Practical ways to overcome isolation for Aboriginal and Torres Strait Islander carers

Literature review
Acknowledgements

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Carers Australia acknowledges and pays respect to Aboriginal and Torres Strait Islander peoples who are the traditional custodians of the lands and islands of Australia.
About Carers Australia

Carers Australia is the national peak body representing over 2.6 million unpaid carers in Australia. Our Vision is of an Australia that values and supports the contribution that carers make both to the people they care for and to the community as a whole. Our Mission is to promote and support carers and the people they care for through effective advocacy, quality programs and community awareness activities that respect and enhance these relationships while meeting carers' needs. Carers Australia advocates on behalf of Australia's unpaid carers at a national level.

Who are carers?

Carers are people who provide unpaid care and support to family members and friends who have a disability, mental illness, chronic condition, terminal illness, an alcohol or other drug issue, or who are frail aged. Carers are an integral part of Australia's health system and are the foundation of our aged, disability, palliative and community care systems. Caring may include help and support in any of the activities of daily life of the person being cared for. Caring roles are diverse and may include providing assistance with physical and personal care including dressing, lifting, showering, feeding or providing transport. Caring may also involve helping the person they are caring for with organisation and independence as well as dealing with emergencies. Commonly carers are responsible for the management of medications and for providing emotional, social and financial support.

Whilst the majority of carers will say that caring for someone is very rewarding and something they want to do, it is noted that it is not always easy with 35% of primary carers provide care for 40 or more hours a week, often for many years. Carers are noted to have poorer health and wellbeing than non-carers. Caring responsibilities can also adversely impact upon family finances due to the costs involved in caring, and because of reduced opportunities to work and save. Awareness of these issues means that Carers Australia, governments and other support organisations can assist carers who are struggling, and drive change to make the lives of carers easier.
Executive Summary

Carers Australia acknowledges that there is a lack of information about Aboriginal and Torres Strait Islander carers, their profile across Australia, health and wellbeing, and experiences in using carer services, programs and resources.

Carers Australia has undertaken a study into the isolation experienced by Aboriginal and Torres Strait Islander carers including the following literature review.

This literature review begins with a profile of Aboriginal and Torres Strait Islander carers based on information from the Australian Bureau of Statistics and Australian Institute of Health and Welfare. This is followed by a discussion of the Australian literature on Aboriginal and Torres Strait Islander carers, and the international literature on Indigenous/First Nations carers. The literature comprises journal articles, reports, and conference proceedings. The literature selected is relevant to unpaid carers who provide assistance to a family member or friend with a disability, mental illness, chronic condition, terminal illness, an alcohol or other drug issue, or who are frail aged. The literature on foster carers, kinship carers or grandparent ‘parents’ was excluded. The literature was sourced through internet searches, searches of online academic databases, and requesting information from services providers and researchers. The Australian literature search resulted in 54 key documents being identified. These were reviewed in-depth and each document summarised. The following themes were determined based on this literature: 1) The lived experiences of Aboriginal and Torres Strait Islander carers; 2) Barriers to Aboriginal and Torres Strait Islander carers seeking support and accessing services; and 3) Ways to better enable support for Aboriginal and Torres Strait Islander carers. The international literature search resulted in 15 key documents being identified. Discussion of the international literature was to primarily make inferences to the findings from Australia. In general, there is limited information available specific to Aboriginal and Torres Strait Islander carers and Indigenous/First Nations carers. The majority of information is based on qualitative research, focus groups and community consultations.
Profile of Aboriginal and Torres Strait Islander carers

Aboriginal and Torres Strait Islander peoples are more likely to take on an unpaid caring role for a family member or friend than non-Indigenous Australians. Furthermore, they are much more likely to need assistance with self-care, mobility or communication. These are aspects of day-to-day living that many carers support. However, Aboriginal and Torres Strait Islander carers are less likely to access services to support them in their caring. The following information is based on Australian Bureau of Statistics Census of Population and Housing 2006 data. The Census refers to carers as those who, in the two weeks prior to Census night, provided unpaid care, help or assistance to another person because of their disability, long-term illness or problems related to old age. It must be noted, however, that there is likely to be under-reporting of caring role amongst Aboriginal and Torres Strait Islander peoples due to lack of carer self-identification. Information about Aboriginal and Torres Strait Islander carers from the Australian Bureau of Statistics Survey of Disability, Ageing and Carers is limited as this survey does not disaggregate data by Indigenous status. Furthermore, the Survey of Disability, Ageing and Carers excludes from the sample very remote communities as well as Aboriginal and Torres Strait Islander communities in other (non-very remote) areas due to logistical reasons.

Total population

It is estimated that in 2006, 12.4% of Aboriginal and Torres Strait Islander peoples provided unpaid care and support compared with 10.5% of non-Indigenous1 Australians (Australian Institute of Health and Welfare and Australian Bureau of Statistics, 2008). There has been an increase in Aboriginal and Torres Strait Islander peoples identifying as carers from 32,581 in 2006 (Australian Bureau of Statistics, 2007) to 45,328 in 2011 (Australian Bureau of Statistics, 2011). It is noted that there was a growth in the number of people identifying as Aboriginal and/or Torres Strait Islander from 455,031 in 2006 (Australian Bureau of Statistics, 2007) to 548,370 in 2011 (Australian Bureau of Statistics, 2011).

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1 ‘Indigenous Australians’ is a term used in some sources to refer to Aboriginal peoples, Torres Strait Islanders, and/or individuals with mixed Aboriginal and Torres Strait Islander heritage.
Figure 1: Carers, by Indigenous status, age and sex, 2006 (Australian Institute of Health and Welfare and Australian Bureau of Statistics, 2008)

<table>
<thead>
<tr>
<th>Age group (years)</th>
<th>Indigenous %</th>
<th>Non-Indigenous %</th>
<th>Indigenous to non-Indigenous ratio</th>
</tr>
</thead>
<tbody>
<tr>
<td>15-24</td>
<td>7.0</td>
<td>4.5</td>
<td>1.7</td>
</tr>
<tr>
<td>25-34</td>
<td>12.1</td>
<td>7.5</td>
<td>1.6</td>
</tr>
<tr>
<td>35-44</td>
<td>14.7</td>
<td>11.2</td>
<td>1.3</td>
</tr>
<tr>
<td>45-54</td>
<td>15.3</td>
<td>15.0</td>
<td>1.0</td>
</tr>
<tr>
<td>55-64</td>
<td>14.0</td>
<td>16.5</td>
<td>0.9</td>
</tr>
<tr>
<td>65 and over</td>
<td>10.4</td>
<td>10.4</td>
<td>1.0</td>
</tr>
<tr>
<td>Total</td>
<td>11.9</td>
<td>10.8</td>
<td>1.1</td>
</tr>
</tbody>
</table>

Males—Age standardised 9.8 8.3 1.2
Females—Age standardised 14.5 12.6 1.2
Total—Age standardised 12.4 10.5 1.2

NUMBERS
Total carers 31600 1,532,057

(a) Persons aged 15 years or over living in private dwellings who provided unpaid care, help or assistance to another person because of their disability, long-term illness or problems related to old age.

Source: ABS 2006 Census of Population and Housing

Age

In 2006, the average age of Aboriginal and Torres Strait Islander carers was 37 years; 12 years less than the average age of non-Indigenous Australian carers (Australian Institute of Health and Welfare and Australian Bureau of Statistics, 2008). This may reflect higher birth rates at younger ages and earlier onset of chronic diseases.

Figure 2: Provision of unpaid assistance by age, Indigenous Australians, 2006 (Australian Institute of Health and Welfare, 2011a)
Gender

It is estimated that in 2006, 14% of Aboriginal and Torres Strait Islander women and 9% of Aboriginal and Torres Strait Islander men had caring responsibilities (Australian Institute of Health and Welfare and Australian Bureau of Statistics, 2008). A large proportion of unpaid assistance (20%) was provided by Aboriginal and Torres Strait Islander women aged between 45 and 54 years (Australian Institute of Health and Welfare, 2011a). Mothers were most frequently the primary carer (29%), followed by other female relatives (6.8%) (Australian Institute of Health and Welfare, 2011b).

Figure 3: Carers of disability support service users, 2008-09 (Australian Institute of Health and Welfare, 2011b)

Need for assistance

In 2006, Aboriginal and Torres Strait Islander peoples aged 0–64 years were 2.4 times as likely to need assistance with self-care, mobility and/or communication than non-Indigenous people (Australian Institute of Health and Welfare, 2011a). Despite the higher prevalence of disability among Aboriginal and Torres Strait Islander peoples, the rate of their specialist service use is similar to that of non-Indigenous Australians (about 330 service users, per 1,000 potential population) (Australian Institute of Health and Welfare, 2011a). Almost half (49%) of Indigenous disability support service users, aged 0–64 years, had carers, compared with 41% of non-Indigenous users (Australian Institute of Health and Welfare, 2011b). Aboriginal and Torres Strait Islander carers were between one-and-a half and three times as likely as non-Indigenous carers to need assistance with self-care, mobility and/or communication (Australian Institute of Health and Welfare and Australian Bureau of Statistics, 2008).
Figure 4: Need for assistance with core activities by Indigenous Australians: rate compared to non-Indigenous Australians, 2006 (Australian Institute of Health and Welfare, 2011a)

Notes:
1. Based on rates standardised to the age- and sex-distribution of the Australian population.
2. Excludes people who did not respond to the Census questions about disability.
3. A rate ratio greater than 1 means that Indigenous Australians were more likely than non-Indigenous Australians of the same age to need assistance with core activities. Higher rate ratios mean larger differences.

Source: AIHW 2009a.

Figure 5: Carers who needed assistance by Indigenous status and age groups, 2006 (Australian Institute of Health and Welfare and Australian Bureau of Statistics, 2008)

(a) Aged 15 years and over, living in private dwellings.
(b) With core activities of self-care, mobility and/or communication.

Source: ABS 2006 Census of Population and Housing
Socio-economic factors

In 2006, Aboriginal and Torres Strait Islander carers were four times as likely as non-Indigenous carers to be living in a low resource household (Australian Institute of Health and Welfare and Australian Bureau of Statistics, 2008). People in low resource households are those with equivalised gross household income in the bottom 20% of incomes, excluding people in households that were owned (with or without a mortgage) by a household member or where a household member was an owner manager of an unincorporated business (Australian Bureau of Statistics, 2011b). A similar degree of relative disadvantage was also evident between Aboriginal and Torres Strait Islander peoples and non-Indigenous Australian people who are not carers.

Data from the 2006 Census suggests Aboriginal and Torres Strait Islander carers were more likely than those not providing care to be living in a low resource household (36% compared with 33%) (Australian Institute of Health and Welfare and Australian Bureau of Statistics, 2008). According to age-standardised data, Aboriginal and Torres Strait Islander male carers median weekly income was $248 compared with $589 for non-Indigenous Australian male carers (Australian Institute of Health and Welfare and Australian Bureau of Statistics, 2008). Aboriginal and Torres Strait Islander female carers median income was $289 compared with $356 for non-Indigenous Australian female carers (Australian Institute of Health and Welfare and Australian Bureau of Statistics, 2008). The median weekly income for Aboriginal and Torres Strait Islander male carers was between $60 and $140 lower than the corresponding income for Aboriginal and Torres Strait Islander males not providing care (Australian Institute of Health and Welfare and Australian Bureau of Statistics, 2008). The median weekly income for Aboriginal and Torres Strait Islander female carers was up to $25 lower than the corresponding income for Aboriginal and Torres Strait Islander females not providing care (Australian Institute of Health and Welfare and Australian Bureau of Statistics, 2008). Non-Indigenous Australian carers were around one-and-a-half times more likely to be employed than Aboriginal and Torres Strait Islander carers (Australian Institute of Health and Welfare and Australian Bureau of Statistics, 2008). Among those who were employed, rates of part-time work were similar for Aboriginal and Torres Strait Islander carers and non-Indigenous Australian carers (Australian Institute of Health and Welfare and Australian Bureau of Statistics, 2008).
Figure 6: Median individual weekly income by carer status, Indigenous males aged 15 years and over in private dwellings, 2006 (Australian Institute of Health and Welfare and Australian Bureau of Statistics, 2008)

Source: ABS 2006 Census of Population and Housing

Figure 7: Median individual weekly income by carer status, Indigenous females aged 15 years and over in private dwellings, 2006 (Australian Institute of Health and Welfare and Australian Bureau of Statistics, 2008)

Source: ABS 2006 Census of Population and Housing
Figure 8: Distribution of Aboriginal and Torres Strait Islander carers by Local Government Area boundaries, Australian Bureau of Statistics, 2011

This product uses a generalised version of ABS geographic boundaries. This removes some of the detail in the boundaries including very small islands and reduces the file size which enables the application to run more efficiently. More information on this is available in the TableBuilder Manual. The exact AGSS and ASGC boundaries are available from the ABS Statistical Geography Portal, www.abs.gov.au/geo.

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Australian literature

1. The lived experiences of Aboriginal and Torres Strait Islander carers

The lived experiences of Aboriginal and Torres Strait Islander carers are diverse and vary according to individual circumstances, the particular family group and community, personal resources, and access to local services and supports. Aboriginal and Torres Strait Islander peoples take on a caring role for numerous reasons: due to necessity, cultural and family responsibilities, and the importance placed upon the care of older people who keep the family together and pass down cultural knowledge and language (Smith et al., 2011). Caring may be considered to be spiritually important (McGrath, 2008). There may be significance in caring for sick or dying family members as family closeness reduces fear associated with dying (McGrath, 2008).

... Who’s your carer? And start [with] that, that can be an interesting conversation because there are very, very different perceptions of the role for us and for Anungu (Carer cited in Lindeman, Bell, & Reid, 2012a, p. 6).

Involvement in caring is more likely where there are strong kinship networks and traditional cultural practices (McGrath, 2008). It is important to understand that not all Aboriginal and Torres Strait Islander families share traditional values. Factors influencing readiness to be involved in the caring role include position in the family and community, fear associated with ‘blame’ and ‘payback’ for the care recipient’s illness or impeding death, and fear about contagions (McGrath, 2008). It has been reported, however, that there is a strong preference by Aboriginal and Torres Strait Islander peoples for family members to be cared for by their own (Carroll et al., 2010; McGrath, 2008).

There are sometimes cultural rules relating to who may be involved in caring, for instance the care of a dying person and who may visit them (McGrath, 2008). The relationship of the carer to the care recipient can also influence the role they play. For example, adult children often act as advocates and assist with day-to-day practical support, whilst Elders have an important role in passing information on from one generation to the next and increasing awareness of health and welfare issues (Aspin, Brown, Jowsey, Yen, & Leeder, 2012; Smith, et al., 2011).
There have been incorrect assumptions about Aboriginal and Torres Strait Islander men not having a role in caring and building family relationships (Pearce, 2000). Although women have traditionally played primary roles in caring, Aboriginal and Torres Strait Islander men are increasingly being involved as carers (Pearce, 2000). Pearce (2000) discusses how male carers have been overlooked by services and the carer agenda.

What I experienced during this time reminded me of a few years ago when I was at a book launch on Caring. Here I was approached by a person of supposed senior standing (in the non-Indigenous community) and was asked by her “what I was doing here” and “what I did for a living”. (The standard intrusive approach by some non-Aboriginal people.) I answered her that I was a parent of a child with a disability and I was interested in how to assist Aboriginal people with a disability in gaining access to services. The person then shouted at the top of her voice to everyone else in the crowded room that I was a Carer (another nugget had been found). I felt insulted at the way I was approached and taken aback to think I was considered, viewed and paraded in this manner. My inquisitor then ask, just what it meant to me to be an Aboriginal man who was a carer? (Pearce, 2000, p. 1)

Caring is difficult and challenging work and in addition to day-to-day support it may also involve the provision of constant emotional and spiritual support, preparation of traditional foods, making music and singing (McGrath, 2008). The pressure to provide continuous care can interfere with work and study (McGrath, 2008). Aboriginal and Torres Strait Islander peoples describe how the impact of caring can include depression, contemplating suicide, loss and grief, anger, anxiety, panic attacks and worry, fear of discrimination, difficulty coping and feeling isolated (Hepburn & Twining, 2005).

A cultural practice associated with caring is ‘yarning’. Yarning means having a conversation or telling stories. Family and friends getting together and having a ‘yarn’ can be both beneficial to the carer and care recipient as it has been considered a form of informal psychological support and an avenue for sharing information (Ward, Jowsey, Haora, Aspin, & Yen, 2011). The support provided by a carer can be solicited or unsolicited. In the study of Ward et al. (2011), Aboriginal and Torres Strait Islander peoples with chronic illness associated unsolicited support with the terms “nagging” and “growling”. The study examined how unsolicited support can cause stress and conflict between the carer and care recipient as it created tensions and ambiguities in relationships and self-management practices (Ward, et al., 2011). Sometimes unsolicited support was effective in motivating people to self-manage though it could also foster feelings of ambivalence and anxiety.
(Ward, et al., 2011). Aboriginal and Torres Strait Islander carers may have added pressures relating to cultural considerations with social interactions. For example, in order not to draw attention to and place shame upon the care recipient, a carer might use sign language or a code to provide support or direction whilst in the presence of others (Ward, et al., 2011).

Many Aboriginal and Torres Strait Islander carers look after more than one person with disability or additional family members such as children at the same time, increasing carer burden (Carroll, et al., 2010; Hepburn & Twining, 2005; Smith, et al., 2011; The Echidna Group, 2009). Furthermore, Aboriginal and Torres Strait Islander workers who are carers can be overwhelmed both professionally and personally (Hepburn & Twining, 2005).

If you have a job you are automatically an advocate for your community. Workers are overwhelmed and ‘on call’ 24 hours a day with work and family obligations. (Carer cited in Hepburn & Twining, 2005, p. 15).

Carer load is increased when the care recipient has multi-morbidity or the carer themselves has a need for assistance (Jowsey, Yen, Aspin, Ward, & the SCIPPS Team, 2011). Carer burnout is multiplied in communities where there are scarce resources, poor supportive infrastructure, competing family priorities, high burden of disease and low socio-economic status (Maguire & Wenitong, 2012). The literature refers to “Granny burnout” where many of the elderly people who should be being cared for are the carers themselves (Maguire & Wenitong, 2012; Sullivan, Blignault, Duncan, & Jackson Pulver, 2007). The burden of grief and stress carried in communities can lead to inconsistencies in care (O’Neil, Kirov, & Thompson, 2004). Family breakdowns and dysfunction and lead to the person with a disability being vulnerable to exploitation or neglected (O’Neil, et al., 2004). It is well established that Aboriginal and Torres Strait Islander peoples experience substantial inequalities in health, education and social outcomes (Freemantle, Officer, McAullay & Anderson, 2007 cited in Priest, Mackean, Davis, Briggs, & Waters, 2012) and that these inequalities are associated with colonisation, oppression, and historical and contemporary racism (Paradies, Harris & Anderson, 2008 cited in Priest, et al., 2012).
2. Barriers to Aboriginal and Torres Strait Islander carers seeking support and accessing services

I know of very little support available. Sink or swim situation (Carer cited in The Echidna Group, 2009, p. 35).

Nothing, we don’t get help from nobody, we just help each other I suppose because we still have that independence as well but, but that’s not the point, sometimes it’s good to have that little bit of help even if it’s moral support. (Carer cited in Smith, et al., 2011, p. 10).

According to the Aboriginal Disability Network of New South Wales (2007), the needs of the vast majority of Aboriginal people with disability are unmet and they often do not receive any support other than what is provided by immediate family or kinship networks. Even strong individuals, families and communities can find it difficult to provide ongoing support for people who struggle to meet their own needs (Maguire & Wenitong, 2012). It has been reported that many Aboriginal and Torres Strait Islander carers, particularly those in rural and remote communities, are “struggling to cope” (Smith, et al., 2011) and are at a “crisis point” (Aboriginal Disability Network, 2007). The literature indicates that many Aboriginal and Torres Strait Islander carers often seek assistance when the situation has reached breaking point (Aboriginal Disability Network, 2007; The Echidna Group, 2009). Unfortunately, when the situation has become a crisis it can result in family members being removed from the family (Aboriginal Disability Network, 2007).

It has been established that although Aboriginal and Torres Strait Islander peoples are more likely to take on an unpaid caring role, and need assistance with self-care, mobility or communication than non-Indigenous Australian people, they are less likely to access services (Australian Institute of Health and Welfare, 2011a, 2011b; Australian Institute of Health and Welfare and Australian Bureau of Statistics, 2008). The reasons for this lack of access suggested by the literature include not identifying as a carer, cultural beliefs relating to the role of caring, socio-economic factors that impact on ability to seek help, lack of awareness of services, lack of availability of services, reluctance to use services that are considered culturally inappropriate, reluctance to relocate for services, over complexity of the system, lack of choice between mainstream and culturally-specific services, and lack of availability of Aboriginal and/or Torres Strait Islander staff.
Aboriginal and Torres Strait Islander peoples who take on an unpaid caring role may not necessarily identify as being a ‘carer’. Similarly, Aboriginal and Torres Strait Islander peoples with disability may not identify as having a disability (Griffis, 2012). The House of Representatives Standing Committee on Family, Housing and Youth Affairs report on the 2009 inquiry into better support for carers found that many Aboriginal and Torres Strait Islander carers see caring as a natural extension of family duty, also reducing the likelihood of their seeking any assistance (Commonwealth of Australia, 2009). However, the assumption that Aboriginal and Torres Strait Islander peoples are ‘being cared for by their families’ can lead to their needs being overlooked (Stokes 1988 cited in O’Neil, et al., 2004). The issue of under-reporting of disability and carer status is frequently mentioned in the literature (Aboriginal Disability Network, 2007; Carers NSW, 2010; Hepburn & Twining, 2005; Monahan & Twining, 2006; The Echidna Group, 2009).

There are a number of reasons for lack of self-identification, including not wanting to experience further discrimination based on a label, differing understanding and constructs of disability and the caring role (The Echidna Group, 2009), no comparable word for disability in traditional language (Griffis, 2010) and disability not being considered unusual by the community (Aboriginal Disability Network, 2007). For example, there may be a focus on physical or visible health conditions rather than mental illness (Aboriginal Disability Network, 2007). There may be stigma associated with disability such as “married wrong way” or “payback” (Griffis, 2010; O’Neil, et al., 2004). Aboriginal and Torres Strait Islander carers may view causes, signs and symptoms of health conditions differently to service providers (Smith, et al., 2011). A study on dementia awareness in a remote Aboriginal community noted “some participants identified the existence of ‘neglect, abuse and fighting’ that might have been linked to a lack of awareness and understanding of dementia and the resultant failure of family members to seek out carer support services” (Lindeman, Taylor, Kuipers, Stothers, & Piper, 2012b).

Aboriginal and Torres Strait Islander peoples may reject the idea of carer support such as respite based on beliefs that families should shoulder full responsibility (Carers NSW, 2010; McGrath et al., 2006). The reluctance of carers to seek help may be based on fears of being seen as a bad caregiver (Aboriginal Disability Network, 2007). There may be fears in accessing support for the care recipient outside of the home due to past government policies of the forcible removal of family members (Carers NSW, 2010). According to The Echidna Group (2009), poor help-seeking knowledge and skills can be associated with past government policies and practices which fractured traditional helping and help-seeking.
channels, and forced dependence. Furthermore, lack of knowledge and skills regarding who and how to access help with caring can be a potential source of shame (The Echidna Group, 2009).

It is frequently mentioned in the literature that many Aboriginal and Torres Strait Islander carers lack awareness or do not receive information about carer rights and entitlements, what carer services are available and how to access them (Aboriginal Disability Network, 2007; Smith, et al., 2011; The Echidna Group, 2009). For example, in the study of Hepburn and Twining (2005), only five out of thirty nine carers interviewed received any carer entitlements, and in a separate group of sixty carers not one received the Carer Allowance. Carers may be misinformed or have perceptions of not being eligible to access services (The Echidna Group, 2009). There have been reports that some Centrelink offices do not support clients to complete forms where literacy is an issue (Aboriginal Disability Network, 2007). According to the Aboriginal Disability Network (2007), many families are unaware of the Home and Community Care home modification program where aids, equipment and home modifications assist the carer in their caregiving role.

"You go through your GP to get all the things like even the amount at Centrelink … fill out all these forms. And sometimes Centrelink have their GPs there, but that’s entirely up to them, if they don’t like you know, the situation, they just knock you back … They just said they just couldn’t find the proof, like I really needed a carer at the moment … Well it made me feel like you know, shit, ‘cause I admit it myself, like you know, I needed a carer. (Participant cited in Jowsey, et al., 2011, p. 35)

Individuals may be confused or overwhelmed by the overly complex, multi-layered and fragmented services that are provided by different Commonwealth, State and local government departments as well as non-government organisations (Stewart, Lohoar, & Higgins, 2011). For example, Aboriginal and Torres Strait Islander peoples who are carers may need to deal with as many as seven different government departments during the early years of the life of a child with disability (Griffis, 2010). According to The Echidna Group (2009), “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” (p.33). Services that are not located under the same roof or that are poorly coordinated result in an increased amount of time taken to manage health and wellbeing in terms of waiting times and consultations with different professionals (Jowsey, et al., 2011). Even those carers who are linked in with certain carer support services are
unaware of other others, indicating that being a current consumer does not always result in further assistance in accessing other services (The Echidna Group, 2009). There is evidence that lack of service coordination impacts on the ability of people to remain living in the community safely (Smith, et al., 2011; Stewart, et al., 2011).

There are very few culturally-specific services, or mainstream services with Aboriginal and Torres Strait Islander staff (Aboriginal Disability Network, 2007). Some mainstream services are noted to have limited experience in inter-relating and conducting meaningful engagement with Aboriginal and Torres Strait Islander peoples with disability and their carers (Aboriginal Disability Network, 2007). Services are often poorly targeted and located (Aboriginal Disability Network, 2007). However, with regards to some community-controlled services, family allegiances can make accessing services difficult (O’Neil, et al., 2004).

The study of Frizzell and Chamberlain (2006) found that in Victoria the overwhelming majority of Aboriginal and Torres Strait Islander peoples preferred to access Home and Community Care services through an Aboriginal Community Controlled Health Organisation, particularly in-home and social support services, due to reasons of cultural safety and reluctance to access mainstream agencies due to issues of distrust, fear, shame, cultural barriers and fees. The limited number of Aboriginal and/or Torres Strait Islander specific services often means that these services are overwhelmed with clients yet under-resourced to provide services (Frizzell & Chamberlain, 2006; The Echidna Group, 2009). These demands for services can result in delays in support due to waiting lists (Aboriginal Disability Network, 2007).

Carers may have had negative experiences accessing mainstream services that were racist, culturally insensitive or inappropriate, poorly coordinated and time consuming. They may have dealt with health and welfare professionals who communicated poorly, were unfriendly or behaved in a patronising manner (Jowsey, et al., 2011). There are reports of Elders being treated disrespectfully by the health and welfare system (Aspin, et al., 2012). Aboriginal and Torres Strait Islander carers may experience feelings of shame or conflict about discussing certain situations with workers of a different gender due to cultural restrictions pertaining to “Men’s Business and Women’s Business” (Carers NSW, 2010). Where carers speak a different language to English, language barriers occur unless translators are used or resources are provided in other languages (Lindeman, et al., 2012b; O’Neil, et al., 2004; Smith, et al., 2011).
The Anunga rules … to ensure that interpreters are available, so that the person can understand questions. There should be a similar set of laws for health settings, for example for people in hospital not understanding medications. Without interpreters there is seldom informed consent. (Service provider cited in Smith, et al., 2011, p. 9).

A lack of cultural competence amongst mainstream services providers is cited (Aboriginal Disability Network, 2007). A significant concern of Aboriginal and Torres Strait Islander carers is that of cultural appropriateness of services such as respite and hospice, and that if these are not culturally appropriate they will therefore not be used (McGrath & Patton, 2007). Western health care facilities such as hospital rooms can be only designed to accommodate a few visitors, and policies restricting numbers of visitors and restricting cultural rites can be very distressing for Aboriginal families (McGrath, 2008).

You do feel intimidated because you’ve copped it for so many years you’ve gone to hospitals, and they make you feel that little and make you feel like shit, that’s the way that I do feel and it’s left an imprint on my soul for years gone by. (Participant cited in Aspin, et al., 2012, p. 3).

There is a lack of availability of disability and carer services and supports in rural and remote areas. The types of services that are notably lacking are specialist, community care and carer support services (Smith, et al., 2011). Cost pressures have resulted in services being concentrated in inner regional and metropolitan areas, meaning that many Aboriginal and Torres Strait Islander peoples are likely to continue to be negatively affected by their lack of access to services (Stewart, et al., 2011). A large proportion of people living in rural and remote areas are Aboriginal and/or Torres Strait Islander peoples (Australian Institute of Health and Welfare, 2008). The lack of services to Aboriginal and Torres Strait Islander peoples in remote communities can be viewed as a form of discrimination or institutional racism (Aboriginal Disability Network, 2007). Where there is a lack of appropriate services this places tremendous pressure on carers and kinship networks of people with disability (Aboriginal Disability Network, 2007).

The tragedy in communities like we’ve got in East Arnhem is that we’ve got a number of high level needs patients who are at risk of slipping through the cracks of the health bureaucracy because you cannot get them into residential care and you would want to get them into residential care. There are no residential beds here … There is no 24-hour respite, so the burden on the family, the direct burden on the
family is very great. The indirect burden on the health facilities and primary health service is also huge, huge, and that's where the aged care program comes in. It is huge. (Service provider cited in McGrath, et al., 2006, p. 152)

The lack of respite, especially in rural and remote areas, has been identified as a particular problem for Aboriginal and Torres Strait Islander carers (Aboriginal Disability Network, 2007). The severe deficiency in the availability of respite services within rural and remote locations negatively impacts upon carers' ability to fulfill their caring duties and places upon them undue physical, emotional and economic stress (McGrath, et al., 2006). The lack of respite services in rural and remote areas also places a burden on health services that are not intended for respite (McGrath, et al., 2006). The hospital may be the only place where carers can gain access to respite (McGrath, et al., 2006). Respite at this venue is ad-hoc, informal or short-term and is dependent on the availability and number of hospital beds (McGrath, et al., 2006). It is noted that health professionals sometimes use assessment of pain and symptoms of the care recipient as a reason to enable families to access respite but still expect refusal by the hospital (McGrath, et al., 2006).

Only place you get it is the hospital and that is the only place put palliative care (patients) in hospital. But nearly impossible to get bed there. Respite is one thing we desperately need. (Carer cited in McGrath, et al., 2006, p. 150).

They're not really admitted as respite they've just sort of been snuck in ... lets look at his pain control ... get him under that one ... sometimes it purely to give the carer a break. (Service provider cited in McGrath, et al., 2006, p. 150).

Other avenues for respite that are used in rural and remote areas include Women's Centres, Aged Care Packages, Meals on Wheels, and flats run by church organisations (McGrath, 2008). To access respite, carers in rural and remote areas often need to relocate to metropolitan areas. However, leaving home can be a problem due to problems associated with travel such as time, distance and costs, and cultural concerns (Aboriginal Disability Network, 2007). Due to the strong bond with family Aboriginal and Torres Strait Islander peoples often do not want to relocate for treatment, and when the prognosis is poor do not want to die away from home (McGrath, 2008). There is also a fear that if a family relocates, other family members may move into their home and this means they can lose their home (McGrath & Patton, 2007).
There is all this huge cultural stuff. Many of these elderly people have never left this island to move them 500 k into Darwin for respite or for permanent placement it not really an option. (Service provider cited in McGrath, et al., 2006, p. 151).

... when I asked, ‘Oh, you want to go to Katherine or you want to go somewhere have a rest (They) said, ‘No, I’m staying with you.’ You know how they get them old people, real demanding and want you there. (Carer cited in McGrath, et al., 2006, p. 151).

Some Aboriginal and Torres Strait Islander carers cannot afford services for family members with disability, and the added expense entailed in caring for a person with disability can disadvantage other members of the family (O’Neil, et al., 2004). Aboriginal and Torres Strait Islander carers are known to be disadvantaged due to both their caring role and Indigenous status (Australian Institute of Health and Welfare and Australian Bureau of Statistics, 2008). There is a range of socio-economic factors that impact on caring and gaining support. For many Aboriginal and Torres Strait Islander carers, lack of access to transport is a major barrier to utilising services and participating in community activities (Aboriginal Disability Network, 2007; Hepburn & Twining, 2005; Jowsey, et al., 2011; Smith, et al., 2011). It is reported that there are certain rural and remote areas that are not covered by Isolated Patient Transport schemes (Aboriginal Disability Network, 2007). A lack of community housing can lead to carers being unable to continue with their caring role resulting in admission of the care-recipient to residential care (Smith, et al., 2011). Some Aboriginal and Torres Strait Islander carers may face problems with lack of resources in the home including electricity and obtaining equipment (McGrath, Holewa & McGrath, 2007 cited in McGrath, 2008), lack of access to a refrigerator to store medication, storage to secure dangerous drugs and washing machines for clean clothing (Sullivan et al., 2003 cited in McGrath, 2008). Limited finances can impact on buying medications, hiring equipment or payment for medical or nursing services (PCA, 2004 cited in McGrath, 2008).

I’ve got two old ladies at the moment, um, one is on an EACH package, um and they have no-where to live. They are living in the backyard of a house in one of the camps with a fireplace and some mattresses that we gave them. This lady cannot walk, she’s incontinent and she lives on the ground in the weather ....
(Service provider cited in Lindeman, et al., 2012a, p. 12).
3. Ways to better enable support for Aboriginal and Torres Strait Islander carers

The literature on Aboriginal and Torres Strait Islander carers describes and makes recommendations on ways to better enable support. These actions can be categorised as ‘downstream’ (individual level), ‘mid-stream’ (group or community level) and ‘upstream’ (broader context, models, systems, infrastructure, policy, legislation).

At a downstream level, actions include culturally appropriate:

- Information and awareness-raising about rights, entitlements and navigating the system (Aboriginal Disability Network, 2007; The Echidna Group, 2009);
- Carer education programs, for example on lifting techniques (The Echidna Group, 2009), medication management (de Crespigny, Kowanko, Murray, Emden, & Wilson, 2005; Kowanko, 2004), relaxation (Sullivan, et al., 2007), the use of aids and equipment (The Echidna Group, 2009), managing dialysis (Ward, et al., 2011), elder abuse, signs and symptoms and managing health conditions (Lindeman, et al., 2012b; O’Keefe & Freeburn, 2006; Taylor, Lindeman, Stothers, Piper, & Kuipers, 2012), and minimizing social surveillance of people with disability (Jowsey, et al., 2011);
- Hardcopy and online resources – written, audio, audio-visual and in plain English, pictorial, traditional languages, large text and Braille formats (Aboriginal Disability Network, 2007; Lindeman, et al., 2012b; Nagel & Thompson, 2010; Taylor, et al., 2012; Williams & Indig & Us, 2009);
- Support groups (Jowsey, et al., 2011; Sullivan, et al., 2007), with a preference for face-to-face groups (Shanley, Roddy, Cruysmans, & Eisenberg, 2004);
- Carer events such as special days, pamper packages and healing camps (Sullivan, et al., 2007; Williams & Indig & Us, 2009);
- Counselling and approaches such as brief interventions, motivational interviewing, systemic family therapy, narrative therapy and art therapy (Hepburn & Twining, 2005; Monahan & Twining, 2006; Nagel & Thompson, 2010) and using best-practice guidelines such as ‘Working together: Aboriginal and Torres Strait Islander Mental Health and Wellbeing Principles and Practice’ (Purdie, Dudgeon, & Walker, 2010);
- Primary health care interventions (Aspin, et al., 2012; Maguire & Wenitong, 2012; Warmington, Haynes, Chong, & Schneider, 2005), including access to Medicare Benefits Schedule items (Jowsey, et al., 2011) and access to diagnosis and early intervention (Aboriginal Disability Network, 2007);
- Home support services (Aboriginal Disability Network, 2007; Carroll, et al., 2010; Frizzell & Chamberlain, 2006);
• Respite and related activities (Carroll, et al., 2010; Kimberley Aged and Community Services, 2008; The Echidna Group, 2009; Williams & Indig & Us, 2009); in particular in-home respite (Frizzell & Chamberlain, 2006; Griffis, 2010; The Echidna Group, 2009); and
• Individual advocacy e.g. assistance with filling in application forms, ensuring carers receive Centrelink payments (Aboriginal Disability Network, 2007; Carroll, et al., 2010; The Echidna Group, 2009).

At a mid-stream level, actions include:
• Policies and practices to ensure culturally safe and ethical service provision and environments (McGrath, 2008; Warmington, et al., 2005);
• Policies and practices that recognise the role of the carer (Aspin, et al., 2012; Jowsey, et al., 2011);
• Streamlining or modifying application processes e.g. Centrelink forms (Carers NT, 2008) and appropriate assessment and care planning (Lindeman & Pedler, 2008);
• Targeted programs for men/women and young people/adults/older people (Carers NSW, 2010; Pearce, 2000; Williams & Indig & Us, 2009);
• Cultural awareness training for staff (Aboriginal Disability Network, 2007; Carers NSW, 2010; Carroll, et al., 2010; Hepburn & Twining, 2005; Jowsey, et al., 2011; Maguire & Wenitong, 2012; Monahan & Twining, 2006; Smith, et al., 2011; Ward, et al., 2011);
• Recruitment, retention, proper pay and support for both male and female Aboriginal and/or Torres Strait Islander staff and community-based staff and managers (Aboriginal Disability Network, 2007; Aspin, et al., 2012; Carroll, et al., 2010; Jowsey, et al., 2011; Kimberley Aged and Community Services, 2008; Maguire & Wenitong, 2012; O’Neil, et al., 2004; Smith, et al., 2011; The Echidna Group, 2009);
• Utilising interpreters (Carers NT, 2008; Carroll, et al., 2010; Lindeman, et al., 2012b; Smith, et al., 2011; Taylor, et al., 2012);
• Community consultation, participation and leadership (Aboriginal Disability Network, 2007; Carroll, et al., 2010; Hancock & Jarvis, 2005; Maguire & Wenitong, 2012; Smith, et al., 2011; The Echidna Group, 2009) for example utilising Elders to disseminate information and lead support groups (Aspin, et al., 2012; Carroll, et al., 2010; Lindeman, et al., 2012b; Sullivan, et al., 2007) and steering and action groups (Carroll, et al., 2010);
• Developing informal support networks (Jowsey, et al., 2011; Lindeman, et al., 2012b; Sullivan, et al., 2007; Winterton & Warburton, 2011);
• Dissemination of information, e.g. via carer expos and use of television and radio media (Kimberley Aged and Community Services, 2008; Williams & Indig & Us, 2009), using a concerted outreach approach (Aboriginal Disability Network, 2007; The Echidna Group, 2009);

• Informal and formal partnerships between organisations, agencies and community groups, particularly mainstream and community controlled organisations (Aboriginal Disability Network, 2007; Aspin, et al., 2012; Carroll, et al., 2010; Frizzell & Chamberlain, 2006; Jowsey, et al., 2011; O'Keefe & Freeburn, 2006; Stewart, et al., 2011; Sullivan, et al., 2007; The Echidna Group, 2009; Warmington, et al., 2005);

• Pooling resources (Carroll, et al., 2010);

• Sourcing funding and support from businesses (Carroll, et al., 2010); and

• Using carer data to plan for services and programs, and monitoring and evaluating programs (Aboriginal Disability Network, 2007; Carroll, et al., 2010; Cass, 2010; The Echidna Group, 2009).

At an upstream level, actions include:

• Support for service coordination (Carroll, et al., 2010; Smith, et al., 2011; Stewart, et al., 2011; Warmington, et al., 2005);

• Further utilisation, development and evaluation of flexible models such as outreach (Carroll, et al., 2010; Maguire & Wenitong, 2012), mobile respite/troopy programs and use of vehicles for respite-related activities on country (Carroll, et al., 2010; Kimberley Aged and Community Services, 2008; Williams & Indig & Us, 2009), telehealth (Maguire & Wenitong, 2012; Winterton & Warburton, 2011), community capacity building (Carroll, et al., 2010; Smith, Grundy, & Nelson, 2010), the use of outstations or other community facilities in rural and remote areas for respite (Carers NT, 2008; McGrath, et al., 2006), co-location of services for example a respite centre incorporated into an Aboriginal aged care service (Kimberley Aged and Community Services, 2008); training and/or subsidising community members to provide care or respite inside and outside of the home (Griffis, 2010; Kimberley Aged and Community Services, 2008; Shanley, et al., 2004; Williams & Indig & Us, 2009); training community members to assist with aspects of health care such as home dialysis and potential payments via the Community Development Employment Project (Villarba & Warr, 2004), after-hours, extended care and emergency services (Carroll, et al., 2010; Kimberley Aged and Community Services, 2008; Williams & Indig & Us, 2009); community controlled models such as ‘Lungurra Ngoora Community Care’ (Carroll, et al., 2010) and ‘Yuendumu Old Peoples Programme – Family Model of Care’ (Smith, et al., 2010), and culturally-specific models to modify
mainstream services such as ‘The Living Model: Aboriginal Palliative Care’ (McGrath & Holewa, 2006) and the ‘Aboriginal and Torres Strait Islander Respite Model for the ACT’ (The Echidna Group, 2009);

- Further trials of consumer directed care and consumer directed respite care with Aboriginal peoples and Torres Strait Islanders (KPMG, 2012);
- Targeted packages and projects relevant to Home and Community Care and respite (Frizzell & Chamberlain, 2006; Hancock & Jarvis, 2005);
- Ensuring there is a level of choice between mainstream, culturally-specific and community controlled services and programs (Aboriginal Disability Network, 2007; Maguire & Wenting, 2012; The Echidna Group, 2009);
- Systemic advocacy (Aboriginal Disability Network, 2007; Carroll, et al., 2010; The Echidna Group, 2009);
- Addressing socio-economic problems such as lack of transport, safe and adequate housing and affordable fresh fruit and vegetables (Aboriginal Disability Network, 2007; Carers NT, 2008; Carroll, et al., 2010; Kimberley Aged and Community Services, 2008; Smith, et al., 2011; The Echidna Group, 2009);
- Support for peak bodies representing Aboriginal and Torres Strait Islander peoples with disability and carers (Aboriginal Disability Network, 2007; Carroll, et al., 2010; Griffis, 2012; The Echidna Group, 2009);
- Adequate funding and resource allocation to ensure the sustainability of services (Aboriginal Disability Network, 2007; Carers NT, 2008; Frizzell & Chamberlain, 2006; Jenkins & Seith, 2004; Kimberley Aged and Community Services, 2008; The Echidna Group, 2009); and
- Improvements to data and further research, for example to investigate the lack of service usage (Aboriginal Disability Network, 2007; Carers NT, 2008; Cass, 2010; Hancock & Jarvis, 2005; Jenkins & Seith, 2004).

Case examples

A major gap in the literature is formal and/or independent evaluation of services, programs and resources for Aboriginal and Torres Strait Islander carers. The following are examples of ‘what has shown to work’ and ‘what requires further development’ for Aboriginal and Torres Strait Islander carers, through varying degrees of evaluation.
Example 1: Relaxation program and support group for older Aboriginal women offered by an Aboriginal Medical Service

An Aboriginal Medical Service has offered a program for older Aboriginal women in New South Wales (‘Murri Grannies’), including an eight week ‘Relax to the Max’ program and the ‘Graniators support group’. A need for this program was identified by a Counsellor and an Aboriginal Mental Health Worker at the Aboriginal Medical Service in 2004. The program initially included relaxation sessions, guest speakers, and group discussion on how to take care of oneself mentally, emotionally and spiritually. Then an ongoing support group formed for 25 of the ‘Grannies’ meeting on a fortnightly basis as a form of social support and social outlet. In early 2005, the focus of the group widened to include addressing social issues in the community affecting young people. The Aboriginal Medical Service and ‘Graniators’ have established partnerships with organisations such as the police (a once a month movie night for families in the community), municipal council, State government Department of Housing, the local primary school (assisting 30 school children to make breakfast every weekday) and special young service group. At the end of 2005, the program was formally evaluated and documented positive changes for the ‘Grannies’ in gaining strength and confidence, and for the wider community in raising community spirit and the ‘Grannies’ acting as role models.

Source: Sullivan, et al., 2007)

Example 2: The Lungurra Ngoora Community Care Service

The Lungurra Ngoora Pilot Project was developed from a needs assessment conducted by the University of Western Australia on the service gaps, current care initiatives, and unmet needs of Aboriginal people with disabilities, the elderly and their carers in the Kimberley region of Western Australia. The pilot project was conducted in the Looma community and funded by a one-year grant by Home and Community Care (Department of Health WA), Western Australian Country Health – Mental Health Service, and the Disability Services Commission. The model of care was developed with the assistance from community focus groups, a steering committee, a local action group, a facilitator, a project coordinator, community workers, experts in the field of health and education, and study investigators. Target areas for service provision included home services, respite/activities, service coordination and communication, workforce, accountability, and training and development.
Respite increased from 3 activities at baseline to 940 at 12 months (total over 12 months was 4,057 activities). Meals increased in both regularity and distribution from a baseline of 105, 942 recorded at six months, and 654 recorded at 12 months (total over 12 months was 8,230 meals). Home support services increased from 21 at baseline, 400 recorded at six months, and 194 recorded at 12 months (total over 12 months was 2,000 home services). Health assistance increased from 0 at baseline to 39 at 12 months (total over 12 months was 103 health assistance services offered). Transport usage increased from 11 at baseline, 201 recorded at six months and 154 recorded at 12 months (total over 12 months was 1,436 transport services offered). Advocacy services increased from 0 at baseline to 115 at recorded six months and 131 recorded at 12 months (total over 12 months was 1,303 advocacy services). Education services increased from 0 at baseline to 95 recorded at six months and 254 recorded at 12 months (total over 12 months was 1,131 education services).

There was an increase in the number of community-based Aboriginal staff in paid positions, and certain staff completed 11 training workshops over the 12 month period including Certificate III and IV in Aged Care, Mental Health First Aid, Dehydration Workshop, Alcohol and Drugs Workshop, Dementia Training, Kimberley Aged and Community Services Assessment training, Mental Health General Workshop and Management training. A steering committee, comprising key agencies, developed shared strategies and plans for the project, and this assisted with service coordination and communication. Local action group meetings provided a formal method to ensure service providers honour their commitments. The project coordinator position was crucial in advocacy and following up with services, updating information for agencies and on ground logistics. Local businesses donated goods throughout the project. This project was independently evaluated and reviewed positively, with all objectives being met.

Source: (Carroll, et al., 2010)
Example 3: A Targeted dementia awareness resource piloted in three Aboriginal languages and English

Alzheimer’s Australia Northern Territory produced a 16 minute DVD ‘Looking out for dementia’ in English, Warlpiri, Kriol and Djambarrpuyngu. With funding from the Alzheimer’s Australia Hazel Hawke Research Grant in Dementia Care, the Centre for Remote Health undertook a pilot of the resource in several remote communities in the NT in 2010. This resource was developed with interpreters and community members so that it was ‘localised’. A qualitative evaluation was conducted with input from an advisory group, an Indigenous researcher, focus groups with Indigenous aged care workers, community members and aged care service users, interviews with health care professionals and service coordinators, and observation of the resource being implemented. Overall, the resource was effective in raising awareness of dementia as a health issue in remote Aboriginal communities. All groups interviewed appreciated having the resource in local languages. The resource increased health literacy and allow participants to better engage in discussion about dementia issues. It also improved relationships between carers and individuals with dementia due to an increased understanding of the causes of dysfunctional behavior. A skilled facilitator was able to manage any misinterpretation of the resource. Accessible information prompted people to connect with service and reduced their sense of isolation.

Source: (Taylor, et al., 2012)

Example 4: Looking After Ourselves training package for Aboriginal carers and service providers

Carers NSW received funding from NSW Health to deliver Aboriginal carer and service provider facilitator training for the ‘Looking After Ourselves’ Aboriginal Health and Wellbeing training package that was developed during 2009-10. A component of the content of this resource was originally developed by Carers NT. Carers NSW tailored the ‘Looking After Ourselves’ resource to suit the needs of Aboriginal carers in NSW, with input from Aboriginal communities and the oversight of an Aboriginal Advisory Committee. The kit itself contains a trainers handbook, a carers handbook, a PowerPoint Presentation, a DVD/CD ROM set in addition to the Carers NSW Aboriginal carer relaxation CD. Karla Grant of SBS televisions Living Black and Aboriginal carer Bea Ballangarry feature in the DVD.
‘Looking After Ourselves’ received the Indigenous Social and Emotional Wellbeing award at the Mental Health Matters Awards 2011. The aim of the training was to: 1) Increase the capacity of Aboriginal and non-Aboriginal service providers to support Aboriginal carers maintain their own health and wellbeing; and 2) Provide Aboriginal carers with facilitating skills to deliver the training in their local communities, as well as provide skills so they could facilitate local Aboriginal carer support groups. Carers NSW ran workshops in Penrith, Coffs Harbour, Dubbo and Sydney in 2011 and in Tamworth, Central Coast, Newcastle and Wagga Wagga in 2012. In 2011, 78 Aboriginal and non-Aboriginal service providers participated in the training. In 2011, the majority of participants (82.3%) indicated that following the workshop they felt better able to offer carers better support.

Source: (Carers NSW, 2011)

Example 5: Commonwealth Respite and Carelink Centres capacity building projects

The Department of Health and Ageing provided funding as part of Commonwealth Respite and Carelink Centres capacity building to selected Commonwealth Respite and Carelink Centres and a few of these in Western Australia conducted projects relating to Aboriginal respite options. In 2009, in the Goldfields South East Coastal Commonwealth Respite and Carelink Centre region, a survey was conducted with Aboriginal carers and recommended: 1) That Aboriginal people (i.e. nominated members of the community) are trained to provide respite, both within and outside the home environment; 2) That there is a ‘young carers mobile respite activity van’; 3) That healing camps and day trips for carers are provided; 4) Provision of a ‘Troopy’ respite program; 5) The establishment of an Aboriginal Respite Centre in the area; and 6) TV advertising to promote and encourage Aboriginal participation in respite services.

In 2010, in the Mid West Commonwealth Respite and Carelink Centre region, a Community Day Care Centre was established in Carnarvon as a joint initiative between Carnarvon Medical Service Aboriginal Corporation (Kundimia Home and Community Care program), Silver Chain Carnarvon, Disability Services Commission and ARAFMI Carnarvon – operating with minimal operational funding under a partnership agreement. Prior to this service the only respite options available within the community was a bed in the aged care facility or limited mobile respite services. The Mid West Commonwealth Respite and Carelink Centre noted that the many different respite programs in small communities can impede service
delivery – competitive funding processes do not foster collaborative or cooperative partnerships among service providers. In 2008, Kimberley Aged and Community Services contracted a consultant to determine if carers of people with disabilities in the Kimberley region access appropriate and sufficient respite. Separate consultations were conducted with carers and with service providers in a number of different communities. Key findings and recommendations related to: 1) The need to increase respite beds in the region; 2) Better pay and conditions for care staff and to ensure the work of Aboriginal staff does not cut across their cultural obligations; 3) The need for carer training in care provision; 4) The need for carer support groups for social interaction and relaxation; 5) The need for transport options for carers; 6) Accommodation for care workers such as caravans; 7) Creation of a DVD to explain what respite is, how people can get respite services and Centrelink benefits; 8) Building of a specific mental health respite facility; 9) Co-locating aged care and respite services in some communities; 10) Exploration of how groups of carers can be hired for respite or do this on a volunteer basis; 11) Culturally-specific and appropriate resources for carers; 12) Ensure 24 hour respite is available; 13) Get an advocacy body to explain carer rights; 15) Exploration of mobile respite service; 16) Guidelines fitting needs of carers and care recipients; 17) Use of radio to disseminated carer information; 18) Holiday houses for respite; 19) Subsidised phone service with ring out numbers for carers to get help with care; and 20) Use of Home and Community Care vehicle for respite.

Sources: (Denton, 2010; Kimberley Aged and Community Services, 2008; Williams & Indig & Us, 2009)

Example 6: Trial of Consumer Directed Care and Consumer Directed Respite Care

Between 2010-2012, the Department of Health and Ageing undertook an initiative to trial consumer directed care and consumer directed respite care places as part of community aged care service delivery under the Innovative Pool Program and National Respite for Carers Program. KPMG were contracted to evaluate this initiative between November 2010 and November 2011. There were very few participants of this initiative who were of an Aboriginal and/or Torres Strait Islander background. Service providers found it difficult to recruit and retain Aboriginal and Torres Strait Islander carers for a number of reasons including lack of time to build rapport and understanding about Consumer Directed Respite Care with Aboriginal and Torres Strait Islander communities, pressure on carers to share
Consumer Directed Respite Care resources with other community members (‘humbuggin’), and for carers living in rural and remote areas difficulties relating to geographic isolation. KPMG suggests that the initiative’s focus on the individual, rather than the broader family or community, may be inappropriate in the Aboriginal and Torres Strait Islander context. KPMG highlight that it was unclear as to the extent of Aboriginal and Torres Strait Islander consultation in the development of the initiative. KPMG were unable to draw any conclusions on the benefits or impact of Consumer Directed Care/Consumer Directed Respite Care for Aboriginal and Torres Strait Islander peoples due to the low uptake.

Source: (KPMG, 2012)
International literature

Native American or First Nations carers

In studies involving focus groups with Native American or First Nations carers in the United States and Canada, caregiving is considered as serving an example to other family members and allowing the carer to pass down their traditions and values from one generation to the next (Crosato, Ward-Griffin, & Leipert, 2007; Scharlach et al., 2006). In some groups, girls and women are traditionally chosen to be the caregivers for the elderly (Crosato, et al., 2007). Experiences such as discrimination, poverty, isolation and displacement has resulted in distrust of government and the dominant culture, and being reluctant to utilise carer support services (Scharlach, et al., 2006).

A hundred years ago they (Americans of European Origin) were the conquerors and slaughtered us … Each one of us can tell of somebody that has been attacked by this dominant culture so it says something about not wanting to trust. (Carer cited in Scharlach, et al., 2006, p. 146)

Native Americans and/or First Nations peoples may not want to be further stigmatised because of labels relating to disability or caring.

… if we try to encourage them to apply for Ontario Disability Support Programme … because that helps open up a variety of doors for them to help them as well. And a lot of them, they don’t want to be labelled with that, they’re already labelled as troublemakers …. (Participant cited in Keightley et al., 2011, p. 146)

Yet caring can also be considered central to communities working together to revitalize their culture and to feel strong and proud (Crosato, et al., 2007).

A lack of awareness of carer services and support and how to access this information has been cited, exacerbated by lack of resources in native languages and lack of interpreters (McCallion, Janicki, & Grant-Griffin, 1997; Scharlach, et al., 2006). Native American and/or First Nations carers frequently turned to tribal organisations and workers because they felt that mainstream service providers did not, and could not, understand their special needs; they wanted to see the services provided by people like themselves (Keightley, et al., 2011; Scharlach, et al., 2006).
Native American and/or First Nations carers may view causes, signs and symptoms of health conditions differently. For example, symptoms of Alzheimer’s disease and other types of dementia are often attributed to normal ageing rather than psychopathology, little stigma is associated, and the spiritual dimension of the condition is emphasised (Kramer, 1996; Voss, Douvill, Little Soldier & Twiss, 1999 cited in Kane & Houston-Vega, 2004). Spiritual remedies and shamanic healing may be sought (Kane & Houston-Vega, 2004).

Smyer and Clark (2011) discuss how although there is a long history of respect for Elders in the Native American community, elder abuse is becoming an increasing problem due to demographic, social and economic factors. Tribal leaders have identified that there is a lack of reservation codes for addressing elder abuse issues and there is a need for increased training about elder abuse (National Indian Council on Ageing, 2004 cited in Smyer & Clark, 2011). The most common form of elder abuse was financial abuse followed by neglect and psychological or verbal abuse (National Indian Council on Ageing, 2004 cited in Smyer & Clark, 2011). Cultural expectations to share resources with family members can obscure financial abuse among Native Americans (Clouse, LaCounte, Eagle Shield & Barber, 1998; NICOA, 2004 cited in Smyer & Clark, 2011).

It has been reported that poor interpersonal relationships, including inconsistent caregiving to family members, is more likely where Native Americans have higher rates of depression and anxiety disorders, substance abuse, and post traumatic stress disorder (Barnard, 2007 cited in Smyer & Clark, 2011). The migration of younger Native Americans to urban areas due to education or work means that Elders rely on fewer family members for informal care (McCallion, et al., 1997; Smyer & Clark, 2011). Services for the elderly can include meal programs sponsored by the tribe, tribal service providers and Indian Health Services staffed by public health nurses that utilise community health representatives or lay carers employed by the tribe (Smyer & Clark, 2011). Federal appropriations within the Indian Health Services does not fund support nursing homes or long term-care, meaning that there are very few tribal assisting living facilities or nursing homes on reservations, and this necessitates Elders leaving the community for care (Smyer & Clark, 2011). Under Medicaid there are limits to the family’s ability to visit a distant facility and be involved, and carers are concerned about the level of care the Elder will receive without the advocacy of the family (Hendrix, 2000 cited in Kane & Houston-Vega, 2004; Smyer & Clark, 2011).
In a study of Mi’kmaq experiences during recent hospitalisation, it was found that participants expected to be visited by many family members whilst hospitalised, but this was a custom that did not fit well with hospital rules and regulations and appeared to be problematic for staff (Maker, Cormier Caigle, Biro, & Joe, 2000). A study of Native American acquired brain injury clients noted that discharge planning from the hospital was considered to be poor, there were difficulties accessing home care services due to staff shortages in remote areas, and that long travel distance and personal sacrifices were required to gain access to services (Keightley, et al., 2011).

Native Americans and First Nations carers identify that more home health, personal care, nutrition and meals, homemaker services, chore services, transportation, respite care, and outreach information and training are needed (Ludtke et al., 2003 cited in Smyer & Clark, 2011). Barriers to using services relate to availability, accessibility and acceptability (Hendrix, 2000 cited in Smyer & Clark, 2011). Recommended interventions include carer training, assisting carers to develop plans for providing care, the development of tribal elder abuse codes and reporting mechanisms, mediation, and advocacy (Smyer & Clark, 2011). Support groups, recreational groups for children with disabilities, early intervention programs, counselling, and access to health, welfare and legal services, have been found to reduce Native American grandparent carer stress as measured by a modified version of the Parental Stress Scale (Gerard, Landry-Meyer & Guzzell-Roe, 2006 cited in Conway, Boeckel, Shuster, & Wages, 2010).

In one study, involving 42 Native American and Alaskan Native family carers of individuals with dementia, a randomised controlled single-blinded 8-week trial was used to compare a complementary and alternative medicine therapy called ‘polarity therapy’ (a type of bio-field touch therapy) to an enhanced respite control (ERC), to reduce stress and depression and improve quality of life (Korn et al., 2009). Measurement tools included the Perceived Stress Scale, the Center for Epidemiological Studies-Depression scale, the Short Form 36, the Quality of Life-AD, the Pittsburgh Sleep Quality Index, and the Penn State Worry Questionnaire (Korn, et al., 2009). It was found that polarity therapy participants had greater improvements in stress, depression, bodily pain and general health, and that this intervention was considered culturally acceptable and feasible (Korn, et al., 2009). Traditional medicines and forms of complementary and alternative medicine such as use of healers and healing rituals, massage, drumming and signing, are frequently used and considered helpful by Native Americans (Buchwald et al., 2000 cited in Korn, et al., 2009).
Yet there are difficulties incorporating traditional views with the Western medical system (Keightley, et al., 2011). Future studies are needed to compare polarity therapy with other caregiver interventions to determine whether therapeutic touch is more beneficial than counselling or education (Korn, et al., 2009).

The research conducted by Taylor of Stiles Associates Inc. (2011) suggests that First Nations and Inuit peoples of Canada have embraced the internet and social media to “keep in touch with home communities, fight addiction, showcase Aboriginal arts and crafts, preserve cultural identity and support political advocacy” (p. 1). This was considered remarkable even though half of First Nations communities across Canada did not have access to residential broadband (O’Donnell, Molyneaux, Gorman, Miliken, Chong, Gibson, Oakley & Maitland, 2010 cited in Taylor, 2011). There was particularly high uptake and use of internet and social media by young First Nations people (Pasch, 2008 cited in Taylor, 2011) and increasing use by older First Nations people (Taylor, 2011). The National Aboriginal Health Organization has a National Aboriginal Role Model Program and associated blog, and Tyze Personal Networks provides social networking software for carers to mitigate isolation (Taylor, 2011).

Maori carers

Maori culture embodies a strong commitment to wider family, also known as ‘whanau’. In a study of Maori carers of individuals with a mental health condition, understanding of the medical conceptualisation of the illness or diagnosis was dependent on the ability of staff to effectively communicate across cultural differences (Laird, Smith, Dutu, & Mellsop, 2010). Diagnostic labels were regarded as ‘insulting’ where there was a lack of recognition of Maori perspectives (Laird, et al., 2010). Understanding the diagnosis resulted in greater knowledge of how to deal with the illness, less judgment and greater empathy towards the service user, and less blame directed at the family (Laird, et al., 2010).

*Whanau needs to be better valued and more information shared.*

*The diagnostic system should use some Maori ideas on health like wairua [spirit] and mana [power] to help us understand our whanau member’s condition.*

*(Carers cited in Laird, et al., 2010, p. 276)*
In a study of experiences with the disability services sector, concern was raised that Maori carers had to compromise their traditional values and world view in order to access mainstream service, and that Maori carers living in rural areas did not receive support due to the challenges of distributing information and increasing awareness in these regions (Wiley, 2009). Interviews with eight Maori people with disability linked satisfaction with services with “the ability to navigate the system after decades of experience or assistance from advocacy groups” (Wiley, 2009, p. 1210). Unlike the consumer responses, the majority of the eight Maori caregivers who were interviewed reported feeling very unsatisfied with the disability services they contacted (Wiley, 2009). There was a perceived need to be aggressive with disability agencies in order to access services, and that service providers were unaware of their culture, resulting in a preference for family caregiving for the majority of care (Wiley, 2009).

The Maori carers voiced a need for an informal network of support with other carers where stories could be shared and information and guidance could be provided to families in similar situations (Wiley, 2009). Unless funding was accessed through the Accident Compensation Corporation, family members were not eligible for funding to support their role as carers, impacting on wellbeing and ability to maintain employment (Wiley, 2009). The contrast between perceptions of service quality and access, and frustration and dissatisfaction voiced by Maori consumers and carers, highlighted the need for more thorough evaluation and utilisation of findings for project planning and efficient use of resources (Wiley, 2009). Other recommendations from this study included: 1) Collaboration and cooperation across sectors; 2) Workforce development including cultural awareness training and recruitment and retention of Maori staff; 3) Community engagement and building partnerships; 3) Greater number of support for high and complex needs 4) Use of trilingual sign language; 5) Resources in a variety of languages; and 6) Developing a more comprehensive range of long-term services such as vocational rehabilitation, educational transition services, employment support, housing needs, etc. (Wiley, 2009).

In a study of seven Maori carers of stroke survivors, participants discussed their experiences of hospital and community services, including being ignored by hospital staff, not being given information requested, and being excluded from decision-making (Dyall, Feigin, & Brown, 2008). These carers believed that improvements could be made by appropriate cultural assessments, ensuring settings were accessible and comfortable for Maori people, better access to information and support, and residential care policies protecting Maori assets both individually and collectively (Dyall, et al., 2008). One carer
identified concern over income-testing and asset-testing for access to residential care as she was afraid that it opened up the possibility of the loss of Maori land secured through genealogy (Dyall, et al., 2008). Stroke survivors believed that family should be involved in the development of rehabilitation programs; cultural identity could be used as a source of coping and a motivating factor for the stroke survivor (Dyall, et al., 2008). Services who offered home visits were especially appreciated (Dyall, et al., 2008) possibly due to comfort within the home.

Native Hawaiian carers and Pacific Islander carers in Hawai'i

In a study of family carers of older adults with cancer, Native Hawaiian carers downplayed or did not recognise the stress they experienced, stating that caring was “something you do if you are Hawaiian” (Anngela-Cole & Busch, 2011). The Native Hawaiian carers utilised prayer to cope and primarily relied on church organisations for support including social and monetary support and respite care (Anngela-Cole & Busch, 2011). Sadness was associated when family members could not be a part of large family gatherings with cultural food (Anngela-Cole & Busch, 2011). Perceptions of caring were based on a traditional custom of intergenerational living arrangements, where there is always a family member who needs care and there is a cultural responsibility of the whole family to contribute to assist (Anngela-Cole & Busch, 2011). However, in a different study, Pacific Islanders of Hawai'i who cared for a medically fragile child mentioned varying levels of financial stress depending on the availability of Medicaid or insurance, and feelings of isolation (Haley & Harrigan, 2004). In this study, spiritual beliefs and prayer were also considered to be very important to coping, in addition to interacting with nature, and community support such as respite care nurses, neighbours, church friends, and family (Haley & Harrigan, 2004). Carers discussed how using respite nurses allowed them the opportunity for personal replenishment, and that respite could encompass spending time with other children or their spouse rather than being alone (Haley & Harrigan, 2004).
Conclusion

This literature review aims to draw to the attention of the reader that Aboriginal and Torres Strait Islander people are more likely to have a need for assistance due to a disability, health condition or ageing, and are more likely to take on a caring role. The literature suggests that Aboriginal and Torres Strait Islander carers experience isolation and problems in accessing services to a much greater extent than non-Indigenous Australians. There are multiple reasons why Aboriginal and Torres Strait Islander carers do not access services, including: not identifying as a carer; cultural beliefs relating to the role of caring; socio-economic factors that impact on ability to seek help; lack of awareness of services; lack of availability of services; reluctance to use services that are considered culturally inappropriate; reluctance to relocate for services; over complexity of the system; lack of choice between mainstream and culturally-specific services; and lack of choice between non-Indigenous staff and Aboriginal and/or Torres Strait Islander staff. There is congruence between the Australian and international literature about the key issues faced by Indigenous/First Nations carers, the types of services, programs and resources available and the uptake of these, what is known to work/not work, what is considered best practice, and recommendations for improvements to the system and future work. However, caution should be exercised in making inferences between groups that have different cultural backgrounds and historical and social contents. In general there is a lack of formal and independent evaluations, mixed methods research and quantitative research.

There is a diversity of Aboriginal and Torres Strait Islander carers, and as such a one-size-fits all approach is unlikely to work. A universal issue is that there is a lack of culturally-specific services, programs and resources for Aboriginal and Torres Strait Islander carers. Where they are available, it is noted that they are poorly promoted, reviewed and funded. It is highlighted that it is important to provide Aboriginal and Torres Strait Islander carers options of culturally-specific, community-controlled and mainstream services, and to support an Aboriginal and Torres Strait Islander workforce at all levels. Cultural competency standards should be determined and assessed by the community. Services should be appropriately planned and based on local needs but there are obstacles in achieving this such as difficulties accessing sufficient and reliable data, the lack of mapping to identify carers and the reach of programs in different geographical areas, and lack of community-consultation and ownership. It is integral that there are partnerships between services, and where necessary service-coordination, under formal and informal arrangements.
There are solutions to improve the situation for Aboriginal and Torres Strait Islander carers and many of these are practical. There is a need for further research and development of new initiatives. There are existing peak bodies, service delivery models, services, programs and resources that are in need of support and funding to ensure their sustainability.
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