



# Aboriginal People with Disabilities

## Getting Services Right



making a difference



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Who is this booklet for?

This booklet is for agencies wanting to develop services for Aboriginal people with disabilities and to make current services more responsive to Aboriginal people.

It is also for Aboriginal people with disabilities, their families and service providers, in particular those who participated in the yarning sessions and interviews that helped us gather the valuable information reported in this booklet.

Why develop this booklet?

Little is known about the lives and experiences of Aboriginal people with disabilities and their families and the types of support they want or need. This booklet begins to fill the gap based on yarning with 319 people living in metropolitan, rural and remote areas of Western Australia during 2003 and 2004 - 97 Aboriginal people with disabilities or family members and 222 Aboriginal and non-Aboriginal agency staff.

Little is known, also, about the level and types of disability within the Aboriginal population. A small amount of evidence suggests that the level of disability and handicap may be around twice as high as that of the total population. The factors contributing to greater levels of disability are likely to be complex and to be linked to the extreme social disadvantage experienced by many Aboriginal people since European settlement, dispossession of land and culture, discrimination and disruption of kinship ties. This means that Aboriginal people with disabilities, their families and carers need access to disability information and services which they can understand and relate to, and which respects and integrates Aboriginal culture. This booklet provides examples of ways to develop culturally responsive information and services in partnership with Aboriginal people. These examples are only the beginning. Much more is still to be done.

How was information collected?

Consultations and yarning sessions with Aboriginal people with disabilities, their families, carers and service providers took place across Western Australian during 2003 and 2004. Information from consultations was used to develop policy and strategies to address issues raised at local and statewide levels in partnership with Aboriginal people. This booklet reports issues raised during consultations and examples of strategies developed by consumers, the Commission and other agencies to address issues.

A full report of literature and consultation findings, 'Addressing the Unique Needs and Issues of Aboriginal Western Australians with Disabilities' is available from the Disability Services Commission.

# Aboriginal people's view of 'disability'

Very little is written about how Aboriginal people think about disability and respond to people with disabilities.

Prior to colonisation it appears that Aboriginal people with impairments were treated and cared for no differently from other members of the group or clan. People with physical disabilities appear to have been cared for within the extended family kinship system and accorded the same social roles and responsibilities as others.

Perceptions of disability were different to Western perceptions. Engagement with family and fulfilment of family roles influenced how 'able' Aboriginal people felt, and, generally, Aboriginal people with disabilities were not aware how much they were limited by their condition.

Having a disability did not separate people from the rest of their community. For example, the Ngaanyatjarra, Pitjantjatjara and Yankunytjatjara people had no general word for disability that separated people with impairments from the rest of the community.

The consultations found that Aboriginal people are, in general, less familiar with the term 'disability' and the way in which it is understood in Western culture.

Some Aboriginal people maintain cultural and mythological beliefs about the reasons for a disability occurring and it is important that service providers understand this. For example, the cause of a child being born with a physical disability in a rural or remote community may be attributed to the child's mother doing something accidental or ill-advised when she was pregnant such as treading on the back of a goanna. These causes do not appear to result in discrimination against the family or child.

## Aboriginal people's view of 'disability'

Many Aboriginal people consider both health and disability-related conditions to be 'disabilities'. This is not surprising given that many health issues such as renal failure, diabetes and chronic asthma – some of those named by Aboriginal people to be disabilities – can result in restrictions to everyday activity.

Aboriginal families consider themselves to be more accepting and supportive of family members who have a disability than are non-Aboriginal people. People with disabilities were reported to be included within their extended families and able to assume kinship roles and responsibilities where possible.

Aboriginal families may not as readily recognise that a person has a disability or the way in which support and services could assist in fostering health, skill development and independence. This is considered to be partly due to the natural inclusion of Aboriginal people with disabilities in community life where disabilities are not emphasised, and partly due to lack of information about the Western understanding of disabilities.

**My daughter's Aboriginality comes before her disability. It is very important to me that service providers understand that she is Aboriginal first and then has a disability. (metropolitan participant)**

**Family members provide support. In our house there are three generations – they all provide care to my two sons. The family felt because of this we did not need a lot of contact with the Disability Services Commission. (Goldfields participant)**

**I feel my son is really included in this community. People are protective of him and will look after him. (Great Southern participant)**

**My daughter's Aboriginality comes before her disability. It is very important to me that service providers understand that she is Aboriginal first and then has a disability. (metropolitan participant)**

The information in this section gives a flavour of the ways in which Aboriginal people understand disability and respond to a person with a disability. Taking time to understand a local Aboriginal perspective to disability is an essential part of developing services or supports in partnership with individual, family or community, that are culturally relevant, acceptable and likely to be effective.

## Information about disability

The consultations found that Aboriginal people want more information about different types of disabilities and the range of services available to provide support. This is particularly important as some Aboriginal people feel that there is a stigma associated with being registered with a disability services agency and need to know of alternative supports. Others have a misconception that some services are only available to non-Aboriginal people.

Information needs to be made available in different ways. A number of Aboriginal people are unable to read English and prefer alternatives to printed books and pamphlets, including radio, television and informal meetings. Where printed information is used it should contain plain English, no jargon, and feature visual information using familiar environments and Aboriginal people.



*Yarning with Aboriginal carer, Warmun*

Agencies must work alongside Aboriginal communities and agencies to develop effective information strategies for Aboriginal families and agencies.

**Aboriginal people are 'shamed' and don't ask for help. This stops them getting the information they should be getting and they miss out on services.** *(Kimberley service provider)*

**Aboriginal people are reluctant to use services as they feel they are for whitefellas.** *(Wheatbelt participant)*

**Aboriginal people are often fobbed off when it takes a lot of courage to seek help.** *(metropolitan participant)*

**We need to bring Aboriginal families together to support and share information.** *(Great Southern participant)*

Information pamphlets have been developed by disability workers in partnership with Aboriginal people. Pamphlets feature Aboriginal artwork, designs and photos, inclusion of the Aboriginal flag, and the use of plain English.

An Aboriginal home page is provided on the Disability Services Commission's Information for You website.

Local Aboriginal communities and agencies meet with staff from disability-related and other agencies to have a yarn, form relationships and share information. For example, a 'Being Together' day was held in the metropolitan area where Noongar (Aboriginal people of the South West) and Wadjella (non-Aboriginal people) disability workers talked about commonalities and differences in their culture.

Local Aboriginal art, posters and photos are displayed in disability offices in metropolitan and country areas.

Aboriginal radio is used to broadcast information about disability issues and events in the Kimberley.

Aboriginal people have shared their stories and experiences of disability in a short DVD by the Disability Services Commission to inform Aboriginal people about disabilities and services.

**What other ideas could assist Aboriginal people to learn about services for people with disabilities, their families and carers?**

# Access to culturally responsive supports and services



## Information pamphlets

Many Aboriginal people are reluctant and, even afraid, to ask for information and assistance from agencies due to negative experiences with past government policies and practices.

To overcome this, Aboriginal people must be actively encouraged and welcomed by agencies, for example:

- by receiving assistance from Aboriginal staff or from non-Aboriginal staff who are aware and sensitive to the needs of local Aboriginal people;
- by placing Aboriginal posters on office walls to signal a welcome;
- by developing registration forms which are easy for local Aboriginal people to understand and complete; and
- by developing service approaches that respond to the unique needs of local Aboriginal groups.

**There were bad experiences in the past for Aboriginal people. White people need to understand that Aboriginal people have had a hard time and are still going through it. There's that fear to work with Wadjellas and government agencies. (Wheatbelt participant)**

**Non-Aboriginal people don't understand the ways of Aboriginal people. They should learn. (metropolitan participant)**

**Wadjellas have got ways of talking that Noongars don't understand. (Lower Great Southern participant)**

**The registration/eligibility process puts people off getting the help they need. (Kimberley participant)**

**Aboriginal people need support to talk up and ask for help. Interpreters should be employed to do this. (Goldfields participant)**

**I wasn't happy with the service I was getting. My Wadjella friend told me I should jump up and down and shout. But that's not our way. I just kept quiet. (metropolitan participant)**

**We need to use Aboriginal staff to break down barriers. The employment of local people in agencies would encourage Aboriginal people to access services. (Kimberley participant)**

## Initiatives to address service issues

More Aboriginal workers have been employed in disability-related jobs including policy and planning, Local Area Coordination and direct support to people with disabilities and their families.

A range of strategies have been adopted to increase employment including:

- the revision of job selection criteria to ensure Aboriginal people are not disadvantaged;
- developing job advertisements to attract Aboriginal people;



*Aboriginal Senior Policy Officer discussing cultural history*

- using Aboriginal newspapers, job networks and radio to advertise jobs; and
- adopting more Aboriginal-friendly interviews and selection processes.

## Initiatives to address service issues

Aboriginal people are involved in key decision-making roles, for example on the Board of the Disability Services Commission, as members of the Advisory Council to the Minister for Disability Services and on the Steering Committee overseeing implementation of Aboriginal disability policy and practice.

Non-Aboriginal disability workers receive training to understand Aboriginal history and culture, develop relationships with local Aboriginal communities and provide services in a culturally responsive and respectful way. Two examples include:

- during NAIDOC week, disability staff were invited to explore the impact of previous government policies and practice in Western Australia on current provision of disability services; and
- a yarning session was facilitated by a member of the Yirra Yaakin theatre group to help Noongars and disability workers get to know each other and to introduce Noongars to disability services.

Aboriginal agencies are used as a base to meet Aboriginal people who may need information about disability services. In Roebourne, for example, a well-established Aboriginal agency provides a weekly meeting space for Aboriginal people and the local area coordinator.

Services have been developed in partnership with Aboriginal people to meet the unique needs and cultural requirements of local Aboriginal people. For example, a Family Fun Centre in Cue was established by local therapists in consultation with members of Aboriginal and non-Aboriginal communities.



*Aboriginal therapy assistant, Family Fun Centre, Cue*

The centre provides stimulation for young children by offering toys and games, craft for parents and encouragement for parents to read books to their children. Aboriginal people feel comfortable to meet with other Aboriginal and non-Aboriginal people at the centre and to learn more about stimulating activities from Aboriginal therapy assistants.

In remote areas where distances are vast and communities difficult to reach, local Aboriginal people are being trained as support workers to assist people with disabilities to get around home and community or to participate in recreational activities. In the Kimberley, Pilbara and Mid West regions, for example, creative partnerships between disability, health and other agencies enable Aboriginal health and community support workers to add disability specific skills to the types of services offered when they visit remote communities. In Fitzroy Crossing, Aboriginal people working at a local employment agency are trained to make simple repairs to wheelchairs to minimise delays when equipment is repaired in Derby.

Disability awareness training is provided to Aboriginal health students at Curtin University, Marr Mooditj College and Kadajiya Mia by the Disability Services Commission's health resource and consultancy team.

Disability workers in Fremantle hold an annual get-together with Aboriginal families and agency workers to build relationships with the local Aboriginal community.

**What other ideas could assist Aboriginal people to access services for people with disabilities, their families and carers?**



*Aboriginal carers workshop, Lansdale Farm*

The consultations found that many Aboriginal carers do not have sufficient support, that they were not aware of available services to give them a break, or even where to go to find out.

**Families are not aware of services and are taking care of people with disabilities without knowing what help there is. There needs to be more information given to families.** *(Kimberley service provider)*

**Aboriginal carers don't have anyone to cover their family responsibilities when they accompany a family member with a disability to Perth.** *(Mid West service provider)*

Many Aboriginal people, usually women, care for their family member with a disability and, at the same time, support or care for others such as grandchildren or older parents.

Aboriginal people prefer to get a break by using help from other family members than by bringing in outside help. However, some did not have extended family willing or able to help out, leaving the carer without support and in danger of burn out or unable to follow their own interests, for example, art or attending to cultural and ceremonial responsibilities.

Developing services to support carers must be done in partnership with Aboriginal people to respect local family and community preferences. Aboriginal carers expressed a strong desire for safe, reliable, accountable and trained staff to provide regular breaks.

Carers need to be culturally acceptable to Aboriginal families, for example to be in the same language group. It was noted also that Aboriginal women may not be permitted to offer physical assistance to men, which poses unique problems as caring is not viewed as a man's role.

# Initiatives to address carer support issues

In 2004 the second Western Australian 'Focus on Carers' Symposium was held at Burswood Convention Centre. As it was daunting for many Aboriginal people to attend, a pre-symposium workshop was held at Lansdale Farm earlier to assist Aboriginal woman identify and share their unique issues as carers and encourage them to attend the state wide event. Eighteen Aboriginal carers attended from the Kimberley, Lower and Upper Great Southern, Midlands and metropolitan regions with eight Aboriginal carers deciding to attend the Burswood symposium.

To build on the above, several video conferences were held to link Aboriginal carers, to share ideas and to form an Aboriginal carers network and local carer groups.

Services to support Aboriginal carers have been developed in the Western Desert, Pilbara and Kimberley regions. In Roebourne, for example, Aboriginal grandparents caring for children with a disability, are supported by the Pilbara Homecare service with culturally appropriate carer respite and family support services tailored to the specific requirements of the family.

Local area coordinators help support a Perth Aboriginal carers' network, organised by a metropolitan Aboriginal agency.



## Access to other disability-related services

The consultations found that there are many disability-related issues of relevance to mainstream and other agencies.

### ● Housing

Houses need to be more accessible and located in areas that enable Aboriginal people with disabilities to travel to appointments and participate in family and community activities.

**Some Aboriginal families live in old houses made of asbestos and tin. They have no insulation, narrow doors, the toilets and showers aren't accessible, there are steps and no ramps. (Great Southern participant)**

**Aboriginal families need to visit extended families, so all houses need to be more accessible. I and a friend have to lift my mother (in a wheelchair) up steps for her to visit my house. This is uncomfortable for my mother. I have problems with my heart.**

*(Great Southern participant)*

### ● Finances

Many Aboriginal families live in relative poverty and find it difficult to cope with the additional costs of caring for a person with a disability. Government and other assistance play a crucial role yet are not always sufficient, particularly for people with disabilities and their families living in remote areas where food, clothing and petrol costs are much higher.

### ● Local transport

Lack of public transport in many small towns limits opportunities for community participation. Public transport, where it is available, is often not accessible by people with disabilities. Many Aboriginal families do not have cars. Taxis, where available, are expensive and generally not accessible.

## ● Education

In some areas of the State, concern was expressed about children not attending school regularly and hence not achieving adequate numeracy and literacy skills. Lack of school attendance increases the likelihood of involvement in substance abuse and other anti-social activities.

**If kids don't attend school, they don't get routine assessment provided by therapists to identify educational and therapy needs.** *(Mid West service provider)*

## ● Work opportunities

There needs to be more information and support for young Aboriginal people with a disability to access work after leaving school. Some of the barriers to employment include:

- young Aboriginal people have less contacts with the business community to help them get work;
- there are insufficient Aboriginal mentors in relation to employment; and
- employers have little understanding of Aboriginal culture and cultural obligations.

**There is little chance of getting a job. A job should be a right as it gives pride and extra income.** *(metropolitan participant)*

**There are barriers against employing Aboriginal people in this town.** *(Great Southern participant)*

**There needs to be more Aboriginal people in senior management positions in mainstream agencies and on boards of agencies.** *(Goldfields service provider)*

# Cooperation and coordination between agencies



*Work opportunities, Carnarvon*

There is need for improved coordination of services for many Aboriginal families facing multiple issues involving a range of agencies:

- Aboriginal agencies;
- agencies dealing with housing and related matters; education, training and employment; health services (including services for mental health and alcohol and substance use); and
- financial support (including government benefits); disability; and matters relating to police and the criminal justice system.

Aboriginal agencies often take a lead role in addressing poor coordination between agencies, even though they are not funded for this function. These agencies need better support from disability and mainstream agencies.

**A family may have to visit five or more agencies to get each part of the service they need. There are divisions or barriers between government and non-government agencies which prevent collaboration.**

*(Goldfields service provider)*

**Many families are dealing with multiple issues and have to deal with multiple agencies.**

*(Mid West service provider)*

**The family would like to take the boys on family outings, especially to take them out bush to learn culture. This is very difficult as we can't access transport.**

*(Goldfields participant)*

**Accessible transport is very limited and prevents people with disabilities and those who are old to participate in community activities. The wheelchair-accessible bus is generally not available on weekends and after hours.**

*(Mid West service provider)*

### ● Appointments in cities and regional centres

Aboriginal people from regional and remote areas experience many problems travelling to and making their way around Perth or regional centres. As a result, important medical and specialist appointments are missed. In addition, Aboriginal people express reticence about asking questions and clarifying information with professionals. This impedes effective follow-through of programs.

**Aboriginal people find it hard to make their way around Perth. People from remote areas are physically vulnerable in Perth. Hospitals are overwhelming. They are large and impersonal and people get no help to find their way around.** *(Mid West service provider)*

**There are lots of problems with transport to appointments. Traveling to Perth with a non-Aboriginal driver is uncomfortable for many Aboriginal people. Specialists often work from 9am to 12 noon, so Aboriginal people have to travel up to Perth the night before and have accommodation issues. Specialists only travel to this town once every 3-4 months.**

*(Great Southern service provider)*



### *Working with Aboriginal Health Agency, Wiluna*

In 2004, disability workers in the metropolitan area participated in a cultural awareness day which strengthened relationships with Aboriginal families and agencies, such as the Maamba Aboriginal Corporation and the Nanakaat Family Support Services. The day included Aboriginal hosted visits to significant sites, shared history, stories and Aboriginal tucker.

In 2004, the first Pilbara Aboriginal health conference was held focussing on working with Aboriginal people and creating interagency partnerships.

In 2003 Karratha hosted a two-day regional workshop for teachers and related service providers which focussed on supporting Aboriginal students. This was very successful in linking service providers with a common focus.



*Agencies forming connections with disability services, Albany*

In 2003, following consultations in the Great Southern region, over 30 people from mainstream and Aboriginal agencies met in Albany to discuss feedback and to develop ways to improve connections between local Aboriginal agencies, disability services, mainstream agencies and Aboriginal people with disabilities, their families and carers. Regular contact has continued.

Strong interagency collaboration has facilitated the reuniting of Aboriginal people with disabilities and their families.

For example, metropolitan disability workers have collaborated with Aboriginal groups, Yorgum and Derbarl Yerrigan, and disability workers in the Northern Territory to reunite an Aboriginal man with his family in Darwin.

**What other ideas could promote cross-agency collaboration to improve overall services for Aboriginal people with disabilities, their families and carers?**

*Local area coordinator in an advocacy role, Pilbara (left)*

Many Aboriginal people do not speak English well or understand government systems, and are reticent in their dealings with government and other agencies. In addition, many Aboriginal people experience greater vulnerability, greater avoidance from non-Aboriginal people and less support due to being Aboriginal and having a disability.



As a result, there is a need for strong advocacy on behalf of Aboriginal people with a disability, their families and carers at an individual level and at a systems level, including advocacy for accessible public facilities, such as footpaths, wheelchair access, and transport in rural and remote areas.

**I provide support to an Aboriginal adult living independently in a flat. He has had difficulty getting a taxi as he appears drunk (due to his disability) and is Aboriginal. He has also been arrested by police as he appears violent (due to his disability) and is Aboriginal. He has had his belongings stolen in boarding houses, been taken advantage of by caretakers, and then evicted. *(metropolitan service provider)***

# Initiatives to address advocacy issues

Aboriginal families in Fitzroy Crossing have formed the Fitzroy Consumers Disability Advisory Group to identify and address local disability issues.

Aboriginal health workers in the Great Southern Region are advocating for the needs of carers of children with disabilities.

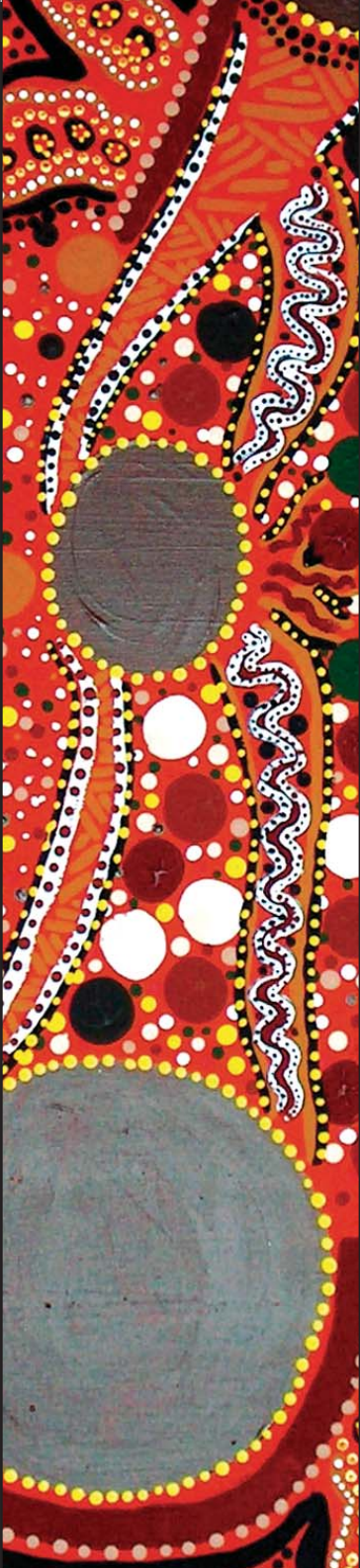
Local area coordinators are advocating for funding and services for Aboriginal people in their area.

**What other ideas could improve advocacy for Aboriginal people with disabilities, their families and carers?**

*Fitzroy Crossing Consumers Disability Advisory Group (below)*



Cover artwork courtesy of Brodie Murphy (Jullumia)



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