A review of the literature on disability services for Aboriginal and Torres Strait Islander peoples

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Contents

Acknowledgments

Abbreviations

ABS	Australian Bureau of Statistics
AHT	Allied health therapist(s)
APAIS	Australian Public Affairs Information Service
ARIA	Accessibility/Remoteness Index of Australia
ATSIC	Aboriginal and Torres Strait Islander Commission
CBR	Community-based rehabilitation
CDEP	Community Development Employment Project
CINAHL	Cumulative Index to Nursing and Allied Health Literature
CRS	Commonwealth Rehabilitation Service
CSDA	Commonwealth State Disability Agreement
CSTDA	Commonwealth State/Territory Disability Agreement
DSC	Disability Services Commission
ECU	Edith Cowan University
HACC	Home and Community Care
ICF	International Classification of Functioning, Disability and Health
ICIDH	International Classification of Impairments, Disability and Handicap
IDAR	Indigenous Disability Action Research Project
NDAR	National Disability Advocacy Review
NHMRC	National Health and Medical Research Council
WA	Western Australia
WHO	World Health Organization

Introduction[1]

The new Commonwealth State/Territory Disability Agreement (CSTDA) directs special attention to the 'heightened vulnerability' of Indigenous people with a disability [1, p3]. This special attention reflects the increasing recognition by the various government agencies responsible for coordinating disability support services that there was 'a need to raise awareness about the needs of Indigenous people with disabilities and the unique cultural issues that are involved' [2, p10]

In attempting to better understand the needs of Indigenous people with disabilities in Western Australia, the Disability Services Commission (DSC) established in October 2001 an Access for Indigenous People Steering Committee to oversee the development of culturally responsive disability policy and services for Indigenous people. Recognising that little was known about the needs and issues experienced by Indigenous people with disabilities and their families and how to respond to them, the Steering Committee supported the development of the Indigenous Disability Action Research (IDAR) Project by the DSC in partnership with Edith Cowan University (ECU). The IDAR Project involved state-wide consultations and action planning with Indigenous people with disabilities, their families, carers and service providers.[2]

To ensure that the IDAR Project benefited also from the existing literature about disability support services for Indigenous people, DSC commissioned this literature review. The specific aims of the review were to:
- identify the unique issues confronting Indigenous people with disabilities, their families and communities;
- understand the ways in which contemporary Indigenous people view the concept of disability and identify the implications of this view(s) for providing support and care to a person with a disability; and
- identify barriers that prevent Indigenous people with disabilities, their families and carers from accessing family, community and formal services.

This paper summarises the findings from the literature review. After outlining the methodology used, the following sections: review Indigenous perceptions of disability; provide a brief overview of the burden of disability among Indigenous people; summarise information about caring for Indigenous people with a disability and the use of disability support services. This is followed by sections reviewing issues affecting the access by Indigenous people to disability services, and workforce issues impacting on the availability and accessibility of disability support services to Indigenous people.

Every attempt was made to locate and collect all relevant literature, much of which is in the so-called 'grey literature'.[3] A considerable body of grey literature was identified and collected, but it is likely that some useful sources have not identified.

Methodology

The Australian Indigenous Health*InfoNet* Bibliography was the initial source of information about disability among Indigenous peoples. That bibliography includes details of around 8,000 items, including journal articles, books and book chapters, government and other reports, and theses. Searches of Science Direct, HealthSTAR, Australian Public Affairs Information Service (APAIS), Cumulative Index to Nursing and Allied Health Literature (CINAHL) and Medline were used to check the completeness of this bibliography. Relevant documents were recorded in a separate EndNote library.

The identification, collection and inclusion of the grey literature were initiated also.[4]

These mechanisms of identifying relevant materials were supplemented by targeted searches using standard Internet search engines, particularly Google. In many cases, these searches were informed by clues gained from perusal of previously collected materials.[5] In other cases, reports and other materials were identified by searching relevant Internet sites (such as the

Productivity Commission, which is currently undertaking a review of the Commonwealth Disability Discrimination Act).

Indigenous perceptions of disability

As with many aspects of Indigenous life before the colonisation of Australia that began in 1788, little is known about disability – in terms of Indigenous perceptions of disability, the levels of disability, or the ways in which people with a disability were cared for by others. And, reflecting the great diversity of Indigenous peoples – Australian Aborigines and Torres Strait Islanders – living on the Australian mainland, Tasmania, the Torres Strait Islands and other islands, there would be multiple ways in which disability would have been conceived and responded to.[6]

It is somewhat surprising, however, that 'there are only passing references to people with impairments in the journals and writings of the early explorers, missionaries and anthropologists' [3]. While noting that the status of people with impairments in Indigenous communities prior to the direct impact of colonisation is 'primarily based on speculation and conjecture', Ariotti concluded that they were 'treated and cared for no differently from other members of the group or clan' [4, p218]. Historical and anthropological sources reviewed by Ariotti suggest that people with severe impairments were, on occasion, left behind to die, and infanticide was practiced to a limited degree throughout Australia [3, 4].[7]

As a part of his intensive research among the Ngaanyatjarra, Pitjantjatjara and Yankunytjatjara people living in the cross-border region of Western Australia, South Australia and the Northern Territory,[8] Ariotti found that there were discrete Pitjantjatjara words for specific impairments, but that there was no word for disability – that is, there was no abstract term that 'differentiated between or separated people with impairments from the rest of the community' [4, p218]. Having no word for disability, contemporary Anangu have attempted to adapt an existing word, *nyumpu* (crippled or maimed), to make sense of the concept of disability. This adaptation is not without problems, however, as some people have objected to its use, feeling that they were being 'labelled and stigmatised, not about their personal limitations, but about their perceived social standing' [4, p219]. This reaction reflects the fact that 'it is not the functional limitations of impairment which constitute the greatest problem faced by disabled individuals, but rather societal and social responses to it' [5 cited in 4].

The holistic way in which impairments have been, and are, perceived among the Anangu people is, of course, consistent with the holistic way in which Indigenous peoples generally have perceived health and related issues [6-8]. It is important, as Ariotti points out, that 'services providers work from a framework that recognises that disability is perceived in broad holistic terms and does not stay confined to the limitations and sense of loss experienced by the individual person' [4, p221].

Ariotti's findings among the Anangu are similar to those of a less rigorous study undertaken in the Top End of the Northern Territory in 1984 [9]. This study, of Indigenous people living in Darwin, Katherine, Bamyili and Ngukurr, found that: disability only became an issue if it caused a handicap;[9] and social stigma did not attach to disability or beliefs about cause(s). The management of handicaps by Indigenous people may be quite different to non-Indigenous ways and a person with a disability must be viewed 'through their individual perception of handicap and in the context of their culture and lifestyle' [9, p12]. These findings about Indigenous perceptions of disability are consistent with international findings that where sociability is prioritised above productivity in a cultural group there is no limit to participation in ordinary life events by people with a disability [10, 12 cited in 11].

In recognition of differences in perceptions of disability in non-western cultures generally, and also of differences between urban and remote Australian Indigenous communities, field testing of the International Classification of Impairments, Disabilities and Handicaps (ICIDH) included study of definitions, services required and outcomes expected in two Indigenous

communities in the Northern Territory [13]. It was found that engagement with family and fulfilment of family roles influenced how 'able' Indigenous people felt, but that geographical inaccessibility was a handicap and an impediment to a 'healthy' life. Generally, 'people were often not aware of how much they were limited by their condition. Some people had different expectations of health and different perceptions of what is normal and expected' [13, p9].

The study found that a distinction was made between congenital disabilities and those caused by accidents – the former often being attributed to some maternal wrongdoing [13]. Attitudes also differed in relation to physical and mental disability, with intellectual or behavioural problems being simultaneously attributed to medical and supernatural causes.

An earlier study in the Northern Territory had noted that highly visible bodily impairments (such as amputations) were more likely to be seen as disabilities, while age-related restrictions were regarded as part of being 'just old' [11].

All of the research discussed above relates to Indigenous people living in remote parts of Australia – or still having close cultural and temporal links with remote communities – and little attention has been directed specifically at the perceptions of disability of Indigenous people living in the rural and urban areas of southern Australia. The valuable research that has been undertaken in New South Wales [14-18], Victoria [19, 20] and Western Australia [21] has focused largely on the current issues regarding access to and use of disability services by Indigenous people. Much of this research included attention to cultural and social aspects, but mainly in relation to the barriers to services. As such, the scope of this research is not as broad as that undertaken in more remote parts of the country, from which most information about Indigenous perceptions of disability is derived.

The general features emerging out of the research are:
- Indigenous people with a disability are generally not excluded from or stigmatised in their communities;
- some disabilities may be seen as a 'pay-back' for a past wrongdoing, and other may be seen as something 'special';
- independence may not be seen as a major issue in some Indigenous communities;
- disability may be viewed as a family or community problem, rather than a personal one;
- some people with severe disabilities may be seen as the responsibility of 'welfare'; and
- a person may be identified and named after their disability (for example, a person with an eye injury may be known as 'one eye') [22]

Reflecting the holistic ways in which Indigenous people viewed – and still view – health and related issues [6-8, 23], it is not surprising that many Indigenous people tend not to separate disability and health conceptually [21].

Perhaps this tendency should not be surprising – even from a non-Indigenous perspective – in view of the fact that disability is an 'umbrella term for any or all of: an impairment of body structure or function, a limitation in activities, or a restriction in participation' [26, p332]. Measurement of the prevalence of disability in Australia has reflected this continuum, with the Australian Bureau of Statistics using in its 1998 Survey of Disability, Ageing and Carers the definition: a 'limitation, restriction or impairment which had lasted, or was likely to last, for at least 6 months and which restricted everyday activities' [24]. Recent refinements by the World Health Organization have seen a much greater focus on activity limitations (difficulties an individual may have in executing activities of daily living) and participation restrictions (problems an individual may experience in involvement in life situations) [25, pp7-10].

The potential for conceptual confusion arises also from the way that responsibility for services is divided in Australia: people who acquired a disability before reaching 65 years of age are generally regarded as the responsibility of the disability services sector, while people who acquire disabilities at older ages are generally the responsibility of the health or aged care services sector [26]. This division tends not to apply, however, for many activity

limitations and/or participation restrictions due to chronic health conditions, such as those resulting from severe heart disease, diabetes and chronic renal disease.

Thus, it is not difficult to imagine why the Indigenous community, for whom chronic health conditions make such a major impact, tends not to separate disability and health conceptually.

The pattern of disability among Indigenous people

The main sources of information about the level and types of disability in Australia are the periodic surveys conducted by the Australian Bureau of Statistics (ABS), but these surveys have never included sufficient numbers of Indigenous people to enable any definitive conclusions about disability.

There have been few studies of disability in the Indigenous population, but evidence suggests that the level of disability and handicap among Indigenous people is likely to be much higher – 'perhaps at least twice as high as' – that of the total population [27, p223].

This estimate is consistent with a study undertaken in 1991 in the Taree area of New South Wales [28, 29]. The study, which followed the methodology used by the ABS in its national surveys of disability, found that 227 (25%) of the 907 Indigenous people living in households in the Taree area had one or more disabilities [28].[10] After adjustment for differences in the age structures of the Indigenous and non-Indigenous populations, the levels of reported disabilities among the Indigenous regular residents of the Taree area were 2.5 times higher for males and 2.9 times higher for females than for males and females in the total Australian population. (It should be noted that these estimates are based on a very broad definition of disability used by the ABS – including impairment of body structure or function, limitation in activities, and/or restriction on participation – much broader than the criteria used in establishing the eligibility for disability support services.) Almost one-fifth (19%) of regular Indigenous residents reported having a disability of the sense organs, such as hearing loss (8.4%) or loss of sight (1.4%) [28]. The next most frequently reported disabilities were 'disorders of the musculo-skeletal system and connective tissues' (16%), 'circulatory system disorders' (15%), and 'respiratory system disorders' (13%). Bearing in mind that the study excluded people living in health establishments and institutions – whose residents would be expected to have higher levels of disability – the levels of disability reported were much higher than those for the total Australian population. The authors noted that the high levels of disability found in the Taree study highlighted the fact that Indigenous people living in other parts of Australia needed to be assessed, so that the full extent of the problem could be gauged and appropriate action taken [28]. To date, there has been no similar study undertaken anywhere in Australia.

Caring for Indigenous people with a disability

As noted above, little is known about how Indigenous groups viewed and addressed disability prior to the commencement of colonisation in 1788. However, based on his review of historical and other sources, Ariotti concluded that people with impairments were 'treated and cared for no differently from other members of the group or clan' [4, p218]. As Berndt and Berndt noted about people with obvious disabilities (such as 'lameness, blindness, deafness, cleft palate, boomerang legs (a sequela of long-standing yaws infection), face or limbs eroded by yaws of leprosy'), 'other things being equal, such a person is cared for in the framework of the kinship system within which he or she has a place which does not rest on physical appearance or physical achievements' [8, p192].

As with other aspects of life in 'traditional' times, the group's particular kinship system provided the 'blueprint' to guide its members in their social interactions [8]. Centred around 'the elementary or nuclear family as the basic kinship unit', the key group for normal living responsibilities was the clan, 'a group of people who claim to be descended in one line from the same putative ancestor or ancestress' [8, p43, p89].

Ariotti's research found that, for the Anangu, the care of a person with an impairment was the responsibility for the person's family [3, 4]. This responsibility was emphasised by Elliot: 'handicapped people are regarded by all as being the responsibility of the family. Handicapped people are not a community issue. An "outsider" will not interfere in the personal business of a family' [9, p6]. Reflecting broad kinship links, the responsibility for care of a person with an impairment (and of old people) lies with the broad extended family (not just the nuclear family) [30, 31]. This type of responsibility is likely to have been the case throughout much (if not all) of mainland Australia and probably Tasmania prior to the direct impact of colonisation, but much less is known about the situation in Torres Strait Island communities.

These complex kinship systems, involving broad family responsibility for the care of people with a disability, varied across Australia, and 'are still strong in many areas, including urban environments' [22]. Thus, throughout Australia – in remote, rural and urban areas – most Indigenous people with a disability were, and are, cared for within their extended family.

It is true, however, that not all extended families are able to provide an optimal level of care for the family member with a disability [31]. For example, a review of the needs of aged Aboriginal people in the metropolitan area of Perth concluded that 'the myth that Aboriginal people are being cared for by their families can lead to their needs being overlooked' [32]. Many families did care for their elderly, but a breakdown in traditional structures had contributed to areas of neglect. The following reasons why some Indigenous families couldn't care adequately for their disabled member(s) were identified:

- many Indigenous people live in poverty and often cannot afford to care for more needy members of their group – the added expense entailed in caring for a person with a disability can disadvantage other members of the family;
- people with a disability can be very vulnerable to exploitation in environments where alcohol misuse and family breakdown have occurred;
- the burden of grief and stress carried in many communities can lead to inconsistencies in care;
- family allegiances can make accessing services difficult; and
- many people are disadvantaged by not knowing how to care and what services are available [21].

As well, the proportion of Indigenous people with profound or severe handicaps requiring continual and/or frequent assistance in activities of daily living is higher than that of non-Indigenous people [33]. This has implications for the capacity of families to care for the family member with a disability.

Respite care is usually arranged within the family unit or community. This is often the best arrangement, but it can cause some difficulties [21]. It is often difficult to find a suitable carer, especially if support needs are high. There is no community-based training for carers: 'training for carers may impact positively upon the community's ability to provide respite care. Training needs to be provided in the communities in a culturally appropriate form' [34].

The fact that many Indigenous families face other pressing issues – such as health and housing issues – also needs to be taken into account in considering their capacity to care for a person with a disability. This aspect was identified explicitly for Indigenous people in New South Wales [35], but almost certainly applies to Indigenous people across Australia.

The use of disability support services

As a part of the Commonwealth State/Territory Disability Agreement (CSTDA: previously Commonwealth State Disability Agreement (CSDA)), information about the use of disability support services covered by these agreements has been collected on a 'snapshot' day each year. On the 2002 snapshot day, 1,670 or 2.5% of CSDA consumers (or 2.7%, excluding the 5% of consumers for whom Indigenous status was not stated) were identified as being of Indigenous origin [26].[11] This was very similar to the proportion (2.6%) of Indigenous Australians in the general population aged under 65 years [36].

Overall, two-fifths (42%) of all CSDA consumers reported needing continual support in 'activities of daily living' (self-care, mobility and/or communication) [26]. A slightly higher proportion of Indigenous consumers of a CSDA service reported this need (46%) than did other consumers (42%). Around 15% of Indigenous consumers reported needing no support with activities of daily living (including those who needed only aids) as did 19% of non-Indigenous consumers.

The number of times services were used by Indigenous people was greater than the number that would have been expected if the age-specific use of services by Indigenous people was the same as that of all consumers. However, if one considers the much higher level of disability documented for one Indigenous sub-population [28], then these data suggest that one out of three Indigenous people with a disability did not use the services available [37].[12] If this apparently low level of usage is true, it could be due to differences between the Indigenous and non-Indigenous concepts of disability (and responses to disability) and/or the fact that Indigenous people do not know enough about the services available.

Issues affecting the access by Indigenous people to disability services

There is a wide variety of issues affecting the access of Indigenous people with a disability to support services. Some of these issues relate to specific environments – such as urban, rural and remote locations – but many share commonalities based on cultural, historical and socio-economic factors. These commonalities are such that a recent House of Representatives' inquiry into the needs of urban dwelling Indigenous people noted that there was a 'continuum rather than an absolute distinction between urban and non-urban contexts' [40, p3].

The commonalities are also of such importance to the uptake of services by Indigenous people that the following sections have been structured according to issues of that type, rather than according to the urban, rural and remote location. This is not to say, of course, that geographic location is not important, but rather that many of the issues faced by Indigenous people are similar regardless of location. Generally, however, the service-related issues faced by Indigenous people living in remote and very remote locations can be characterised by their availability – that is, many services are just not available.[13] At the other end of the geographic continuum, in the major cities, the characteristic service-related issue faced by Indigenous people is their accessibility – that is, they may be physically available, but, for a variety of reasons, may not be readily accessible [38-40]. These aspects are considered more fully in the following sections.

Cultural, social and other aspects

Different understandings and values

Despite the presence of a wide range of issues affecting the access by Indigenous people to disability services, the differences in values and cultural understandings have been identified as the most significant obstacle to effective service provision [41].

As noted earlier, the concept of disability is not a familiar one to many Indigenous people. Without this understanding, it is not possible for many Indigenous people to identify that the problems they face could be addressed through access to specific services. They may not be able to ask for services, provide feedback or criticise existing services, and exercise their entitlements to assistance.

The great diversity of Indigenous communities across Australia also means that it is difficult for an outsider to understand the belief systems and politics impinging on disabilities in each community, and to develop a working rapport, especially when visits are infrequent [21]. This may result in insensitive and inappropriate interventions, 'despite positive personal qualities of the service provider' [21, p142].

In Australia-wide consultations, the National Disability Advisory Council was advised that major barriers to Indigenous people with a disability accessing services were: unwarranted assumptions made by service providers and other professionals; and culturally inappropriate procedures [42].

There is a tendency among service providers and policy makers to underestimate the influence of cultural beliefs and to lack an understanding of the extent of cultural diversity [11]. This can result in cultural disjunction with unsuitable services being offered (for example, culturally inappropriate activity programs in day care centres and major institutions).

The concept of 'shame' is a specific cultural factor which has been identified as significant in Indigenous responses to disability [3]. Shame refers to situations where a person has been singled out for any purpose from the security and anonymity provided by the group [43]. There may be considerable concern expressed if the impairment or disability is perceived as likely to cause a 'shame job' [44]. Ariotti found that shame may be associated with amputations [3]. Shame has been identified also as having a substantial impact during rehabilitation highlighting for staff 'gaps in their cultural knowledge of Aboriginal people' [11, p43]. Being identified as having a disability has been recognised also as shameful for Indigenous people living in New South Wales [45, 46]. The term 'handicapped' is also considered shameful by some [47]. Regardless of its context, the shame felt by some Indigenous people is likely to be a major impediment to access to disability support services.

Language barriers

Language barriers may exist, especially with older people in remote areas. Overall, one-eighth of Australia's almost 460,000 Indigenous people reported in the 2001 Census of Housing and Population that they spoke an Australian Indigenous language at home [48].[14,15] Of the 81,000 Indigenous people living in very remote areas (including most of the Torres Strait Islands), 55% spoke an Australian Indigenous language at home.[16] Indigenous people in other parts of Australia have developed their own particular varieties of English – Aboriginal English.[17] The use of Aboriginal English is very common among urban and metropolitan Indigenous people as well as among those living in rural and remote areas [49].

There are believed to be over 100 Aboriginal and Torres Strait Islander languages still being used by particular communities, but most of the original 250 Aboriginal languages and cultures have died out [50].

Unless translators are used, language presents a major barrier for people who speak English as a second language. And, while Aboriginal English and Standard Australian English are

usually mutually intelligible, there are significant differences that may lead to misunderstandings between service providers and Indigenous people [40].

Language barriers, different understanding of the same word, the use of jargon by service providers, and different life conceptions may lead to misunderstanding and ineffective service provision [51]. Some of the words associated with disability service provision are often misunderstood. For example, 'rehabilitation' is confused with environmental, prison or alcohol rehabilitation [21, 52], and 'disability' is often taken to mean sickness.

Generally, factors such as not speaking English and lack of literacy are more acute in remote areas and interfere more with accessing and delivering services. This is particularly the case with government programs, which tend to have complex bureaucratic requirements, provide sometimes inappropriate materials, and rely on mail for contact.

Socioeconomic circumstances

The 2001 Census of Housing and Population provided a number of indicators of the extent of the socioeconomic disadvantage experienced by Indigenous people [48]:

- the mean equivalised gross household income for Indigenous people was $364 per week, compared with $585 per week for non-Indigenous people; income levels generally declined with increasing geographic remoteness, but the mean equivalised income in outer regional areas was slightly lower than that in remote areas;
- Indigenous households were larger than other households (3.5 compared with 2.6 people per household); the average number of people per household ranged from 3.2 in major cities to 5.3 in very remote areas; 45% of all multi-family Indigenous households were located in very remote areas (where 22% of households were multi-family); an extra bedroom was required in almost 16% of Indigenous households overall, and in 46% of those in very remote areas;
- overall, 70% of Indigenous households had a registered motor vehicle owned or used by them (or parked at or near their dwelling), compared with 84% of non-Indigenous households; only 51% of Indigenous households in very remote areas owned or had use of a registered motor vehicle.

In terms of take-up of disability support services, poverty has been identified as an inhibiting factor, even when services are free [21, 50, 53].[18] Poverty presents obstacles to obtaining a service – these are often not recognised by service providers and/or misinterpreted as stereotypic characteristics, cultural differences or personal lack of commitment. Poverty may affect Indigenous people in a number of ways, including [16, 55-58]:

- they may not be able to afford the cost of services, some of which are provided privately;
- they may have restricted access to transport, and hence to services;
- they may not be able to visit relatives in institutions and hospital;
- they may have limited resources for purchase of clothing, which may inhibit presentation for services and/or work;
- they may not be able to carry through recommendations, such as purchase of equipment;
- they may be more susceptible to family difficulties (arising from financial difficulties);
- they may not have the stable background and supports required to take advantage of a program or service; and
- they may be more vulnerable to exploitation.

The fact that poverty may lead to incarceration also has implications for accessibility to some disability support services. For example, a criminal record can compound problems for disability employment agencies. This is a problem for anyone who has a disability and a criminal record, but it is especially significant for Indigenous people due to the high rates of incarceration.

Even though substantial, the differences noted above between Indigenous and non-Indigenous people in motor vehicle ownership don't truly reflect the much greater transportation limitations experienced by Indigenous people. As noted below under 'Transport problems',

the limited access of Indigenous people to motor vehicles has major implications for their capacity to access disability support services. This is true for most Indigenous people, wherever they live, but is particularly so for those living in remote communities.

Other aspects

Other cultural and social issues that need to be considered in the delivery of disability services to Indigenous people include:

- mobility between communities – a 'vital characteristic of contemporary Aboriginal life' [59, p195] – has substantial implications for the provision of services, including disability services [59, 60]. The mobility of Indigenous people is much greater than that of non-Indigenous people in most areas of Australia, but the pattern of Indigenous mobility differs between remote and other areas – mobility in remote areas is more of a short-term nature for social and economic reasons, whereas that in urban and rural areas more generally involves a change of residence [40, 59-62]. Among the Anangu, mobility was noted to result in fragmentation and instability in the care of older people with a disability [3];

- the use of alcohol and other substances can contribute to family and community dysfunction. This may lead to neglect of people with a disability and be a barrier to service provision because some agencies will not accept clients who have a drinking problem [21]. The issues may need to be dealt with concurrently. Furthermore, alcohol-related distress within a family can impact on a client's ability to follow through with a program; and

- family feuding – instances have been reported of people choosing to use services in another town due to feuding family members being involved in the local service [21].

Lack of knowledge about disability rights and services

Lack of knowledge of entitlements, rights and powers of appeal has been consistently identified as a barrier to the utilisation of disability support services [16, 17, 21, 46, 53, 63, 64].

People are often unaware of the services available to them. This is true of non-Indigenous people but is further compounded in the Indigenous population by factors such as communication difficulties, distance and lack of understanding about the Western concept of disability. Considerable client confusion about which agency provides what service has been identified (for example, a disability services officer may be asked about a social security or housing issue) [21]. Apart from confusion about what disability is, this relates to a more holistic view of life circumstances by Indigenous people than the segmented Western view.

There is a vital need for provision of information [9]. Lack of culturally suitable reference material has been identified as a reason for lack of knowledge of services [46, 57, 63]. A pamphlet showing non-Indigenous people attending physiotherapy in the metropolitan area, for example, has little significance to Aboriginal people living in remote parts of the country, such as the Kimberley region of WA [21].

A lack of knowledge of the types of services available compounds the weak position of Indigenous clients in remote areas and 'operates as a major barrier to the development of responsive service delivery' [55, p18].

A study in WA on the use of advocacy services by Indigenous people with a disability found a complete lack of awareness of advocacy or advocacy agencies among participants [65]. Aboriginal 'shyness', poverty, effects of long-term discrimination, powerlessness, the wider Aboriginal background of abuse, not having Aboriginal workers in advocacy agencies, and tensions between Aboriginal groups were identified as barriers to accessing advocacy. There is a need for involvement of Indigenous peoples in all aspects of community care, including meaningful, early and ongoing participation in policy development and planning [66].

During consultations for the 1999 review of the National Disability Advocacy Program, the Steering Committee was advised that:

> Aboriginal communities accept advocacy services best when given the opportunity to nominate someone from their own community to act as an advocate; however that advocate may not be able to access other communities; an advocacy model needs to be developed for working with Aboriginal communities; current advocacy models are culturally inappropriate for working with Aboriginal communities. In Aboriginal communities, advocates must take far greater account of family and extended family members; and (there are) insufficient resources to provide specialised services although they may be justified in Aboriginal communities [67, p25].

Drawing on this advice, the Committee recommended that strategies to address the needs of Indigenous people with a disability should be developed in consultation with appropriate advocacy services [67].

Limited access to services[19]

The provision of health and human services is generally excellent in Australia's major urban areas, but there are significant problems in ensuring that these services are available for people living in rural and remote parts of the country. Generally, the availability of services – particularly of specialised services (such as disability services) – decreases with distance from major urban areas.[20] Thus, issues about the availability of disability support services are likely to be of particular concern for people living in the more remote parts of Australia. The two broad issues relating to the provision of services to isolated areas of Australia are: (1) costs; and (2) the range of services.

Cost of services

The costs involved in providing services generally increase with increasing distance from major urban areas. The factors contributing to higher costs include: labour-related costs; freight costs; airfares and travel allowances; travel-related subsidies; professional infrastructure; and commercial isolation [68]. An indication of the extra costs involved can be gauged from the experience of people operating a service in the AP Lands of north-western South Australia: 'It costs between $1 and $1.30 for a litre of diesel and we use a lot of fuel, covering an area which is larger that the state of Tasmania. Food costs up to twice as much as it does in Adelaide. We pay freight on all items brought in. Our phone bills are bigger. The list goes on. The cost of bringing in professional people is astronomical. It means, for example, chartering planes and paying for days rather than hours of their time' [69].[21]

Availability of specific services

Reflecting the relatively small number of clients within the specific geographic regions, it is difficult to provide some specific services, including:

- therapy services – follow-through with programs is difficult due to the low number of therapists [21, 55];
- home help and personal care [47];
- respite – lack of options for appropriate respite is an issue which has been often identified. This is particularly so for Indigenous families living in remote areas [21, 33, 34, 70], but is also a problem for those living in urban and rural areas [20, 21, 45].
- education – disability among children in remote areas is compounded by their difficulty accessing education. The general educational disadvantages experienced by students in rural and remote areas (availability, accessibility, affordability and acceptability) were particularly true for children with disabilities [71, 72].

Accessing services

Even if disability services are available, such as in urban areas, there may be issues relating to the actual accessibility of these services. These accessibility issues reflect both the attitudes of Indigenous people to mainstream services and aspects about the services themselves.

Attitudes to mainstream services

Indigenous people may be reluctant to use mainstream services [16, 21, 56, 73]. Many are wary of using services due to past government policies that separated children, people with severe disabilities and frail elderly people from their families.

> Aboriginal people have experienced a long history of their children being taken away from them and placed into institutions. This institutionalisation and the policies of cultural decimation have led to generations of physical, mental and intellectual disabilities [46, p13].

More generally, many Indigenous people 'have had some degree of misunderstanding or discrimination when dealing with officials and/or their representatives' [51, p3]. As a result, they fear that they will be abused or shamed. Others are reluctant to access services through fear of being exploited [21].

Establishing need for services

Service providers have expressed doubts about the relevancy of their services. They say it is difficult to gauge the need for a service in the absence of a request for it [21].

It is difficult to:
- determine the level of need for a range of reasons;
- survey people with a disability living in remote areas;
- survey people who are very mobile; and
- survey people who find the concepts being surveyed irrelevant and/or hard to understand.

'It may be that Aboriginal people are ignorant of service options, they may be uncertain of their rights to access such services, or lack the skills or confidence to advocate for themselves before the service bureaucracies. Whatever the actual case for particular individuals, the net result is a lack of pressure applied to policy officers and service provider agencies to address circumstances of need' [47].

Transport problems

Transport issues have been consistently identified as a problem in accessing services [16, 21, 56, 74, 75]. The kinds of transport problems include:
- low levels of vehicle ownership, and relatively poor condition of many vehicles;
- inadequate or no public transport facilities for remote area residents;
- outdoor mobility problems due to rough terrain;
- difficulty for service providers having to access communities during periods of very heavy rains and flooding; and
- lack of money prohibiting access to transport.

Bureaucratic requirements and procedures, including referral and service continuity issues

According to service providers, many Indigenous people are not referred to them. Many services rely on referral from a doctor, and Indigenous people often tend not to use doctors unless there is a crisis. As well, service providers in WA commented that doctors are often unaware of disability support services in their area [21].

When Indigenous people are referred, assessment procedures may be inappropriate [20]. For example, there can be difficulties in providing a suitable service due to restrictive and culturally inappropriate eligibility criteria, and conditions of the agency. This may mean that some Indigenous clients do not persevere past the initial stage [21].

Indigenous clients may have difficulty filling in time sheets (as for Attendant Care) and the forms associated with accessing a service. The appointment notification – be it verbal or written – may not be fully understood. Appointment information may be passed on to a family or community member with whom communication with the client is not appropriate.

There are a number of issues related to maintaining service provision once initial contact has been made, including the relatively high mobility of many Indigenous people and the procedures used by mainstream services in interacting with clients [21].

Service providers have commented that Indigenous clients often move away without notifying the service – this may lead to fragmentation and instability in the care of elderly people with a disability [3], and to lack of follow-through with programs [73].

The procedures used by mainstream services, generally reflecting the 'dominant social and economic circumstances of the time and place from which and for which they were written', are often not appropriate for Indigenous people [76, p2]. For example, the standard way of communication with clients – by post – may not always work for Indigenous people. Many Indigenous people have to rely on a post office box, and they may not check their mailbox frequently and thus miss receiving appointments on time. Based on the experience of social security administration in the Northern Territory, the development of non-standard procedures – including innovative options for arranging follow-up – may be necessary to 'make things work' for Indigenous people living in remote areas [76, p4].[22]

Lack of coordination between agencies and levels of government

Insufficient (or lack of) coordination between services, agencies and levels of government adversely affects the ability of Indigenous people to access services [63, 77-80]. Sara and Couzic comment that the Federal government's policy of self-determination and self-management for Indigenous people remains a 'pipe dream' because service provision continues to be largely uncoordinated and ad hoc, with little involvement of Indigenous clients (or their carers) [78].

Workforce issues

Recruitment and retention of staff

The recruitment and retention of appropriately trained staff, specifically therapists, has been identified as a major problem in many areas outside major urban centres, but particularly in remote areas [47, 55]. This can result in:
- complete gaps in availability of specific therapy services;
- failure of allied health therapists to deliver on many of their core goals and tasks;
- poor continuity of care and therapy follow-up;
- a limited ability to support family carers;
- an inadequate capacity for training of the local workforce in aged/disability care; and
- an inability to provide timely services for clients in need of treatment and rehabilitation [55]

As well, 60% of allied health therapists working in remote areas of the Northern Territory felt their professional support was not adequate, and that they received at most minimal support from their professional associations in their work with Indigenous people [47].

Together, these factors contribute to a relatively high turnover of staff, often with limited or no hand-over to new staff [21]. This impacts on continuity of care, and often results in the loss of valuable informal knowledge [47, 55]

Inadequate training and support for service providers

Despite a well-documented need for cross-cultural training [20, 21, 47], the huge distances and the cost involved in providing services in rural and remote areas makes training provision and supervision difficult. A survey of allied professionals working in rural and remote areas of the Northern Territory found that 60% felt that they were not receiving adequate

professional support and nearly half were unhappy with the level of supervision [47]. Eighty-six percent rated their work stress as higher than average and more stressful than any job they had held previously. Due to difficult conditions, isolation, lack of support and distance from family and friends, there is high staff turnover. When staff are not replaced immediately, loss of information and transferable experience occurs due to lack of hand-over. As well, many new staff are unaware of the limited facilities and support mechanisms that are available in many Indigenous communities [53].

Insufficient numbers of Indigenous staff

The need for Indigenous services and the employment of Indigenous staff is a strong theme in the literature [16, 56, 65, 75]. The people who best understand Indigenous circumstances and culture are Indigenous people. Many Indigenous people prefer to access services that have Indigenous providers [65, 75]. The preference for Indigenous staff is a strong finding, but some Indigenous people prefer to deal with a non-Indigenous person (due to complex inter-familial disputes, for example).

Valuable insights about the issues faced by Indigenous people employed in the disability field were obtained from research in Western Australia in the early 1990s [21], in which the following problems were identified:

- Conflicting demands between the job and responsibilities to the community. For example, Aboriginal service providers were often put in the difficult position of being asked for transport or money when to provide these may conflict with agency regulations. On the other hand, to refuse may undermine credibility with the community and their own values;
- Services were spread too thinly. Because of the complex and difficult nature of the problems faced by their client group, the work was intensive at an individual level and they often had large areas to service, and other work responsibilities besides case work (such as staff training – formally and informally – and meeting their own training needs);
- Insufficient Aboriginal staff to meet the need;
- Aboriginal staff were expected to be experts on every aspect of Aboriginality. There are commonalities, but the Aboriginal population of Australia is diverse – Aboriginal workers commented that they are expected to be experts on all aspects of Aboriginal culture, history and welfare. Aboriginal staff may have been raised away from their families and culture, which makes this even more difficult;
- Expertise was not valued. Because Aboriginal staff have often been employed without formal qualifications, they have been employed on lower salaries and with lesser work conditions. This occurs despite having more difficult workloads, more difficult working conditions and, in some cases, a wider brief than colleagues working with non-Aboriginal clients;
- Discrimination within the workplace and in the course of carrying out their duties. One worker described being regularly pulled over by police when he was driving the work car. The assumption was that Aboriginal people don't drive expensive cars – he must have stolen it. Structural obstacles existed to professional advancement. Because of lack of formal qualifications Aboriginal staff were not able to apply for promotion, but the structures and supports were not given to allow them to obtain the qualifications. Apart from structural obstacles, racism existed;
- Employment expectations were unrealistic. In an outcome-driven environment, they were expected to reach targets that were difficult because of their clients' complex backgrounds;
- Unaware of rights with regard to appeal and workers' compensation; and
- Personal cultural responsibilities were not recognised. One worker said that he had taken a lot of time off work due to family responsibilities and was warned that his employment would be terminated if he took more time off. When a family member died he was expected as an Elder to assume responsibilities, but, in fear of losing his job, he did not go to the funeral. Following this he was shamed and heart-sick. He became so depressed that

he was unable to continue working and walked out of the job, taking none of the entitlements accruing to someone who had worked in the public service for many years.

Racism

Racism has been identified as an issue, both in the community and by service providers [21, 35]. For example, it has been noted in referring to brokerage services that 'some services don't want to be accessed by Aborigines' [21].

More generally, a recent survey of the attitudes of non-Indigenous people towards Indigenous people in two diverse communities in Western Australia noted:

> Our results support previous findings regarding the declining prevalence of old-fashioned prejudice, but indicate that prejudice is still commonplace. Additionally, the findings – especially those concerning false beliefs – suggest that the public should be given more information about Aboriginal history and issues, and that other strategies be put into place to address the problem of prejudice [81].

Many disability services rely on volunteer staff to augment their services. With emphasis on de-institutionalisation and home care, volunteers are an important source of care, but it was noted by Western Australian service providers that some volunteers were reluctant to deal with Aboriginal people and others have paternalistic or uninformed ideas about assisting them [21]. Service providers who seek to place Indigenous people in employment note that the job is difficult due to employers with racist attitudes. This appears to be more of a problem in regional areas where options are more restricted than in urban areas.

Racism can occur at all levels of service provision. It can range from misinformation, fear, and stereotyping to exclusionary racism. This has an impact depending on the model of service delivery – for example, a senior bureaucrat in a hierarchical structure can block service provision at a grass-roots level.

Summary

Little is known about the actual burden of disability experienced by Indigenous people Australia, but it is likely to be considerably greater that that experienced by other Australians.[23]

Similarly, there are no firm data about the extent to which the use of disability support services by Indigenous people reflects their burden of disability. Indirect estimates of the use of disability support services by Indigenous people suggests that as many as one-third of Indigenous people with a disability may not be taking advantage of the services available. Even if this estimate is not entirely accurate, there is a substantial body of evidence suggesting that disability support services are neither as available nor as accessible to Indigenous people as they should be.[24]

The factors contributing to Indigenous use – or non-use – of disability support services are complex, ranging from differences between Indigenous and non-Indigenous people in attitudes to disability to racism among service providers. The literature suggests that many Indigenous people view a disability within a holistic perception of wellbeing – effectively occupying a part of a continuum from perfect wellbeing to death. This is, of course, very much in line with current international approaches, which focus on activity limitations and participation restrictions rather than on a disability per se.

Reflecting this perspective, caring for a person with a disability is generally seen by Indigenous people as the responsibility of the family and immediate kin, with only people with a severe disability being seen as the responsibility of 'welfare'.

Caring for a person with a disability is not straightforward for Indigenous families (or for non-Indigenous families), of course, and various support services can play a valuable role. These include general and disability support services. The relative poverty of many

Indigenous people has major implications for many aspects of daily living, including housing and associated facilities, and transportation. The relatively low level of vehicle ownership – coupled with limited or no access to public transport – poses great difficulties for many Indigenous people in accessing general and disability support services.

For many Indigenous people, particularly those living in remote parts of the country, the real problem is the lack – or very limited availability – of general and disability support services. This aspect has been identified for therapy services, home help and personal care, specialised disability services (including equipment services), and respite services, for example.

Even if services are available, many Indigenous people with a disability and/or their families experience substantial difficulties in accessing general and disability support services. These difficulties include:
- differences between Indigenous and non-Indigenous people in understandings and values – this can result in service providers making unwarranted assumptions on behalf of or about Indigenous clients and/or following culturally inappropriate procedures, and in overt discrimination and racism;
- language barriers – these may lead to misunderstandings between service providers and Indigenous people, particularly those living in remote areas, unless translators are used; and
- poor coordination between services agencies and between levels of government.

Some services, despite being accessible to Indigenous people, experience issues related to staffing. These issues, which impact on service quality and are more common for services in remote areas, include:
- recruitment and retention of appropriately trained staff;
- inadequate orientation and training of staff for work with Indigenous people;
- insufficient Indigenous staff.

The issues summarised in this review should contribute to raising awareness about the needs of Indigenous people with disabilities and the unique issues that influence their access to disability support services. The review provides a sound basis for the development of culturally responsive disability policy and services for Indigenous people.

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Appendix

The nature and assessment of disability

Concepts of disability

Concepts of disability are complex and have changed over time [37]. There are historical, social, legal, and philosophical influences on the perception of disability, and further complexities in spiritual interpretations. The experience of disability is unique to each person, but there are common elements. The identification of these elements is essential for providing support, enhancing community understanding, and minimising marginalisation. There are obvious needs:

- to address the factors contributing to disability;
- to make interventions where appropriate;
- to overcome barriers to participation in all areas; and
- to improve access to disability support and other relevant services.

Various conceptual models have been used to direct services for disability—medical, psychological, and sociological models of disability, all of which have been criticised to some degree [91]. The labelling of people, in medical and rehabilitation models, as *people with a disability* can have negative consequences: they may feel ashamed of their condition and may be stigmatised and looked down upon by their community. In sociological models, disability is viewed within a wider social context and people with a disability may be considered to be a minority group—with the associated possibility of being oppressed. Recognition of oppression has led to an *independent living model*, through which people with a disability have demanded independence and responsibility.

Generally, social models of disability have proven to be the most valuable, but many still rely on a distinction between what is 'normal' and what is 'not normal'. As this distinction is itself socially defined, models relying on it are open to criticism, and it has been argued that a universal approach is preferable [82]. Universalism decreases limitations for people with disabilities and opens their scope of opportunities, allowing them to live as 'normal' a life as possible. It has been argued that universalism serves people with disabilities more effectively than a civil rights or a 'minority group' approach [82].

The nature of disability

There are generally five broad categories that are currently used to define the type of disability that a person has. These categories are, however, multi-dimensional, and include people with varying degrees and severities of a particular condition/s.

Physical disabilities are those that result in restricted activity due to decreased mobility and manipulation, and can include conditions of the brain, spinal cord, muscular, nervous and respiratory systems [71].

Intellectual disabilities refer to conditions caused either by genetic disorders or infections, and can result in limitations and slowness primarily in general learning ability as well as communication and information retention [71].

Psychiatric disabilities are the most varied in terms of their scope and effects. They usually include people with underlying medical conditions such as schizophrenia, manic depression, phobias, and neuroses [71].

Blind or vision-impaired disabilities can affect visibility to varying degrees, from a total absence of vision, to useable vision [71].

Deaf or hearing-impaired disabilities account for those who have varying degrees of hearing impairment. In the strictest sense, individuals usually have no useable hearing and

communicate through Auslan (Australian Sign Language). Individuals with less acute forms of hearing impairment usually communicate through oral [71].

Defining disability

Although there are difficulties in conceptualising disability, there is a need for an agreed definition of 'disability' for 'the collection and analysis of meaningful data on people needing services, the services they receive and the outcomes from services, and for ensuring that these data are in some way comparable for different population groups' [83]. To that end, the Disability Data Reference and Advisory Group was established in 1996 to advise the Australian Institute of Health and Welfare (AIHW) on how generally to improve, harmonise, and standardise data collections (see Box) [83]. The Group also acted as an advisor and consultant in its role as an Australian reference group for the development of the World Health Organization's (WHO) International Classification of Functioning, Disability, and Health (ICF), a revision of the International Classification of Impairments, Disability and Handicaps (ICIDH). The process of redevelopment and testing took several years and involved the WHO and its Collaborating Centres, which included the AIHW [26]. As part of the testing in Australia, the AIHW sponsored a test of ICF concepts in two Indigenous communities in the Northern Territory [13].

Box   Definition of disability

The new International Classification of Functioning, Disability, and Health (ICF) is a conceptual framework for the understanding of functioning and disability and includes the following definitions:

Disability is the umbrella term for any or all of an impairment of body structure or function, a limitation in activities, or a restriction on participation.

Body functions are the physiological functions of body systems (including psychological functions).

Body structures are anatomical parts of the body, such as organs and limbs and their components.

Impairments are problems in body function or structure, such as significant deviation or loss.

Activity is the execution of a task or action by an individual.

Participation is the involvement of an individual in a life situation.

Activity limitations are difficulties an individual has in certain activities.

Participation restrictions are problems an individual experiences in involvement in certain life situations.

Environmental factors make up the physical, social, and attitudinal environment in which people live and conduct their lives. These factors are classified as either *facilitators* or *barriers* (both on a 5-point scale) to indicate the effect they have on a person's functioning.

Source: AIHW, 2001 [83]

The ICF uses the concept of 'participation restriction' instead of 'handicap'. The neutral terms, which include all people, not only those with a disability may therefore be seen as an improvement on the terms used previously. The revised classification system focuses on inclusiveness and reflects the universal approach discussed by Bickenbach and colleagues [82].

Disability support services

It is generally accepted in Australian society that people with disabilities may need assistance from others to continue participating in all aspects of community life. Different types and varying levels of disability require different levels of care and the use of different types of services. Daily activities are categorised according to self-care (bathing, dressing, eating); mobility (movement, public transport); and communication (understanding, speaking, etc) [84].

The Australian context of disability support services

The planning, policy setting, and management of disability support services in Australia is undertaken within the framework of the Commonwealth State/Territory Disability Agreement (CSTDA) [85]. The current CSTDA, which covers the period 2002-2007, is the third such agreement (the previous agreements were known Commonwealth State Disability Agreements (CSDAs)).

The CSTDA agreement, which is binding between the Commonwealth and State and Territory governments, outlines the roles and responsibilities of each in their jurisdictions [85]. The agreement provides both a national framework for disability services enabling the contribution of funds by Commonwealth, State and Territory governments, and a bilateral agreement that provides for strategic activity between the Commonwealth and individual States and Territories.

In acknowledging the principles and aims of the Commonwealth *Disability Services Act 1986*, the *Disability Discrimination Act*, and complementary state and territory legislation,[25] the agreement prioritises access to generic services by people with a disability; the development of across-government linkages;[26] strengthening the capacity of individuals, their families and carers; improving accountability, performance reporting and quality; and putting in place long-term strategies that respond to, and manage the demand for, specialist disability services [85].

The CSTDA is aimed primarily at people aged less than 65 years, with people older than that age only being eligible for services if their disability had been manifest before they turned 65 years [86].[27]

The specialist disability services covered by the CSTDA comprise accommodation support, community support, community access, respite, employment, advocacy, information and print disability [85]. The agreement does not cover services provided as veterans' entitlements or those with a specialist clinical focus. Responsibility for advocacy, information and print disability services is shared by the Commonwealth and the States and Territories, as is research and development (the Commonwealth is expected to provide 'national leadership and coordination' in this area). The Commonwealth has responsibility for specialist disability employment services, and the States and Territories for the specialist disability services in the areas of accommodation support, community support, community access, and respite.

Accommodation support provides accommodation and housing in the form of institutions, residential, hostels, group homes, attendant care, outreach support, and alternative family placement. It is the largest support service accessed by all people with a disability [87].

Community support and access services are equally accessed and in some areas there appears to be some overlap in the services that each provides. Community support however, can be viewed largely as being based on a therapeutic and holistic approach. It provides early childhood intervention, recreation, holiday programs, therapy, case management, behaviour interventions, counselling, brokerage, self-help, and resources [87]. Community access on the other hand, provides services to continue education, post-school options, training, independent living, day programs, and social events [87].

Respite services provide care for those profoundly restricted by their disability on a temporary basis in that their carers may be given a break. Respite services can be in the form of own

home, centre, host, peer, and flexible or combination respite support [87]. It is the least accessed of all support services, as many individuals with a profound level of disability are usually institutionalised (as represented in accommodation support figures) [87].

As well as the specialist disability employment services provided by the Commonwealth, individuals seeking supported employment and sheltered employment options are assisted by the employment sector of state employment agencies [87, 88].

Apart from generic community services, other important services for people with a disability include income support and rehabilitation, neither of which is covered by the CSTDA. Income support for people with a disability is provided by the Commonwealth, mainly in the form of Disability Support Pensions. Rehabilitation services are provided through a number of mechanisms, including CRS Australia (known previously as the Commonwealth Rehabilitation Service) and a variety of State and Territory agencies.[28]

Performance reporting will be based mainly on data from the CSTDA National Minimum Data Set (developed by the National Disability Administrators in partnership with the AIHW) [85]. This will form the foundation for a publicly available account demonstrating achievements 'in the delivery of specialist disability services and national progress in implementing agreed national policy priorities' [1].

Consumer-focussed, government and non-government service providers represent people with a disability in the direction and implementation of disability policy in Australia, and the Commonwealth, State and Territory governments share responsibilities for funding advocacy, information and research services [85].

The National Disability Advisory Council (NDAC), appointed by the Commonwealth Minister for Family and Community Services, acts on Ministerial referrals about matters pertaining to people with a disability [89]. The Council gives relevant advice and information, promotes opportunities for consultation and discussion between the Commonwealth and clients, their carers and service providers, and advances matters that it thinks warrant further investigation.

Under the terms of the CSTDA, the Commonwealth also provides financial support for State and Territory advisory bodies [85]. The national, state and territory advisory bodies are expected to consider issues such as the CSTDA, deinstitutionalisation (and the subsequent need for community housing); employment opportunities and income support; appropriate health care; associations between ageing and disability; and access to education and training.

In 2001, the Commonwealth decided to support the establishment of an Australian Federation of Disability Organisations to become an advisory voice for people with a disability across Australia [90]. In addressing its task of setting up this new organisation, the eight leading disability organisations set up a Federation Working Party, which included a representative from the Interim National Indigenous Disability Network (INIDN). It is anticipated that the first meeting of the Federation's Board will take place in 2004.

In relation to information about disability, the Australian Bureau of Statistics (ABS) is piloting a question on disability for the 2006 population census. It is anticipated that this should improve the quality of information about relatively small groups of people in smaller geographical regions (such as Indigenous people living in remote areas).[29]

In an effort to promote a consistent and constructive approach in service provision to people with a disability the Australian Institute for Health and Welfare (AIHW) has developed an Australian ICF User Guide, and has included ICF concepts in the CSTDA national minimum data sets (NMDS) [26]. The incorporation of the ICF definitions and concepts in national data collections is seen to advantage both providers and clients by increasing understandings about roles and responsibilities. For instance, the redeveloped CSTDA NMDS recognises the importance of primary carers, especially those who are ageing, and the mutual support evident among people with a disability.

Endnotes

1   An appendix summarising disability concepts, the assessment of disability, and the provision of disability support services in Australia is provided for readers who are not familiar with these areas.
2   The report from the IDAR Project has been provided to the DCS, and a version is due for publication in early 2005.
3   Grey literature was defined at the Fourth International Conference on Grey Literature as 'that which is produced on all levels of government, academics, business and industry in print and electronic formats, but which is not controlled by commercial publishers' [96, 97]. The grey literature may include: reports (progress and advanced reports, technical reports, statistical reports, etc.), theses, conference proceedings, technical specifications and standards, non-commercial translations, bibliographies, technical and commercial documentation, and official documents not published commercially (primarily government reports and documents).
4   It was recognised that identification and collection of the grey literature is an ongoing process, which needs to continue beyond the timeframe of this review.
5   For example, the bibliography of a journal article or grey literature item may include reference to an unpublished report, a copy of which may be available as a PDF document on the Internet.
6   Despite definite similarities, there was enormous diversity in cultural and technological aspects in environments ranging from dense rainforests to deserts [92]. The fact that there were some 200–250 different Australian Indigenous languages (and even more dialects), gives some indication of the great diversity that existed in Australia prior to 1788. This diversity is reflected in the great heterogeneity of Indigenous people in Australia today.
7   Such practices were not uncommon in hunter-gatherer societies, being recognised as a part of the balance between individual and societal rights.
8   The people refer to themselves as Anangu.
9   'Participation restriction' or 'activity limitation' using current terminology.
10 The study did not include Indigenous people living in institutions.
11 As is the case with most statistics derived from administrative data collections, the identification of Indigenous people is likely to be incomplete in these data. As well as the 5% of cases in which Indigenous status was not stated, it is almost certain that in some records Indigenous people have been incorrectly identified as non-Indigenous. Thus, the CSDA data almost certainly underestimate the actual use of disability support services by Indigenous people.
12 Not only is there uncertainty about the actual extent and nature of disability among Indigenous people (see the section entitled 'The pattern of disability among Indigenous people'), there are major problems in assessing the use of disability support services by Indigenous (and by non-Indigenous) people. It is beyond the scope of this report to explore these issues in detail. Interested readers should refer to reports from the AIHW, which is working actively on the development of better information. To gain an accurate measure of the relative use of disability support services by Indigenous and non-Indigenous people, it is necessary to adjust the usage figures according to need, as has been attempted here. This estimate of use based on need is quite speculative because it assumes (1) the numbers of disability support services used on the snapshot day are representative of the overall use of services; (2) the estimates of disability prevalence for Indigenous people living in the Taree area of New South Wales can be extrapolated across the country; and (3) the proportions of people identified as disabled who actually need disability support services is the same for the Indigenous population of Taree and the total population. These are major assumptions, but, in the absence of any other estimates of the extent to which Indigenous people are taking advantage of the disability support services that are available, they appear justified.
13 The terms 'remote' and 'very remote' are those used by the Australian Bureau of Statistics in measures of 'remoteness', added recently to the Australian Standard Geographical Classification (ASGC) [94, 95]. They are two of the five categories of remoteness, which, based largely on the Accessibility/Remoteness Index of Australia (ARIA), express the remoteness of a location in terms of the road distance to the perimeter of an urban centre (where various health and human services are available). Defined according to the ARIA value of their ABS Census collection districts (CDs), the five categories are: 'major cities' (average ARIA value of 0-0.2); 'inner regional' (average ARIA value > 0.2 and <= 2.4); 'outer regional' (average ARIA value > 2.4 and <= 5.92); 'remote' (average ARIA value > 5.92 and <= 10.53); and 'very remote' (average ARIA value > 10.53).
14 About three-quarters of these people also reported speaking English well or very well.
15 Australian Indigenous languages included the various creole languages: ones that have developed out of some amalgamation of the language native to an area and the introduced language (English). Because they are linguistically different from creole languages in other parts of the world, those of the northern Australian mainland are known as Kriol [93]. The language in the Torres Strait is most commonly referred to as Torres Strait creole.
16 The proportion of these people who speak English 'well' or 'very well' was not reported.
17 Aboriginal English comprises a continuum of dialects ranging from close to Standard Australian English through to close to the creole languages.
18 It is beyond the scope of this report to explore the various definitions of poverty, and to present detailed data about poverty among Indigenous people. Instead, the report accepts the conclusion of a recent Australian Senate inquiry: 'on all the standard indicators of poverty and disadvantage, Indigenous people emerge as the most socially and economically deprived' [54, p301].
19 As noted in the introductory comments to this section, the word 'available' is used to mean that the services are present in a particular area. The term 'accessible' is used in a broader sense to mean both the geographic availability of the service and the lack any barriers to use of the service.
20 The Accessibility/Remoteness Index of Australia (ARIA) is used to assist in the planning and assessment of access to health-related services for people living in regional, rural and remote locations.

21 At the time, the cost of diesel fuel in Adelaide, the closest capital city, was around 73 cents. And, of course, expensive four-wheel drive vehicles are essential in these remote areas.

22 An example of trying to 'make things work' in relation to Indigenous 'breaches' of social security regulations (due largely to failure to respond to mailed correspondence) is the suggestion by social security administrators in the Northern Territory of allowing Indigenous people to be 'physical check-in' or 'no correspondence' clients if they wished [76, pp6-7].

23 The burden of disability – in terms of prevalence and types – was not a focus of this review, but clearly any thorough approach to addressing the needs of Indigenous people with disabilities requires much firmer baseline data than are available at present.

24 As noted earlier in this report, 'available' means that a service is present in a particular area, while 'accessible' means both the availability of a service and the lack any barriers to its use.

25 For an historical overview, see AIHW 1993 [26, pp266–279]

26 Bilateral agreements between the Commonwealth and each of the states and territories are being negotiated and will aim to improve the interface between employment services and community access services.

27 Services for people with a disability aged 65 years or older are provided largely through the Home and Community Care (HACC) program or as a part of the services in residential aged care.

28 Since July 2002 CRS Australia has operated as a business unit within the Commonwealth Department of Health and Ageing.

29 A similar strategy was successful in Canada in 2001.