiatives;
- Developing and implementing an overarching Aboriginal Employment Strategy applicable to ACT respite services;
- Enforcing the Aboriginal Employment Strategy via a Memorandum of Understanding with respite services;
- Establishing partnerships that will support the employment of Aboriginal and Torres Strait Islander staff in respite services (e.g. with Aboriginal employment agencies);
- Increasing Aboriginal and Torres Strait Islander awareness about available careers within respite services;
- Determining procedures and opportunities for Aboriginal and Torres Strait Islander volunteers and work experience placements within respite services;
- Determining procedures regarding the development of positions descriptions and selection criteria within respite services;
- Ensuring methods of advertising and interviewing or employment positions are conducive to increasing Aboriginal and Torres Strait Islander employment within respite services;
- Ensuring a structured work environment with clear expectations, assisted by induction programs, compulsory staff training, and protocols and procedures regarding the management of cultural and community issues as relevant to Aboriginal and Torres Strait Islander employees;
- Establishing effective staff support and mentoring mechanisms;
- Establishing effective mediation mechanisms;
- Establishing effective employee and career development opportunities and pathways for Aboriginal and Torres Strait Islander employees; and
- Establishing and implementing an effective framework of measures to enable the monitoring and evaluation of the implementation and achievements of the Aboriginal Employment Strategy.

Information & Awareness

Information and awareness regarding respite care services available for Aboriginal and Torres Strait Islander peoples with disability and carers includes:

- The ability to be exposed to or find culturally appropriate information;
- Awareness of how the service system addresses disability and caring, including an understanding of the terms 'carer' and 'respite';
- The ability to make contact with and negotiate services;
- Knowledge of how the respite care system works;
- Knowledge of rights and entitlements;
- Knowledge of the 'language' of respite care and the service delivery system; and
- How such information is constructed and disseminated.

Bin-Sallik & Ranzjin (2001 p.17) note:

...most Aboriginal people find out about services via the Aboriginal grapevine rather than the mass media or deliberate promotions. The challenge is then to find ways to better take advantage of the existing grapevine.

The Disability Services Commission (2006) note examples where this theory has been put into practice; where Aboriginal organisations and groups are used as the base from which to identify Aboriginal people who may need information about disability services.

Effective Communication

Effective communication refers to:

- Communication from respite services to care recipients, carers, and family and kinship networks;
- Communication from respite services to Aboriginal organisations and groups;
- Communication between respite services; and
- Communication between respite services and other sectors.

Communication needs to be culturally appropriate, timely, and aided by mechanisms that can prompt communication to occur, and serve as 'safety nets' ensuring that information does not get 'lost through the gaps' along the way.

Increase Respite Service Availability & Accessibility

Increasing Aboriginal and Torres Strait Islander respite service availability and accessibility involves:

- Adequate service provision to meet the level of need within the community;
- Hours of service availability suited to the employment and study needs of carers;
- Service provision to be of high quality and culturally appropriate;
- Affordability of high quality services;
- Focus on effectiveness of service provision, not efficiency;
- Services available within the local region;
- Physical accessibility;
- Provision of transport;
- Appropriate and effective entry criteria, assessment procedures, and referral pathways;
- Community awareness of service availability and accessibility;
- Coordinated response across service providers;
- Access to aids and equipment; and
- Adequate funds to enable high quality service provision.

Education – Consumer & Professional

Consumer education refers to:

- Education and training that should be made available for carers and other members of the family and kinship network to provide them with skills to assist them in care provision (e.g. lifting techniques, use of aids and equipment).

Professional education refers to:

- Education and training that should be made available for staff of respite services, to ensure their knowledge and skills are up-to-date and of a high standard;
- Education and training within institutions such as TAFE that ensure that care workers receive as part of their qualification, cultural competence knowledge and skills;
- Education and training that should be made available for health professionals and key stakeholders in other sectors, to assist referral of potential clients; and
- Education and training that should be made available to staff of Aboriginal organisations and groups to enable them to build capacity to provide high quality respite services.

Community-Centred, Family-Inclusive Approach

A community-centred, family inclusive approach requires a focus on the family and kinship network, rather than the individual, acknowledging the partnership that exists between the care recipient, carer and other members of the family and community.

By consulting and working with the wider family and kinship network in providing information, planning and monitoring of respite care, there can be increased active family and kinship network involvement in decision-making, as well as enhancement of the family and kinship network, and larger community as a resource.

Flexibility

Flexibility refers to the ability of respite services to tailor services to the needs of the client, rather than make the client fit pre-existing models of service provision. It incorporates the ability of respite services to accommodate and respond appropriately to:

- The unique circumstances and needs of the care recipient, carer, and family and kinship network;
- The multiple needs of care recipients, carers and the wider family and kinship network; and
- The changing nature of the caring situation.

Partnerships, Support & Cultural Mentoring

The available evidence shows that Cultural Competence Training programs that provide only short-term exposure to aspects of Indigenous culture and required skills to achieve culturally appropriate service delivery typically fail to achieve any real outcomes relating to knowledge and behaviour change.

However, exposure can be increased through the provision of cultural mentoring for non-Indigenous staff. This may involve the availability of Aboriginal and Torres Strait Islander consultants who can be contacted to provide advice and information to assist a staff member of a respite service in managing a particular issue or client.

Mentoring has been successful in Cultural Competence Training for general practitioner registrars across Australia, producing increased awareness of cultural issues and Indigenous health problems and culturally appropriate communication skills, with participants reporting high levels of satisfaction with the opportunity to interact with Indigenous peoples (Yaxley 2001).

Exposure is also increased through the establishment of partnerships between respite care services and Aboriginal organisations, groups, and key community members. Such arrangements can range from informal relationships between workers, to formal documented agreements. Mentoring and partnerships should be equally beneficial for both parties, with each providing support for the other.

Participation in, or establishment of interagency meetings is another means of providing support for non-Aboriginal respite service providers and increase their cultural competence.

Responsive Respite Services

Aboriginal and Torres Strait Islander respite care services need to have the ability to continually monitor care provision, matched against the needs and circumstances of the care recipient, carer and wider family and kinship network, and respond accordingly, ensuring that service provision is always optimal.

Such monitoring and the development of responses must be done in partnership with the care recipient, carer and family and kinship network. Responsive respite services must also have functional and transparent complaints mechanisms that consumers can access without fear of reprisal, with clear pathways to the development and implementation of responses.

Recommendations

1. Consultation / Communication

1A.

Increase the level of Aboriginal consultation and control over issues relevant to Aboriginal and Torres Strait Islander respite care. This includes monitoring and evaluation, and complaints and other feedback mechanisms, and the analysis and interpretation of findings resulting from such mechanisms.

1B.

Communication pathways should be mapped in consultation with the Aboriginal and Torres Strait Islander communities of the ACT, to ensure there are clear, open and known pathways of information transfer. 'Safety net' mechanisms should be developed where necessary and appropriate, to reduce the loss of information and breakdown in communication.

1C.

Develop culturally appropriate information about the range of respite services and support available, and how they can be accessed. This should be done in a variety of formats, and should include stories from other Aboriginal and Torres Strait Islander peoples who utilise respite services, talking about their experiences. Respite services should work with Aboriginal and Torres Strait Islander communities, organisations and groups to facilitate the dissemination of this information to community members.

2. Delivery of Respite

2A.

Develop and enact an implementation strategy relating to the implementation of the Aboriginal and Torres Strait Islander Respite Care Model detailed in this report. This strategy should be overseen by an Aboriginal and Torres Strait Islander management committee or steering group.

2B.

Provide or advocate for the provision of adequate support and resources to:

- Enable the development of Aboriginal and Torres Strait Islander respite services in the ACT;
- Enable identified members of Aboriginal and Torres Strait Islander family and kinship networks to feasibly provide optimum respite care;
- Enable existing Aboriginal organisations and groups in the ACT region to deliver respite care services;
- Enable existing Aboriginal and Torres Strait Islander respite care services to ensure quality service provision; and
- Ensure Aboriginal and Torres Strait Islander access to aids, equipment, education and training relating to respite care.

2C.

Ensure that all aspects of respite care are culturally appropriate and reflective of Aboriginal and Torres Strait Islander views, perceptions of disability and caring, and historical and economic factors, by:

- Conducting research into Aboriginal and Torres Strait Islander perceptions of disability and caring as relevant to the Aboriginal and Torres Strait Islander peoples of the ACT;
- Conducting ongoing qualitative and quantitative research to determine the prevalence and experience of disability, and of care recipients and carers in the ACT Aboriginal and Torres Strait Islander community;
- Incorporate research findings into respite care service provision;
- Review respite care planning and assessment procedures; and
- Develop standards for culturally appropriate service delivery in regards to respite care. This can be aided by the *Principles of Culturally Appropriate Service Delivery* (see Appendix B)

2D.

Ensure Aboriginal and Torres Strait Islander respite care service delivery is:

- Flexible enough to be able to be tailored to the needs of the client, rather than requiring the client to fit a pre-existing model of service provision;
- Enables clients to exert choice over the respite care they receive;
- Prioritised according to the level of need of the care recipient rather than the presence or absence of a carer;
- Provided as a service separate from and additional to crisis care and long-term accommodation; and
- Monitored and evaluated regularly against Key Performance Indicators based on the Aboriginal and Torres Strait Islander Respite Care Model principles and components.

2E.

Assessment, care planning, and general respite care service delivery must include full consultation with the care recipient, the carer, and other members of the family and kinship network together by way of family meetings, as appropriate to that situation, to ensure all members of the group receive the relevant information, and to enable decision-making by the group as a whole.

3. Workforce Development / Training / Mentoring

3A.

Increase the cultural competence of all staff within respite services through the implementation of a comprehensive and customised Cultural Competence Training program. This includes:

- Incorporating training into orientation for new staff;
- Ensuring any staff subcontracted by the service have also completed the program; and
- Pressing learning institutions providing courses that lead to the qualifications acceptable to employment in respite care services to include cultural competence within the curriculum.

3B.

Ensure availability of regular education and training for:

- Staff of respite services to enable them to update their knowledge and skills and maintain high quality service provision;
- Health professionals and other key stakeholders in other sectors, to enable them to effectively refer potential clients to respite care services; and
- Staff of Aboriginal organisations and groups, providing them with knowledge and understanding of accessing respite care, and skills related to caring which they can then impart to Aboriginal and Torres Strait Islander carers and family and kinship network members.

3C.

Increase the employment of Aboriginal and Torres Strait Islander workers in mainstream respite services.

3D.

Partnerships should be fostered and established between mainstream respite services and Aboriginal organisations and groups, that can enable the following:

- The provision of cultural mentoring for non-Aboriginal staff;
- The provision of mentoring for Aboriginal and Torres Strait Islander staff in areas they require support;
- Arrangements whereby staff from both services can work together with clients requiring respite care, particularly in regards to assessment and care planning activities; and
- The establishment of, and attendance at existing, Aboriginal and Torres Strait Islander Interagency Network meetings.

4. Care Support Other Than Respite

4A.

Respite care for Aboriginal and Torres Strait Islander peoples in the ACT should incorporate elements of advocacy into service provision. Advocacy should involve both:

- i. Individual advocacy, to ensure that Aboriginal and Torres Strait Islander peoples with disability, carers, and the family and kinship network have access to the services and support they require, and
- ii. Systems advocacy, such as working with other agencies to increase a collaborative, holistic approach to service provision, and enabling the needs of care recipients and carers to compete with other contemporary issues affecting the Aboriginal and Torres Strait population.

Such advocacy should be available on an outreach basis. A specific focus should be placed on advocating for Aboriginal and Torres Strait Islander peoples with disability and carers in relation to matters regarding housing, home modifications, aids and equipment, accessing community facilities, and financial issues.

4B.

Advocacy for Aboriginal and Torres Strait Islander peoples with disability and carers can be further provided through the establishment of an Aboriginal and Torres Strait Islander Disability Network for the ACT, as currently operates in NSW, and supporting the development of a National Aboriginal and Torres Strait Islander Disability Network.

4C.

Education and training should be made available for Aboriginal and Torres Strait Islander carers and other members of the family and kinship network to provide them with skills to assist them in care provision (e.g. lifting techniques, use of aids and equipment). This education and training should be provided on a one-to-one basis with the group, at the home of the care recipient, to provide a more comfortable and non-threatening learning environment, to ensure carers and members of the family and kinship group are able to attend, and to enable specific care issues related to the care recipient within their usual environment can be addressed.

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Appendix A

Respite for Aboriginal & Torres Strait Islander Peoples in the ACT

A. The Current Situation – How do things work now?

1. How do people find out about available respite services (both Indigenous-specific & mainstream)?
2. How do people access available respite services (referral, criteria)?
3. What sort of care is available?
4. How are care needs assessed, and available options determined?
5. Who provides the care (Indigenous carers, non-Indigenous carers)?
6. Where is the care provided?
7. How are carers supported?
8. How care clients supported?
9. How are grandparents who are carers supported?
10. How are decisions made regarding care needs and options (consultation with individual, family)?
11. How does the Aboriginal & Torres Strait Islander community have a say in how respite services in the ACT are provided (involvement in advisory groups, consultation activities)?
12. How are respite services for Aboriginal & Torres Strait Islander peoples monitored and evaluated?

B. What Works – What aspects of the current system work well?

1. Awareness of available services
2. Access to services
3. Types of care available
4. Assessment
5. Who provides the care
6. Where the care is provided
7. Support for carers
8. Support for clients
9. Support for grandparents who are carers
10. Decision-making
11. Community involvement in respite service provision
12. Monitoring and evaluation of services

C. What is Needed – How can things work better?

1. How can people be better aware of available respite services (both Indigenous-specific & mainstream)?
2. How can access to respite services be improved?
3. What types of care should be available?
4. How should care needs be assessed, and available options be determined?
5. Who should provide respite care?
6. Where should respite care be provided?
7. What support should be available for carers?

8. What support should be available for clients?
9. What support should be available for grandparents who are carers?
10. How should decisions be made regarding care needs and options (eg. consultations with family rather than just individual)
11. How can the community be better involved and participate in decision-making regarding how respite services are provided?
12. How should respite services for Aboriginal & Torres Strait Islander peoples be monitored and evaluated?

D. Principles of Respite Care for Aboriginal & Torres Strait Islander Peoples in the ACT

What important principles should guide any delivery of respite care for Aboriginal & Torres Strait Islander peoples in the ACT?

Appendix B

Principles of Culturally Appropriate Service Delivery

The following principles of culturally appropriate service delivery include strategies and initiatives that can be developed across systemic, organisational, professional and individual levels of cultural competency (NHMRC 2006), and across the dimensions of knowledge and awareness, skilled practice and behaviour, and strong relationships (AHMAC, 2004). Included with these strategies and initiatives are related performance indicators. Some of these have been adapted from Goode (2004) and Valuing Organizational Improvement and Community Excellence (VOICE) (2006). They have been divided into the following categories:

- Context – the philosophical, social, physical environment and geographical location of an organisation;
- Practices – the functioning and management of an organisation, including policies and procedures;
- Relationships – collaborative partnerships; and
- Service Delivery – outcomes.

Table 1: Context

<p>Category: Context – the philosophical, social, physical environment and geographical location of an organisation</p> <p>The organisation aims to:</p> <ul style="list-style-type: none"> ▪ Promote and foster a culturally-friendly environment; ▪ Be located in an area accessible to Indigenous persons; and ▪ Have staff who display attitudes and behaviours that demonstrate respect for Indigenous cultural groups. 	
Strategies	Performance Indicators
<p>The Mission Statement and goals of the organisation incorporate principles and practices that promote cultural diversity and cultural competence.</p>	<p>Mission Statement Incorporates principles and practices of Cultural Respect</p> <p>Strategic Plan reflects organisation’s goals of promoting cultural diversity and cultural competence and commitment to meeting needs of Indigenous community/population it serves.</p>
<p>Ensure equitable access for Indigenous peoples to all services provided by the organisation.</p>	<p>Indigenous consumers are actively informed of their rights and responsibilities when accessing and using services provided by the organisation.</p>

	<p>The organisation has actively promoted awareness of its services in the Indigenous communities it serves, using a variety of appropriate methods and media.</p> <p>The organisation takes steps to negotiate the most appropriate and effective work environment when engaging with Indigenous consumers and other key stakeholders.</p> <p>Services are provided in a location that is physically accessible to Indigenous clients.</p>
<p>Ensure that the physical environment, materials and resources of the organisation reflect the Indigenous cultures of the community/population it serves.</p>	<p>Use of pictures, posters and other materials that reflect Indigenous cultures of the target community/population.</p> <p>Use of magazines, brochures, posters and other printed materials in reception areas that are of interest to and reflect the Indigenous cultures of the target community/population.</p> <p>Use of materials for education, treatment, or other interventions that are specific to and reflect the Indigenous cultures of the target community/population.</p>
<p>Staff are trained in and motivated to display and practice attitudes and behaviours conducive to the principles of Cultural Respect, as well as locally-specific cultural issues such as:</p> <ul style="list-style-type: none"> ▪ Pre- and post-colonisation history ▪ Cultural norms ▪ Kinship norms and responsibilities ▪ How to indicate respect for Elders ▪ Social structure of the community ▪ Differences in local cultures ▪ Spirituality 	<p>Staff orientation cultural competency training for new staff members</p> <p>Ongoing staff development including cultural competency training, staff participation in cultural events, and the understanding and application of appropriate communication methods.</p> <p>Cultural Respect principles included in staff performance evaluation</p> <p>The development and enforcement of sanctions applicable to attitudes and behaviour that is culturally destructive.</p>

<ul style="list-style-type: none"> ▪ Current social problems and the historical context of these problems 	<p>Procedures to ensure that all visual or written materials connected to or used by the organisation are screened for negative cultural and racial stereotypes before use.</p>
<p>The organisation ensures fiscal support for developing culturally appropriate Indigenous service provision.</p>	<p>Budgetary policies and practices that allocate resources and fiscal support to achieve organisational competency</p>

Table 2: Practices

<p>Category: Practices – the functioning and management of an organisation, including policies and procedures.</p> <p>The organisation aims to:</p> <p>Develop policies and procedures that take cultural matters into consideration;</p> <p>Provide programs that encourage participation by Indigenous persons; and</p> <p>Use appropriate communication methods and language.</p>	
Strategies	Performance Indicators
<p>Ensure that communication methods and language used by the organisation and its staff are appropriate for the Indigenous cultures of the community/population it serves.</p>	<p>Use of locally-specific key words, names and terminology in verbal and written communication.</p> <p>Knowledge and use of appropriate body language, gestures, visual aids and physical prompts.</p> <p>Knowledge of acceptable behaviours, courtesies, customs and expectations specific to the Indigenous communities/population served.</p> <p>Access to and use of interpreters.</p> <p>Access to and use of Indigenous staff within the organisation, or key Indigenous individuals outside of the organisation who can accompany, assist and/or advocate for clients.</p> <p>Monitoring of frontline staff performance.</p>

<p>Ensure that service provision caters for Indigenous definitions and concepts of health and ill-health, wellbeing, disability, helping, family, and gender issues</p>	<p>Holistic approach to health and wellbeing.</p> <p>Indigenous styles of helping as applicable to ageing, disability and carer's issues investigated and built into service provision.</p> <p>Availability of Indigenous staff.</p> <p>Choice of male and female staff.</p>
<p>Ensure policies and procedures regarding staff performance and service provision facilitate cultural competence.</p>	<p>Policies and Procedures are documented regarding the promotion of cultural diversity and cultural competence within the organisation, including service provision and staff performance, particular to the Indigenous community/population it serves.</p> <p>Policies and procedures are documented that address the employment of Indigenous staff (including volunteers), including recruitment, selection and appeal processes, advertising of positions, and retainment and support strategies.</p>
<p>Ensure a process of continual monitoring, review and adaptation of the organisation's performance in relation to cultural competence</p>	<p>Documented policies and procedures detailing monitoring, review and adaptation methods.</p> <p>Staff performance evaluation.</p> <p>Monitoring of frontline staff performance.</p> <p>Levels of Indigenous employment and retainment within organisation.</p> <p>Consultation activities with Indigenous community and key stakeholders.</p> <p>Consultation activities with staff (both Indigenous and non-Indigenous).</p>

Table 3: Relationships

Category: Relationships – Collaborative Partnerships	
<p>The organisation aims to:</p> <ul style="list-style-type: none"> ▪ Have knowledge of local Indigenous groups; ▪ Have knowledge of local Indigenous protocols for collaboration and communication with local Indigenous persons and groups; ▪ Actively involve Indigenous persons and groups; and ▪ Have a strategy for community engagement. 	
Strategies	Performance Indicators
<p>The organisation seeks active involvement with the Indigenous communities/population it serves.</p>	<p>Indigenous community (especially consumer and carer) participation in the development, implementation and evaluation of service provision.</p> <p>Formal and informal partnerships with Indigenous community groups.</p> <p>Membership and/or representation from Indigenous persons on the organisation's governing committee, advisory bodies, and selection panels.</p> <p>Community engagement strategies, including the opportunity for employees and volunteers to actively interact and engage with Indigenous persons.</p> <p>Participation in Indigenous community events and celebrations.</p> <p>Availability and use of internal or external advisors/consultants for specific cultural matters.</p>

Table 4: Service Delivery

Category: Service Delivery - Outcomes	
<p>The organisation aims to:</p> <ul style="list-style-type: none"> ▪ Develop and implement a collaborative service delivery model with other organisations relevant to the specific cultural needs of Indigenous clients; ▪ Provide culturally responsive services that meet the cultural needs of Indigenous clients. 	
Strategies	Performance Indicators
<p>The organisation liaises and collaborates with relevant specialist service providers who have specific knowledge of Indigenous community issues or provide Indigenous-specific services for that Indigenous community to promote a coordinated approach to service provision.</p>	<p>Established networks, partnerships and referral pathways with Indigenous community and Indigenous-specific services.</p> <p>Employment of Indigenous Liaison staff positions, or Indigenous-identified positions whose tasks include liaison activities with relevant key stakeholders.</p> <p>Consultation activities with relevant key stakeholders.</p> <p>Staff knowledge of, referral to and consultation with relevant individuals, groups and organisations specialising in Indigenous service provision.</p> <p>Use of Indigenous agencies as a base to meet potential Indigenous clients and to provide information about available services.</p>
<p>Ensure that all aspects of service provision are culturally appropriate and evidence-based.</p>	<p>Indigenous perceptions and conceptualisations of relevant issues are acknowledged and catered for (eg. Indigenous perceptions of disability and how to respond to people with a disability).</p> <p>Formal assessments of the cultural needs of Indigenous employees, volunteers and persons accessing services.</p> <p>Use of culturally validated assessment and review instruments</p>

	<p>and tools.</p> <p>Evaluation of service provision and programs.</p> <p>Research and development activities relevant to Indigenous ageing, disability and carer's issues.</p> <p>Use of recent research findings to inform service provision.</p> <p>Links with external agencies that have a research focus on Indigenous ageing, disability and carer's issues.</p> <p>Data collection systems that allow comprehensive collection of client data.</p> <p>An annually updated profile of the Indigenous communities within the organisation's service region identifying data such as population size of each community, demographic characteristics, social economic status, etc.</p> <p>Monitoring of outcomes for Indigenous clients.</p>
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