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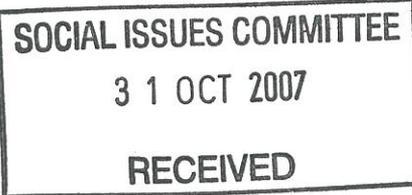
## INQUIRY INTO OVERCOMING INDIGENOUS DISADVANTAGE

**Organisation:** Aboriginal Disability Network NSW  
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**Position:** Chairperson  
**Telephone:** 02 9370 3100  
**Date received:** 31/10/2007

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30 October 2007



Standing Committee on Social Issues  
Parliament House  
Macquarie St  
SYDNEY NSW 2000

**Re: Inquiry into Overcoming Indigenous Disadvantage**

Dear Committee Members,

Thank you for the invitation to make a submission to the Standing Committee on Social Issues inquiry into overcoming Indigenous disadvantage.

By any measure Aboriginal and Torres Strait Islander people with disability remain amongst the most disenfranchised members of the Australian community. They often face multiple barriers to their meaningful participation within their own communities and the wider community. Aboriginal and Torres Strait Islanders with disability are very unlikely to be employed or to have participated in the education system in any significant way.

The prevalence of disability has been recently quantified as 37% of the Aboriginal and Torres Strait Islander population by the Council of Australian Governments Steering Committee for the Review of Government Service Provision. This is in fact considered a conservative figure as it does not recognise the prevalence of mental illness which anecdotally at least suggests a normalisation of depression and anxiety for instance amongst the Indigenous population.

The Aboriginal Disability Network NSW (ADN) has been existence since 2002. The ADN is a network of and for Aboriginal and Torres Strait Islanders with disability living in NSW which seeks to promote and protect the human rights of Aboriginal and Torres Strait Islanders with disability. Until recently it has been reliant on private sector funding to conduct its advocacy work.

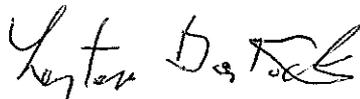
In 2004-05 the ADN undertook a major community consultative project that saw the network visit 33 Aboriginal communities across NSW. To date it remains the most thorough consultative project undertaken directly with Aboriginal and Torres Strait Islander people with disability and their associates. During these consultations Aboriginal and Torres Strait Islander people with disability and their associates raised a broad range of systemic issues that exposed the degree of unmet need. Furthermore the consultations exposed the lack of service provision and the violations of the most fundamental of human rights for Aboriginal and Torres Strait Islanders with disability resulting in many Aboriginal and Torres Strait Islanders with disability living in extreme poverty.

There is much to be done to address the serious disadvantage that many Aboriginal and Torres Strait Islanders with disability encounter. The community consultations whilst exposing the degree of unmet need also provided the network with some valuable insights into meaningful ways forward.

In the interests of expediency the ADN would like to submit a copy of our report entitled *Telling It Like It Is: a report on community consultations with Aboriginal people with disability and their associates throughout NSW 2004-05*. We believe that the report addresses a wide range of issues that are particularly relevant to overcoming Indigenous disadvantage for Aboriginal and Torres Strait Islanders with disability that would be of interest to the Committee.

Myself and ADN Director Damian Griffis would welcome the opportunity to provide advice to the Committee by talking to the contents of our major report. We look forward to the opportunity of representing the views of Aboriginal and Torres Strait Islanders with disability in person.

Yours sincerely,

A handwritten signature in black ink, appearing to read 'Lester Bostock', with a stylized flourish at the end.

Lester Bostock  
Chairperson



# Telling it Like it Is

**A report on community consultations  
with Aboriginal people with disability  
and their associates  
throughout NSW, 2004-2005.**

## **Acknowledgements**

The Management Committee of the Aboriginal Disability Network would like to thank the following people:

- Ms Kerry Reed-Gilbert for the professional way in which she facilitated the community consultations
- Matthew Bowden for the accessible way in which he ensured that individuals could be supported through the services of the Individual Advocacy Unit at People with Disability Australia
- Alanna Clohesy for her advice and support in compiling this report
- Phillip French for his ongoing support of the Network
- Damian Griffis, who was present at virtually all of the community consultations and has been responsible for writing this report along with having primary responsibility for the further consolidation of the Network.

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## **Executive Summary**

'Telling it like it is' is a report of community consultations conducted throughout NSW during 2004/2005 with Aboriginal people with disability and their associates living in New South Wales (NSW).

Historically, much of the focus on Aboriginal people with disability has been from a health perspective. Whilst essential, particularly in terms of determining primary health interventions, this perspective has come at the cost of failing to recognise the social aspects of Aboriginal disability. This has meant that the barriers that discriminate against Aboriginal people with disability remain firmly entrenched and the general well being of Aboriginal people with disability has not improved in any meaningful way.

These consultations were conducted from March 2004 to July 2005. Consultations were held in 32 communities in north, western, central and south coast New South Wales (NSW). Approximately 300 Aboriginal people with disability and their associates attended these consultations plus an additional 100 Aboriginal people with disability were interviewed in their own homes to accommodate their access needs and to ensure privacy when discussing sensitive issues.

In recent years through the work of such organisations as the Aboriginal Disability Network NSW and several state government departments with portfolio responsibility for disability, the needs of Aboriginal people with disability are gaining some increased profile. However, the fact remains that the needs of the vast majority of Aboriginal people with disability remain unmet. In NSW there are very few Aboriginal people with disability who access accommodation or employment services, or any other form of service provision that is designed to meet the needs of people with disability.

Aboriginal people with disability are significantly under-represented on a population basis in beneficial social programs, including health, community and disability services, due to a number of policy and structural failures. These include services that are poorly targeted and located, as well as culturally insensitive or inappropriate services. Furthermore there are very few Indigenous specific disability services, or non-Indigenous disability services with Aboriginal staff.

Many of the communities visited during the consultations experience little or no access to public transport. Participants in the consultations identified lack of transport as a major barrier to inclusion in 'mainstream' and their own community activities. For most communities, there was no public transport infrastructure, let alone accessible transport.

The Aboriginal Disability Network has concerns about the number of Aboriginal people living with disabilities who have serious unmet needs that need to be addressed as a priority.

***Lester Bostock***  
***Chairman***  
***Aboriginal Disability Network NSW Inc.***

# 1. Introduction

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'Telling it like it is' is a report of community consultations with Aboriginal people with disability and their associates living in New South Wales (NSW).

## 1.1 Context

The prevalence of disability amongst Aboriginal and Torres Islanders is significantly higher than of the general population. Until recently the prevalence of disability in Aboriginal and Torres Strait Islander communities has been only anecdotally reported. However a recent report by the Commonwealth Steering Committee for the Review of Government Service Provision made the following conclusions:

The proportion of the indigenous population 15 years and over, reporting a disability or long-term health condition was 37 per cent (102 900 people). The proportions were similar in remote and non-remote areas. This measure of disability does not specifically include people with a psychological disability.<sup>1</sup>

The high prevalence of disability, approximately twice that of the non-indigenous population, occurs in Aboriginal and Torres Strait Islander communities for a range of social reasons, including poor health care, poor nutrition, exposure to violence and psychological trauma (e.g. arising from removal from family and community) and substance abuse, as well as the breakdown of traditional community structures in some areas. Aboriginal people with disability are significantly over-represented on a population group basis among homeless people, in the criminal and juvenile justice systems<sup>2</sup>, and in the care and protection system (both as parents and children).<sup>3</sup>

In recent years through the work of such organisations as the Aboriginal Disability Network NSW and several state government departments with portfolio responsibility for disability, the needs of Aboriginal people with disability are gaining some increased profile. However the fact remains that the needs of the vast majority of Aboriginal people with disability remain unmet. In NSW there are very few Aboriginal people with disability who access accommodation or employment services or any other form of service provision that is designed to meet the needs of people with disability.

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<sup>1</sup> Commonwealth Steering Committee for the Review of Government Service Provision *Overcoming Indigenous Disadvantage Key Indicators 2005 Report*. Page 3.6

<sup>2</sup> Aboriginal people are 11 times more likely to be imprisoned than other Australians. Source: *Overcoming Indigenous Disadvantage Key Indicators 2005; Steering Committee for the Review of Government Service Provision*. There is no empirical evidence to quantify the number of Aboriginal people with disability in particular with intellectual disability and mental illness in the criminal justice system. The prevalence of intellectual disability for instance in the prison population is often contested with wide variation in percentages. However a report by the Law Reform Commission published in 1996 entitled *People with an Intellectual Disability and the Criminal Justice System* noted that 12-13% of the prison population were people with an intellectual disability.

<sup>3</sup> *Overcoming Indigenous Disadvantage Key Indicators 2005; Steering Committee for the Review of Government Service Provision* states 'The rate of children on care and protection orders (for a combination of all states and territories except NSW) was five times higher for indigenous children (20 per 1000 children in the population aged 0 – 17 years) than for non-indigenous children (4 per 1000 children). Pg 9.5

Aboriginal Home Care services are the most likely to interact with Aboriginal people with disability, however their focus is narrow in that their primary role is to provide some in-home supports and not a holistic service. Despite this, many Aboriginal Home Care services find themselves in positions where they are called upon to perform duties that are beyond what they are funded to do or beyond their areas of expertise and experience.

Historically much of the focus on Aboriginal people with disability has been from a health perspective. Whilst this is essential, particularly regarding primary health interventions, it has come at the cost of failing to recognise the social aspects of Aboriginal disability. This has meant that the barriers that produce discrimination against Aboriginal people with disability remain firmly entrenched and the general well-being of Aboriginal people with disability has not improved in any meaningful way.

The experiences of many Aboriginal people with disability is that their disability is often medicalised. Interventions often simply treat the individual's health condition without considering the broader implications of their condition, i.e. the social barriers to participation. This is an ongoing problem as significant funds are continually poured into Aboriginal health programs without the foresight to consider the broader social needs of Aboriginal people. As one Aboriginal person with disability put it at one of the community consultations, 'getting a wheelchair helps me around my home but it doesn't help my whole life; I still can't get down to the shops and go to places I want to go because the footpath is too bad'. This response acts as a powerful analogy for the problem of dealing with only one aspect of the life of an Aboriginal person with disability, that is dealing only with the health aspects through the provision of a technical aid without addressing the systemic barriers that impact the person's life, such as an inaccessible community.

Furthermore the impact of colonisation and the resultant dispossession of land and displacement from places of cultural significance have had an impact on the lives of many Aboriginal people with disability which is difficult to measure. Indeed invasion and colonisation can be directly attributed as causal factors of disability amongst Indigenous communities. Lester Bostock, a Bundjalung elder, provides this narration:

With the coming of the Europeans just over 216 years ago, the continuous co-existence with the land was dramatically interrupted, bringing about another dimension to the history of the country. This intrusion brought with it many new diseases never before known on this continent, diseases like cholera, smallpox, leprosy, diseases that Aborigines had no protection against. Not only did the Aborigines have to contend with these new diseases but also the mass slaughters and massacres as these new invaders took over our lands ..... Since that time the Indigenous people of Australia have continued to suffer from ... genocide and [other] discriminatory practices.<sup>4</sup>

As this report will demonstrate, there are very few Aboriginal people with disability who have their needs met in any significant way. Therefore it is safe to assume that the vast majority of Aboriginal people with disability do not receive any support other than that provided by their immediate family or through kinship networks

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<sup>4</sup> Excerpt taken from a paper presented by Lester Bostock, entitled 'Aborigines and disability' for International Day of Persons with Disabilities in Perth 1991 to the National Disability Council.

which themselves invariably have needs of their own that are not being met. It is a situation that is distressing and inexplicable in a country that in many other facets of disability rights is regarded as a world leader.

Aboriginal people with disability are significantly under-represented on a population basis in participation in beneficial social programs (including health, community and disability services) due to a number of policy and structural failures. These failures include services that are poorly targeted and located, as well as culturally insensitive or inappropriate. Furthermore, there are very few Indigenous specific disability services, or non-Indigenous disability services with Aboriginal staff.

In many cases, particularly in rural and remote communities, Aboriginal people with disability are the victims of institutional racism that often results in little or no service provision. Today sadly this remains a major barrier for Aboriginal people with disability in their desire to be able to meaningfully participate in the wider community.

Given these factors, the Aboriginal Disability Network (ADN), in conjunction with People with Disability Australia (PWD) identified an urgent need to talk directly with Aboriginal people with disability and their associates about the extent of these and other issues. To this end, community consultations were undertaken with over 300 Aboriginal people with disability and their associates in 32 communities across NSW. Up to an additional 100 Aboriginal people with disability were interviewed in their own homes in order to identify issues and provide individual advocacy support. Issues are discussed by theme in section three of the report.

## **1.2 About the Aboriginal Disability Network of NSW**

The Aboriginal Disability Network of NSW (ADN) brings together Aboriginal and Torres Strait Islander people with disability living in NSW so that members can

- tell their stories
- give each other support
- be a voice for positive change, and
- self-represent on issues of concern.

For further information on the Aboriginal Disability Network NSW including some historical background please see Appendix 1.

## **1.3 About the community consultations**

The rationale behind the community consultations was based on several factors. Firstly there was a concern amongst committee members that the ADN must have close community linkages to be truly representative of and for Aboriginal people with disability living in NSW. The most effective way and the most culturally appropriate way to achieve this end was to engage with Aboriginal communities directly in their own community settings. Secondly, the Management Committee wanted to ensure that the needs of Aboriginal people with disability living outside

Sydney and other large regional centres were being properly considered. Of particular concern was reaching Aboriginal people with disability in the remote parts of the state.

A third major consideration was that many Aboriginal communities suffer significant consultation fatigue. Throughout NSW Aboriginal communities are consulted on a wide range of issues. However many Aboriginal people with whom facilitators met expressed their frustration with the consultation process. This is because of experiences or a perception that the information that communities provide during consultations is not acted upon.

To address this major issue it was decided that participants should have the opportunity to access individual advocacy support. This was to ensure that participants would have some meaningful opportunity to have their needs met as opposed to setting up a situation where participants would feel that they are simply being used as a source for information. This part of community engagement was central to the effectiveness of the community consultations.

## **2. How the consultations were conducted**

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### **2.1 Where were consultations held?**

The community consultations were conducted from March 2004 through to July 2005. Consultations were held in 32 communities in north, western, central and south coast New South Wales (NSW). Approximately 300 Aboriginal people with disability and their associates attended these consultations plus up to an additional 100 Aboriginal people with disability were interviewed in their own homes to accommodate their access needs and to ensure privacy when discussing sensitive issues.

Consultations were held in:

Armidale (Nganyaywana)  
Bankstown (Eora)  
Bateman's Bay (Yuin)  
Bega (Yuin)  
Blacktown (Dharug)  
Bourke (Wongaibon)  
Brewarrina (Wailwan)  
Broken Hill (Wiljali)  
Campbelltown (Dharawal)  
Cobar (Wongaibon)  
Coffs Harbour (Gumbainggir)  
Coonabarabran (Wailwan)  
Coonamble (Wailwan)  
Dubbo (Wiradjuri)  
Enngonia (Barranbinya)  
Grafton (Gumbainggir)  
Kempsey (Dainggatti)  
Lightening Ridge (Kamilaroi)  
Lismore (Bundjalung)  
Menindee (Danggali)  
Moree (Kamilaroi)  
Narooma (Yuin)  
Narrabri (Kamilaroi)  
Newcastle (Awabakal)  
Port Macquarie (Biripi)  
Redfern (Eora)  
Tamworth (Kamilaroi)  
Taree (Biripi)  
Walgett (Wailwan)  
White Cliffs (Wandjiwalgu)  
Wilcannia (Danggali)  
Wollongong (Dharawal)

## 2.2 Consultation methodology

In planning and conducting the community outreach consultations three factors were considered:

- identifying and attending community
- principles of consultation
- methods.

### Identifying and attending community

Prior to embarking on the community outreach consultations, key communities were identified according to perceived needs and according to the known Aboriginal population in each area.

Thirty-two consultations across NSW were undertaken between February and July 2005. Consultations were undertaken in the following regions:

**Table 1: ADN Community outreach consultations 2004**

<b>Region</b>	<b>Date</b>
New England and Sydney Metropolitan regions	Feb – March 2004
North West and Far North Coast regions	June 2004
Hunter and mid North Coast regions	July 2004
South Coast region	August 2004
Far West region – part one	October 2004
Far West region – part two	December 2004
Far West region – part three	June/July 2005

### Community outreach consultation principles

In developing the community outreach consultation process the following principles were developed and implemented. The principles included that the consultations needed to be:

- accessible (both in terms of disability and culture)
- culturally sensitive and responsive
- conducted by people with community credibility and respect, and
- conducted in a way that took into account cultural learning.

#### *Culturally accessible*

In order to ensure that the community outreach consultations were culturally accessible, they were conducted in an open forum, devoid of hierarchical elements, respectful of individuals' position in community and ensuring that each participant was given a chance to talk. Wherever possible community elders were directly involved in the consultations. The consultations were held in venues and locations where Aboriginal people felt comfortable. This included venues of cultural significance such as rivers and other significant meeting places.

### *Disability accessible*

All participants were asked what participation supports were required in order for them to participate. These supports were provided including the provision of Auslan interpreters, wheel chair accessible venues and flexible consultation programs and times. A flexible approach also meant that some people were visited in their own homes.

### *Culturally sensitive and responsive*

The consultations were conducted in a way that recognised the status of elders and acknowledged country. Consultation facilitators were briefed and acted in a way that recognised that Aboriginal people had stories to tell that were often painful, as a result (in part) of deep generational trauma. Facilitators acknowledged this. In addition, individual advocacy was provided to participants in order to ensure that some action was taken on matters raised, rather than just using Aboriginal people as a source of information and leaving community with nothing tangible such as information, support or infrastructure to deal with the issues raised.

### *Community credibility and respect*

The ADN Management Committee decided that it was vital that a respected Aboriginal person who had both experience and credibility within Aboriginal communities be contracted to facilitate the community consultations. The Management Committee, after using an interview based selection process, confirmed Wiradjuri woman, Ms Kerry Reed-Gilbert, as the consultant to facilitate consultations. Ms Kim Curtis-Newton, an Awabakal woman with disability facilitated consultations in New England and Sydney Metropolitan regions. In addition, Damian Griffis, Project Coordinator of the ADN and Matthew Bowden, Manager Individual Advocacy, People with Disability Australia co-facilitated a number of consultations and individual interviews across all regions.

### *Cultural learning*

Cultural learning principles were applied in the consultations. These included the principle that people learn from each other as distinct from a 'teacher/student' relationship. Western concepts of health, disability, government and services were perceived to be not always relevant or appropriate to the lives of Aboriginal people with disability.

### **Consultation format**

Consultations were conducted using a 'talking circle' format. The consultations commenced with a welcome to country by either a community elder, if they were available, or by a general acknowledgement delivered by the facilitator.

The consultations commenced with a brief introduction of the purpose and aims for the consultation and an introduction of some of the issues that other communities had raised in previous consultations. Participants were encouraged to speak openly and freely.

The information provided by participants was recorded, however individuals or communities have not been identified in this report to ensure personal confidentiality and protect the dignity of individuals. In addition, particular communities have not been identified because the authors of this report did not want to add to the pre-existing negative perceptions of some communities.

In order to ensure that the project provided Aboriginal people with disability with some meaningful support, individual advocacy was provided. Where a person had a matter that required assistance an appointment was scheduled after the main component of the consultation to discuss the matter in private. The interview constituted a formal intake and was passed onto the Individual Advocacy Unit at People with Disability Australia for follow-up action.

Facilitators were acutely aware that the people present at the consultations represented only those people who could access the event. The vast majority of Aboriginal people with disability remain 'hidden away' because they have great difficulty in leaving their homes because of a lack of accessible transport options or because of a reliance on others for support to access events outside their home. And indeed, many experience acute frustration, and may have completely lost faith in consultation processes, particularly those conducted by government authorities. The majority of communities visited expressed this frustration, commenting that they are tired of people coming to their communities and not delivering or making false promises.

The consultation process concluded with a summary of issues and the provision of information to ensure individual support was available. Participants were informed about what would happen to the information provided. The consultation concluded with recognition and thanks to elders.

### *Impact of Consultations*

Due to the sometimes emotional nature of the consultations, the need to be flexible and the importance of allowing participants to speak freely was central to the success of consultations. The experience of the facilitators in dealing with sensitive and emotive issues also ensured equitable and meaningful participation for all those who attended.

Due to the extent of the unmet need amongst Aboriginal communities in NSW, the degree of frustration and anger among Aboriginal participants was palpable. At times the consultations were highly emotional, indicative of the extent of the fundamental human rights abuses experienced by Aboriginal people with disability and their associates.

A contributing factor to the openness of the consultations was the fact that the funding for the consultations came from the private sector and not the government.

Many Aboriginal participants still feel a deep distrust toward government due to past injustices and this can seriously impact on their willingness to be open and frank about their own or communities' circumstances.

### **3. Findings: Issues raised by Aboriginal people with disability**

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#### **Introduction**

The community consultations and individual interviews elicited a depth and quality of information unlikely to have been gathered in the past. Certainly a literary review of Aboriginality and disability in Australia reveals very little research into this issue.

This project is far and away the most significant undertaken in terms of its geographical reach and also in the depth of its consultation. In many communities discussions on disability were historically significant, as the issues had rarely, if ever been given priority. Furthermore Aboriginal people with disability have never been so directly and comprehensively consulted along with their closest associates. This Findings section provides an analysis of the information gathered. The information is collated and analysed by theme.

In analysing and reporting on this information we have attempted to keep faith with the information that people have provided us with, and have not attempted to dilute or change the core of the issue or the depth of feeling expressed by participants. However, in order to protect privacy and the dignity of individuals, no information that can identify people is included in this section. In addition, we have chosen not to identify specific communities in a way that would contribute to the existing pejorative perceptions of these communities.

#### **3.1 Being an Aboriginal person with disability**

Consultant participants first talked about what it was like to be an Aboriginal person with disability and how this affected their lives. Many participants had experienced discrimination both in terms of their Aboriginality and their disability. Aboriginal people with disability often face multiple layers of discrimination at the intersection of their Aboriginality and disability. If we add further dimensions such as gender or age for example then the degree of discrimination experienced by many Aboriginal people with disability is particularly acute.

Consultation participants indicated that having a disability within Aboriginal communities does not mean that the person with disability will experience the same degree of discrimination within their own community as they would in the wider community. Whilst this has an immediate positive effect in the sense of inclusiveness, it means that in some instances the specific needs that relate to the nature of a person's disability may be overlooked. For example, facilitators experienced several situations where the Aboriginal person with disability lived in a well-supported family or kinship environment where they were valued as individuals; however they did not have access to important aids and equipment to support their disability. There are a range of reasons why this may occur including lack of awareness of what supports may be available, and a view that it is the responsibility of family and other kinships networks to provide support to the individual.

The impact of living with disability as an Aboriginal person relates to the whole of life of the individual. It is not enough to assume that an Aboriginal person with disability simply requires support for one facet of their life. The needs of Aboriginal people with disability are often of a complex nature where longer-term support is required to ensure that there is appropriate and equitable participation both in the wider community and also within their own communities. An Aboriginal person with disability is less likely to be able to access employment and education, for instance, which are fundamental to enabling an Aboriginal person with disability to access the necessary advancements to escape a life of poverty.

The lack of visibility of Aboriginal people with disability within some communities means that they can literally be at the margins within their communities and the wider community. However this is more about the capacity of Aboriginal people with disability to access their community as opposed to any sense that their communities are shunning them. A common problem is the fact that many Aboriginal people with disability cannot simply leave their own homes because they are confined by poor egress from their own homes or do not have the necessary aids and appliances to leave their own homes and access the wider community. This can create a situation where the Aboriginal person with disability is totally dependent on support from their immediate family and kinship relations. Whilst this in many instances is entirely consistent with cultural responses to supporting individuals in need within a community it can result in a heavy burden for immediate family and other kinship relationships. The carer or carers then face their own significant difficulties that can result in themselves also being marginalised from the wider community.

Many consultation participants indicated that there are various reasons why they may not identify as having a disability. Amongst the most fundamental of reasons for choosing not to identify is the potential for further discrimination. Aboriginal people are frequently discriminated against because of their race. Therefore, unwillingness to self-identify another potentially discriminatory aspect of one's life has led to the under reporting of disability in Aboriginal communities.

Furthermore, ideas of disability in some instances can be constructed differently in Aboriginal communities. There is a focus on physical or visible types of disability at the expense of recognition of mental illness as a type of disability. This can result in a serious under reporting of disability in some communities, which can lead to a perception by government authorities or non-government agencies that disability is not a significant issue within Aboriginal communities.

Due to the sometimes sensitive nature of discussions about disability in some communities, it is important that any discussion of disability focus upon the human rights and resultant entitlements for the Aboriginal person with disability. The traditional labels of disability be they physical, intellectual, psychiatric, sensory, acquired brain injury or other forms of disability descriptors are problematic when discussing disability in Aboriginal communities. This is because Aboriginal people do not use such ways of describing members of their communities. There are several reasons for this including the fact that disability is not an unusual experience in Aboriginal communities. That is to say, the prevalence of disability

is such that having a physical impairment or a psychiatric disability is seen as not such an unusual occurrence. Associate Professor Lindsay Gething states in the *Aboriginal and Islander Health Worker Journal*:

The concept of disability is often not relevant in the Aboriginal context. In the eyes of the Aboriginal community, issues associated with discrimination and disadvantage from being Aboriginal are more important than disability ..... Problems associated with disability are widespread and accepted as part of life; they are so vast yet secondary to being Aboriginal or of Torres Strait Islander background that they do not rate a mention on any agenda of priorities or needs..... Poor living conditions and their consequences are a common element with the Aboriginal experience.<sup>5</sup>

### *Policy Implications*

- Policymakers need to recognise the multiple barriers that Aboriginal people with disability face in their meaningful participation in their own communities and the wider community.
- Policymakers need to appreciate that Aboriginal people are very reluctant to identify as having a disability because of the implications of such a label.
- Respect for the way Aboriginal communities discuss, understand and construct disability. Learn from Aboriginal communities the positive way in which disability is viewed.
- Allocation of more funds is required to enable better resourcing of existing Aboriginal Home Care services and the establishment of newer Aboriginal-run services that can support or complement the support provided by carers, be they immediate family members or wider kinship relationships.

## **3.2 Cost of disability**

The vast majority of Aboriginal people with disability cannot afford even the most basic aids and appliances. Furthermore many Aboriginal people with disability simply do not know where or how to access aids and appliances. Aboriginal people with disability living in remote and rural communities often have costs associated with their disability that are in addition to the costs that a person with disability would experience living in the city. For example, an Aboriginal person with disability living in a remote community in NSW may be up to an hour away from the nearest grocery store or they may be further away from the nearest significant medical facility. The costs associated with delivering an aid or appliance to a person with disability may also be a factor in getting such devices to an Aboriginal person with disability.

### *Policy implications*

- More funds and resources need to be made available by NSW Health to address critical shortage of appropriate aids and appliances to improve access within communities.

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<sup>5</sup> Narration by Associate Professor Lindsay Gething that appeared in the *Aboriginal and Islander Health Worker Journal* Volume 18 No.3, May/June 1994, pp 30 and 32

- Subsidy schemes need to be established to ensure that Aboriginal people with disability and their associates have equal access to aids and appliances. Significant investment is required in this area.

### **3.3 A voice of our own: Competing priorities**

Aboriginal people with disability who participated in the consultations frequently voiced frustration at having to compete with a range of other issues that confront Aboriginal communities. As Aboriginal people, participants indicated that there was so many pressing issues that required their participation that disability issues were often overshadowed by other community priorities. For example, one local community has a well-developed employment strategy for Aboriginal people. However, including people with disability in this strategy took significant time and representation by local people.

Some examples of competing priorities include the land rights movement, primary health, education, employment, housing, the consequences of dispossession, the stolen generations, reconciliation, domestic violence, substance abuse and economic disadvantage. The challenge is for Aboriginal people with disability to be included into the mainstream Aboriginal rights movement. Of course Aboriginal people with disability have needs in each and every one of the aforementioned priority areas including additional needs that are specific to Aboriginal people with disability.

As an earlier paper on Aboriginal disability advocacy points out:

... disability in some cases may not be recognised by Aboriginal people and if the issue is recognised, it is often not seen as a priority. There are only a few organisations and individuals who are placing the issues on the agenda of Aboriginal organisations.<sup>6</sup>

#### *Policy implications*

- Organisations like the Aboriginal Disability Network NSW need to be recurrently funded so that they can educate stakeholders in the wider Aboriginal rights movement about the wants and needs of Aboriginal people with disability.
- A whole of government approach is required to address the needs of Aboriginal people with disability.

### **3.4 Lack of targeted advocacy programs**

Up until the recent past disability advocacy services throughout NSW have been unresponsive to the needs of Aboriginal people with disability. During the consultations Aboriginal people with disability and their associates often expressed complete ignorance of what is advocacy and what advocacy services may be available in their area.

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<sup>6</sup> Smeaton, T. (1996) *A Voice for All; Advocacy for Aboriginal and Torres Strait Islander People with Disability*. Disability Services Aboriginal Corporation: Sydney, page 19.

In some areas advocacy services have been funded to provide a service to Aboriginal people with disability despite the fact that they only have very limited interaction with Aboriginal communities. Aboriginal people with disability and their associates explicitly stated on several occasions that they want to see a 'black face' when they engage with all services including advocacy services.

When developing targeted advocacy programs for Aboriginal people with disability it is important to recognise that the advocacy needs of Aboriginal people with disability are often complex. It is more likely that the advocacy provided will need to be long term with a focus upon the whole of life of the individual. When an offer for individual advocacy support was taken up during the consultation process, it became quickly evident that the advocacy required was likely to be complex and ongoing because this was the first time that an individual and/or their associate had accessed advocacy. Facilitators commonly found that after one person with disability made contact and obtained advocacy support in a community, then others who had an association with that person would come forward to request support.

### *Policy Implications*

- Advocacy services need to undertake a concerted outreach approach to their service delivery, both educating and informing Aboriginal people with disability, their associates and the wide Aboriginal community about advocacy.
- All advocacy services must develop cultural competencies so that they can contribute to meeting the needs of Aboriginal people with disability.
- Significant funding and resources need to be provided to further build the capacity of the Aboriginal Disability Network NSW as well as the Indigenous Disability Advocacy Service (IDAS) so that both organisations can continue to provide an Aboriginal owned and operated service for Aboriginal consumers. New funding needs to be made available to the Aboriginal Disability Network NSW to enable it to continue to perform its systemic advocacy function which at the time of writing continues to be undertaken by members of the ADN's management committee on a voluntary basis.

## **3.5 Housing and accommodation**

### **Aboriginal housing stock**

Aboriginal people with disability, particularly those living in regional and remote communities, often live in inaccessible and poor standard housing. Much of the housing stock built in the 1950s and 1960s is of poor quality and standard. No or irregular maintenance by public housing authorities including some Aboriginal housing providers has also contributed to the pitiable standard. For example, individual instances of compromised electrical wiring, homes with sub-standard flooring and other basic safety concerns were witnessed on dozens of occasions. Also a common complaint was the lack of accessibility of existing housing stock both in terms of entry and egress.

Consultation participants also said that mainstream and Aboriginal housing authorities do not prioritise the availability of accessible housing in regional and remote areas particularly. Entry criteria varies across Aboriginal housing companies, however disability is not high on the agenda, if it is included at all. Regrettably, consultation participants frequently raised the issue of nepotism across all jurisdictions by Aboriginal housing providers. This results in situations whereupon often those most in need are overlooked in favour of Aboriginal people who come from particular family and/or clan group.

### *Policy implications*

- Aboriginal housing providers need to develop disability action plans and policies in consultation with Aboriginal people with disability;
- Aboriginal housing cooperatives and Land Councils should be encouraged to undertake a comprehensive audit of current housing stock to check quality and safety and accessibility;

### **Public housing**

Consultation participants reported inconsistent levels of availability and quality of public housing stock across NSW. For example, in areas where there is a high Aboriginal population, with low socio-economic status, there is simply not enough stock to meet community needs. While there has consistently been a long waiting list for public housing across NSW for the general population, this is compounded in Aboriginal communities.

Some recent initiatives in the Western region of NSW appear very positive in terms of availability and accessibility (both cultural and physical access). The positive outcomes associated with such initiatives should be evaluated for potential replication in other parts of the state.

However, with this exception, participants consistently reported that the design of public housing stock is often culturally inappropriate. Overcrowding is a major issue for large and extended families. Two-bedroom style accommodation (the majority of housing stock available) is also not appropriate for these reasons. In addition, housing policies do not take into account cultural beliefs and traditions such as the importance of families and kinship relations (especially when visiting) and the need for extended periods away from the primary residence.

Some participants expressed frustration in engaging with the NSW Department of Housing (DOH) and the processes around modification and maintenance. Often this was because people were unclear about their rights as tenants. In other instances Aboriginal people with disability and their associates with low literacy did not have appropriate support to complete forms related to applying for tenancy or relevant to their current tenancy situation. On other occasions, participants reported that they believed staff dealt with them differently because they were Aboriginal. This was compounded in that people did not want to make repeated requests for assistance because of their negative experiences with departmental staff. There were numerous examples where Aboriginal people with disability and their associates simply gave up because of repeated negative experiences.

Stories of negative experiences are told and re-told through community and people learn whether based on reality or perception that the NSW Department of Housing (or other departments for that matter) are not supportive of Aboriginal people with disability.

#### *Policy implications*

- The NSW Department of Housing needs to take a more flexible approach to customer service toward Aboriginal customers, including reviewing application processes to improve accessibility.
- Flexible service delivery, cultural competence and disability awareness training should be implemented through all customer service centres of the NSW Department of Housing.

#### **Private housing**

In some rare instances, consultation participants owned their own homes. Some of this housing stock had become available through subsidised home loan schemes for Aboriginal people. These schemes have provided Aboriginal people with disability a measure of housing security. However, consultation participants indicated that because of general levels of poverty within Aboriginal communities, it is not financially feasible to undertake repair to private housing stock.

Many people were unaware of the availability of Home and Community Care (HACC) home modification schemes that may operate locally or the eligibility criteria for accessing this scheme. In addition, this scheme is limited in its criteria by the type of services it can provide and its geographical application, which can discriminate against Aboriginal people with disability living in remote communities.

The unsafe physical nature of some housing stock, whether private or public, also has occupational health and safety implications for service providers. Some service providers reported that they were reluctant to make some home visits because of the poor and unsafe standards of the homes. This has the potential to have occupational health and safety consequences for the service provider, which in turn could mean the withdrawal of service for the client.

#### *Policy implications*

- Information related to HACC funded services needs to be both culturally and disability accessible.
- A focused campaign is required that addresses the safety problems within existing houses.
- Recognition needs to be made that Aboriginal people with disability who own their own homes are also eligible for housing modification programs.

#### **Supported accommodation**

There were a variety of issues and concerns identified by consultation participants regarding supported accommodation for Aboriginal people with disability. This

includes understanding the level of unmet need and the lack of culturally appropriate supported accommodation services available.

There is no systematic data collection on the number of Aboriginal people with disability that are currently living in supported accommodation funded or provided by the NSW Department of Ageing and Disability Services (DADHC). However, anecdotal evidence suggests that very few Aboriginal people with disability access 'mainstream' supported accommodation services.

Furthermore it is clear from discussions with community members that Aboriginal community based supported accommodation options have been provided on an ad hoc basis. At the time of writing there are no Aboriginal specific accommodation services operating in NSW.

Aboriginal owned and operated supported accommodation services were given a high priority as a preferred method of service delivery by consultation participants. Participants indicated that service delivery must be based on the need of the individual and be flexible in the way that support is provided. Participants stated consistently that Aboriginal owned and operated services are the preferred option.

There was a serious reluctance by participants to support the 'group home' model of service delivery. Reasons included:

- Concerns were expressed that the model was restrictive in terms of Aboriginal culture. Aboriginal people with disability living in supported accommodation are often culturally isolated. People are not supported to participate in Aboriginal community events, nor are staff supported to develop culturally competent skills to facilitate this.
- The physical location of most accommodation services is typically a long distance from Aboriginal communities. Family members and kinship networks raised concerns that distances would prevent them from regular contact with the Aboriginal person with disability that uses the service.
- People expressed fear that living in government owned or run accommodation, away from their family and country, was akin to the historical removal of Aboriginal people from their communities.
- Important cultural features are not included in the design of many accommodation services, such as shared common areas – indoor and outdoor.

### *Policy implications*

- There needs to be wide consultation with Aboriginal people with disability on the most culturally appropriate way to deliver accommodation and related support services.
- Best practice in flexible and individualised accommodation and support services needs to be documented and disseminated to service providers.

- A comprehensive and ongoing cultural competence training program must be provided for non-indigenous service providers.

### **3.6 Community care services**

Aboriginal people with disability, their carers and associates consistently raised the issue of a lack of community care services; particularly Aboriginal owned and operated respite and in-home support services. One of the most consistently identified consequences of a lack of community care services is the tremendous pressure placed on carers and kinship networks and the wider Aboriginal community of Aboriginal people with disability. Consistently throughout the consultations participants expressed frustration and anger at the lack of service provision.

With regard to in-home support services, participants indicated that they were not aware of the type and availability of services. Others indicated that there was a serious lack of availability of services. Some participants just 'make do' with family or no support. This severely comprises opportunities and quality of life. In addition, this dependence solely on informal networks for support can place further pressure on family and the wider community's resources. This is exemplified in the case study below.

#### **Case study – in home support services**

*Jason is 14 years old. He is an Aboriginal person with a hearing impairment who is the primary carer of his grandmother Vera, who also has a hearing impairment. Jason's mother has a disability and cannot fulfil her carer responsibility both as a parent to Jason or as a daughter. Jason no longer attends school because of his caring responsibilities. Jason's father is estranged from the family. Jason and Vera were not aware of the availability of community care services, including Home Care that could provide support in the home.*

The lack of respite and other community care services is placing extreme stress on individuals and communities. The incidence of acquired disability amongst carers as a result of stress and other adverse conditions is reported by consultation participants as very high. This is exemplified in the following case study.

#### **Case study – stress on carers**

*Denise is an Aboriginal woman who is foster carer of two Aboriginal children with disability. One child has very high support needs. Denise has been trying for several years to receive one day a week (or less) of respite. Denise's health and relationships are suffering as a result of the stress of caring for the foster children. Denise's expectation of availability of service was high because she lives in a large regional centre. However, the demand for these services is extremely high, to the extent that a respite vacancy has not become available for some time. The*

*likely consequence is that Denise's health will deteriorate due to the stresses associated with her carer role, which will in turn impact on the quality of life of her foster children.*

Those respite services that do exist are often located far away from Aboriginal population centres. Therefore Aboriginal people with disability and their carers have to leave their community to access respite. This presents a problem because of its perception that is not unlike removal practices where Aboriginal people were forcibly removed from their communities. On a practical level it also makes for a serious imposition upon the Aboriginal person with disability and their associates because they may have to travel long distances but without the means or access to transport to do so.

In addition, participants indicated that, where services are available, but are non-Indigenous they were concerned about the lack of cultural competency.

#### *Policy implications*

- A better understanding needs to be developed through community consultation of the respite needs of Aboriginal carers and Aboriginal people with disability.
- Information about respite services needs to be provided accessibly in a way that clearly explains the role of respite services.
- The crisis in the lack of respite and in-home services needs to be addressed with significantly higher levels of funding; including prioritising the establishment of Aboriginal owned and operated services.
- Flexible service delivery and cultural competency training needs to be made available, as a matter of course, to all community care service providers.

### **3.7 Transport**

Many of the communities visited during the consultations have little or no access to public transport. Participants in the consultations identified lack of transport as a major barrier to inclusion in 'mainstream' and their own community activities. For most communities, there was no public transport infrastructure, let alone accessible transport. The consequences of lack of public transport infrastructure, reported by consultation participants included:

- people confined to homes
- no access to employment, education, etc
- poor health outcomes.

In remote communities where there exists no public transport infrastructure, Aboriginal people with disability are reliant on an informal network to support them to travel between communities or to access important services that may be substantial distances from their own communities. For example, while conducting community consultations in remote parts of NSW, facilitators were asked on several occasions to provide assistance to individuals to travel between communities. This reliance on informal networks is indicative of the degree of need for transport. While it may be workable in some circumstances, it highlights haphazard way that Aboriginal people with disability access transport. The

consequence of this is that often people are unable to make and keep appointments and access and maintain employment.

During several of the consultations, participants cited examples of racially discriminatory practices in the delivery of transport services. For example, two community transport service providers have in place practices that treat Aboriginal people with disability differently from other community transport customers. In one regional community in New South Wales Aboriginal people with disability are charged more than non-Aboriginal people with disability to use the community bus. A second provider in a large regional centre ceases its service two kilometres short of the old mission site where the majority of the Aboriginal community lives, thus making it virtually impossible for Aboriginal people with disability to access it. Participants reported they were reluctant to make complaints because they feared that services would be removed altogether.

Participants cited the lack of funding and resources for Aboriginal community transport operators as a major barrier to the provision of accessible transport options for Aboriginal people with disability. Also the need to provide a flexible approach to service delivery so that family members and carers can accompany clients was seen as an issue of major importance. Furthermore the unique nature of community transport in regional and remote communities is such that large distances have to be covered, and this is becoming increasingly expensive with the increase in petrol prices.

Problems have also been identified with the Isolated Patients Transport Scheme (IPTAS). In some situations, IPTAS does not cover people living in very remote parts of NSW. In short, IPTAS does not meet travel from point of origin. In these situations, the onus is on the family of people with disability to transport people from remotes areas to regional centres. As many Aboriginal people with disability do not have access to private or public transport, this seriously compounds their lack of access to health services.

### *Policy implications*

- While there has been a significant community transport investments in regional areas recently by the NSW Government, there remain key areas in the state that require new services, and others that require supplemented services. In this regard, the NSW Ministry of Transport, in conjunction with the Community Transport Organisation, must immediately conduct detailed analysis of community transport needs for Aboriginal people with disability.
- There needs to be a significant investment in generic public transport and community transport throughout regional and remote NSW.
- Racially discriminatory practices of transport providers need to be addressed as a matter of urgency. The Community Transport Organisation must be supported to develop training programs for providers that raise awareness of culturally appropriate practice.
- Anti-discrimination bodies need to undertake outreach information programs to Aboriginal people with disability to inform communities about possible anti-discrimination remedies.

- NSW Health should conduct a review of the Isolation Patient Transport Assistance Scheme so that this program includes supported travel from the point of origin.

### 3.8 Education

Participants reported that disability has, on occasions, been undiagnosed amongst Aboriginal children in primary school. This lack of early intervention relates particularly to children with hearing and vision impairment. The implications of this is that Aboriginal students with disability do not progress through the education system, leave school at an early age or do not engage with the education system at all. A further consequence of undiagnosed impairment is that Aboriginal students are labelled as ‘trouble-makers’ and are being suspended and/or expelled. Facilitators encountered numerous examples where this had occurred. Indeed several priority individual advocacy matters relate specifically to the issue of Aboriginal students with disability being expelled from school.

In situations where impairment has been identified, participants reported that there was a lack of support for Aboriginal students with disability. For example, in rural and remote areas, where the choice of schools is limited, some students did not have physical access (such as ramps), nor were other resources made available to accommodate their needs. This is a contributing factor to high attrition rates of young Aboriginal people with disability from the education system. In addition, lack of accessible transport options was identified as a significant barrier for Aboriginal students with disability wanting to access the education system at all levels.

At the secondary and tertiary levels of the education system the retention of Aboriginal students with disability is very low. There a wide range of reasons for this among those being that many secondary and tertiary institutions may be long distances away from their kinship supports and networks. Some community consultations participants cited the lack of meaningful employment opportunities available to Aboriginal people with disability as a serious disincentive to wanting to progress through the education system.

The authors of this report have noted some positive recent developments that require wider application, in particular the trial scheme operating in NSW that involves Aboriginal people in educational decision making. It is the view of the authors of this report that this scheme could have particular benefit for Aboriginal students with disability, in that parents, advocates and associates of the student with disability could have a direct say in the student’s educational experience.

#### *Policy implications*

- Greater focus is needed on early intervention for young Aboriginal people with disability.
- A concerted strategy is required to assess Aboriginal children’s hearing and vision at the point where they first engage with the education system if a previous assessment has not taken place.
- Mechanisms need to be set up for the direct involvement of parents, carers and other associates of the student with disability in determining their needs, e.g. following recently established models by the Department of Education that give some power to Aboriginal parents/carers about the appointment of school staff.

- Inequities need to be addressed in the provision of transport support for some Aboriginal students with disability.

### **3.9 Health services**

It is a well-documented fact that the health status of Aboriginal people is significantly worse than the mainstream population, comparable to that of many developing countries. With regard to the health status of Aboriginal people with disability the situation is further compounded. The high incidence of diabetes, renal failure, eye and ear problems are prominent examples of this, each of which has disabling effects that restrict the capacity of the individual to meaningfully participate in their communities. With regard to lifestyle diseases and the dramatically adverse impact they are having on Aboriginal communities, it appears that many Aboriginal people simply do not access the health system in any meaningful way until they are in crisis.

The remoteness of some Aboriginal communities presents a significant barrier to the accessibility of health care services for Aboriginal people with disability who may require regular interactions with a health service. The significance of this coupled with a lack of accessible information for Aboriginal people with disability creates very substantial barriers.

During the consultations in the Far Western region facilitators were informed of situations where Aboriginal people who required dialysis had to go to Adelaide for treatment. This meant that whole families had to leave their communities and attempt to re-establish themselves in a foreign environment away from networks and with little or no resources.

As has been documented previously in this report, a lack of accessible transport options for Aboriginal people with disability throughout the state is a major barrier and has direct adverse health consequences because Aboriginal people with disability may not be able to maintain a regular appointment regime.

Facilitators encountered several examples where an Aboriginal person with disability was in fact living in a hospital because there was no other accommodation option for them. This not only has a detrimental effect for the Aboriginal person with disability but it also places undue pressures on resources on the hospital system.

#### *Policy implications*

- All Aboriginal owned and operated health services must be located in accessible premises.
- Lack of accessible transport needs to be recognised as a major barrier to accessing health services.
- Recognition needs to be made that Aboriginal people with disability may have a range of health needs that is not simply about their primary disability but that they may require education and support for a wide range of health issues.

### 3.10 Access to information and advocacy

Consultation participants identified lack of information about:

- what community services are available and the way that services may assist people in their daily lives
- social security rights and entitlements
- rights as service users of community care services and other consumer services.

In addition, participants identified that if there was information available regarding issues and services, this information was often not provided in an accessible manner. This lack of accessibility included lack information:

- at appropriate literacy levels
- in large print, audio, Braille or other alternate formats
- in culturally appropriate ways, including Indigenous images
- in appropriate community languages.

The consultation facilitators identified many Aboriginal people with disability and their families and carers who were not accessing appropriate social security entitlements or who were unaware of their rights to receive income support.

In addition to lack of information about entitlements to income support, participants identified that access to Centrelink offices in regional and remote communities was often difficult due to inappropriate or infrequent operating hours.

Further, participants identified a lack of support for accessing income security. For example, some Centrelink offices do not provide support to clients to complete application forms, particularly in areas where there is low literacy and English language skills.

Participants also identified that Centrelink did not engage proactive strategies to ensure that people are aware of their entitlements. For example, it appeared that there were no outreach services for individuals or Aboriginal specific welfare services to provide information about availability of income support. It was identified that it was not enough to simply produce brochures and expect that Aboriginal people with disability will then want to engage the service. There must be a concerted outreach strategy developed that explains clearly to Aboriginal people with disability their entitlements and rights.

Participants indicated that the attitude of some Centrelink staff prohibited them from making applications for income support or seeking information about change in status or other matters. Participants indicated that on some occasions individuals were banned from accessing the local Centrelink office; this was a relatively common practice in some regional and remote parts of the state. Facilitators were made aware of several examples where Aboriginal people with disability have accumulated very significant debts to Centrelink for breaches. These were due to the nature of their own disability, and/or because their associates had low literacy levels and were not been able to read the documentation that alerted them to their breaches. As a result they simply slid further into debt.

Community based service providers (government and non-government) were also identified as not providing accessible information to local Aboriginal people with disability about availability and accessibility of services. Unfortunately this lack of information provision to Aboriginal communities in some areas of the state is due to the service provider not wanting to engage or not knowing how to engage with the local Aboriginal community.

### *Policy implications*

Centrelink and community service providers need to identify more appropriate strategies for providing information to Aboriginal people with disability about their rights and entitlements to income support. These strategies should include engaging in a culturally appropriate manner with Aboriginal communities.

- All government departments must produce culturally accessible material as a matter of course.
- A concerted outreach strategy is required to ensure that authorities disseminate information by accessing community directly, rather than expecting that Aboriginal people will independently access information of their own accord.
- A cultural shift is required on the part of service providers, both government and non-government, to place the responsibility to be accessible and visible to Aboriginal communities with service providers. This is in opposition to the existing situation that creates the expectation that Aboriginal people will engage with service providers, without recognising that many Aboriginal people lack the confidence, trust or knowledge of how to do so.

## **3.11 Employment**

Consistently, participants in the community consultations referred to the fact that very few Aboriginal people with disability are employed, either in the supported or open employment sectors. There are isolated cases, however, across the state where Aboriginal people with disability participate in Community Development Employment Projects (CDEP) programs or other Aboriginal employment strategies, but this is not a situation that was consistently encountered.

### *Policy Implications*

- A focused employment strategy for Aboriginal people with disability is required.
- Existing Aboriginal employment strategies must address the needs of Aboriginal people with disability.

### **3.12 Discrimination**

In some instances Aboriginal people with disability and their carers experience discrimination in the area of service provision. Some Aboriginal people with disability are not afforded or cannot access the same degree of service as the non-Indigenous population. In some cases, non-indigenous service providers place different conditions upon Aboriginal people with disability.

In addition, some reports were unfortunately received from community members concerning alleged discriminatory practices by Aboriginal service providers, whereupon some people are given priority over other people who may be from a different family, for example.

Some Aboriginal people with disability reported less overt forms of racial discrimination that nonetheless amount to less favourable treatment on the grounds of their race. These reports included:

- situations where Aboriginal associates of a person with disability were not afforded the same degree of support as non-Aboriginal associates of a person with disability
- situations where an Aboriginal person with disability was not afforded the same degree of respect or was spoken to in a way that was patronising and disrespectful. Many Aboriginal people with disability recount this is a regular occurrence however it remains difficult to substantiate as a racial discrimination complaint because of its covert nature.

#### *Policy Implications*

- Both the Commonwealth Human Rights and Equal Opportunity Commission and the NSW Anti-Discrimination Board need to undertake a regular outreach component to their work. That is, they must physically visit regional and remote communities to conduct information sessions and complaint intakes where appropriate.

### **3.13 Aboriginal children with disability**

Consistently, community elders, parents and carers raised concerns about the situations facing Aboriginal children with disability. Several community elders framed their concerns in the following terms: while they are unable to make any meaningful difference to their own situations, they expressed a strong desire to see change happen now so the next generation can have their needs met.

In the area of education facilitators encountered situations where disability was undiagnosed and therefore some children with disability were not receiving any assistance whatsoever. Furthermore there were several incidences where Aboriginal children with disability have been expelled from primary school; in these cases it was apparent that an undiagnosed disability or the lack of accommodation of a child's disability had been a key part of the child's difficulties at school.

Aboriginal children with disability continue to be over-represented in the out-of-home care environment. There are a range of reasons as to why this continues to occur; these include:

- Aboriginal parents/carers feel reluctant to ask for help due to a concern that they may be viewed as bad parents.
- Lack of awareness of what supports may be available; where services do exist they are often not culturally accessible.
- Parents/carers seek help or are identified as needing assistance only when their situation has reached crisis point, at which time it is likely that the child/ren will be removed.
- Lack of sufficient resources to be able to provide a reasonable level of care for their child with disability. Facilitators encountered several examples where the Aboriginal child with disability did not have access to basic aids and appliances or could not access appropriate ongoing medical supports such as regular medications or other medical supplies.
- Traditional family and community structures are seriously fractured, with the result that traditional ways in which support could be accessed are no longer viable.

#### *Policy Implications*

- Significant investment needs to be made to change perceptions that service providers, be they government or non-government, have of Aboriginal communities. This will take a concerted outreach approach on the part of service providers and a long term approach that recognises the need to focus upon developing relationships with Aboriginal communities that are based on trust and equitable partnerships.
- Recognition that Aboriginal parents/carers and Aboriginal communities in general need more resources to be able to meet the needs of Aboriginal children with disability. This includes development of more Aboriginal owned and operated services.
- A focus upon early intervention programs that will address the ongoing problem of Aboriginal parents/carers only engaging with service providers once they have reached crisis point or when their situation has been compulsorily notified.

### **3.14 Mental Health**

The mental health needs of Aboriginal people are vast. The depth of pain and trauma is difficult to quantify. Furthermore Western approaches to mental health have limited experience in addressing profound mental health needs caused by dispossession and removal and the denial of culture. Nor are existing services well equipped to address the inter-generational trauma that is evident in so many Aboriginal communities.

### **3.15 Access to Justice**

Regularly throughout the consultations, situations where Aboriginal people with disability were in contact with the justice system were raised by Aboriginal people with disability themselves and their associates. Regrettably in the majority of cases Aboriginal people with disability and their associates reported a range of negative experiences.

#### **Police**

During the consultations, regardless of the region in which the consultation took place, the issue of mistreatment and harassment by police was raised. Regrettably the tensions between police and some indigenous communities are a real and regular problem. These negative experiences are acute for Aboriginal people with disability, particularly those Aboriginal people who have a mental illness, intellectual disability and acquired brain injury. However, these experiences are not exclusive to Aboriginal people with these disability types.

Allegations of harassment and intimidation remain very difficult to prove, as there is a natural power imbalance between police and some Aboriginal people that is easily exploitable by police who choose to exercise their power by intimidation. In the case of Aboriginal people with mental illness, acquired brain injury or in some cases intellectual disability, it is not uncommon for the police to be the one and only service that they have had interaction with, particularly in regional parts of the state where there may not be mental health teams or other important intervention services. Rather than being referred to an appropriate mental health service for support, Aboriginal people with disability may instead be reported to police and as a result they are immediately incarcerated without any support for their disability. This is not an uncommon experience for many Aboriginal people with disability.

The crisis in mental health services results in people in need being reported to police instead of receiving the vital mental health services that they require. This not only criminalises mental illness but it also places extreme pressure on police and police resources. Aboriginal people with disability such as acquired brain injury through alcohol abuse, for instance, experience such situations across the state where they are immediately, and in some instances repeatedly, incarcerated, with their disability-related needs being continually overlooked.

#### *Policy Implications*

- Police across the state need to be trained in disability awareness.
- Police across the state need to be trained in cultural awareness.
- The crisis in mental health services needs to be addressed urgently. The consequences for Aboriginal people with disability are that they are having inappropriate interactions with the police, as the police are often the first point of contact in crisis situations.
- Significantly more money needs to be invested into mental health service provision to ensure that Aboriginal people with disability receive specialist support for their disability.

## **Law and the courts**

The law and the courts remain amongst the most inaccessible institutions in Australian society for Aboriginal people with disability from both a cultural and disability perspective.

In recent times there has been growing recognition of the cultural inaccessibility of the judicial system and a range of positive alternatives such as circle sentencing has addressed this successfully. However the judicial system still remains inherently inaccessible to Aboriginal people with disability. The judicial system has been historically poor at meeting the needs of people with disability from a range of access perspectives. These include poor physical access to the court including entry and egress from court buildings to the physical inaccessibility of the courtroom itself. For those Aboriginal people with hearing or vision impairment this may go unrecognised by the court and as a result they may miss altogether or significant parts of court proceedings. Furthermore the cognitive abilities of some Aboriginal people with disability may not be properly accommodated.

### *Policy Implications*

- All those employed within the judicial system must access disability awareness training including magistrates.
- A review of access needs in consultation with Aboriginal people with disability needs to take place.
- An access audit of all courts in NSW needs to be undertaken.

## **Incarceration**

Facilitators encountered numerous examples where an associate of an Aboriginal person with disability attended the community consultation because the Aboriginal person with disability in question was incarcerated. The situation in the prison system where an ever-increasing proportion of inmates are people with mental illness or intellectual disability is well documented. The proportion of Aboriginal people with mental illness and/or intellectual disability in the prison system, whilst difficult to quantify, is understood to be higher than that of the non-Aboriginal prison population.

A key contributing factor to this situation appears to be that very few Aboriginal people with mental illness, intellectual disability or acquired brain injury experience any sort of positive interventions by services other than the police service. This is particularly the case in regional and remote communities where there are no mental health services; no specialist services for people with an intellectual disability and no services whatsoever to support individuals who may be substance abusers. As a consequence, some individuals inevitably find themselves in crisis situations before any assistance is provided; this assistance is then invariably in the form of the police who will incarcerate the individual.

## *Policy Implications*

- The provision of mental health services for Aboriginal people needs to be dramatically increased. As it stands there are very few significant targeted culturally appropriate mental health services. Without any meaningful service provision, Aboriginal people with mental illness will continue to be incarcerated when this could be avoided with the existence of appropriate mental health services.
- The same lack of service provision also applies to Aboriginal people with intellectual disability and acquired brain injury.

### **3.16 Cultural competence of non-Indigenous services (service delivery)**

Many consultation participants cited a lack of cultural awareness on the part of non-Indigenous service providers as a significant barrier to accessing such services. There are very few non-Indigenous service providers in NSW that are providing any significant number of services to Aboriginal people. Aboriginal people are far less likely to engage with non-Indigenous services if they perceive or experience the service as lacking cultural competency.

Too many Aboriginal people with disability and their associates have experienced adverse outcomes because of cultural incompetency on the part of non-indigenous service providers. Some non-Indigenous service providers believe that they are entitled or capable of providing a service to Indigenous people without appropriate cultural knowledge and experience. Furthermore some non-Indigenous service providers access funds that are supposed to be set aside for Aboriginal clients by describing themselves as experts in consultation with Aboriginal people; this is clearly incorrect and offensive to many Aboriginal people with disability and their associates.

### **3.17 Lack of political will**

Outside the Aboriginal rights movement, it is evident that there is a lack of political will with regard to Aboriginal people with disability. It is still the case today that many of the most influential people in government have had very limited, if any, experience in spending significant time in Aboriginal communities.

The current Commonwealth agenda of mainstreaming Aboriginal services is particularly problematic when it comes to its consequences for Aboriginal people with disability. As this report has repeatedly identified, there are a wide range of issues that are specific to Aboriginal people with disability and the communities in which they live. Mainstream service providers, and indeed the 'mainstream' in general, simply have little or no experience inter-relating with Aboriginal people, nor do they have a proven track record of meaningful achievement. We only need to look at the damning statistics regarding life expectancy to know that mainstreaming health services or a general will to mainstream Aboriginal people

altogether has an inherently adverse impact on the lives of many Aboriginal people.

Currently, the Federal, State and Territory Governments fund no systemic advocacy or representative organisations for Aboriginal and Torres Strait Islanders with disability. This has a number of very serious implications:

- It is indicative of the serious population group inequity and structural disadvantage that faces Aboriginal and Torres Strait Islanders with disability.
- It perpetuates this disadvantage as there is no specific representative voice for Aboriginal and Torres Strait Islanders capable of arguing for greater equity in the allocation of resources or improved cultural sensitivity and adaptation in policy, program and service design. As other constituency groups do have a funded representative voice, policy program and service priorities tend to be skewed towards those constituencies, further disadvantaging Aboriginal and Torres Strait Islanders with disability.
- It is virtually impossible for Aboriginal and Torres Strait Islanders with disability to influence policy, program and service delivery decisions that affect their lives at a structural or systemic level.
- It frustrates the principle of self-determination and participation that ostensibly underpins policy, program and service developments for Aboriginal and Torres Strait Islander people, including those with disability.

#### *Policy Implications*

- More senior bureaucrats and other senior decision makers such as politicians need to spend more time actively engaged with Aboriginal communities in their community settings.
- Funding needs to be provided to assist ADN NSW to perform a range of advocacy functions including systemic advocacy.

## 4. Summary and recommendations

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This report makes the following substantive recommendations:

- *That quantitative research be immediately undertaken to determine the prevalence of disability in Aboriginal communities nationwide.* This research needs to be administered by Aboriginal people with disability themselves to ensure culturally appropriate delivery.
- *That ongoing qualitative research be undertaken to enable Aboriginal people with disability to have their voices heard and reported to relevant authorities.*
- *That the same communities and additional communities throughout NSW be revisited in 2006 with a view to delivering rights based training informing communities and Aboriginal people with disability directly of their human rights.* This training should address domestic anti-discrimination legislation and international conventions protecting and promoting the human rights of indigenous people and indigenous people with disability.
- *That an ongoing media campaign be undertaken to expose the gross violations of human rights that continue on a daily basis throughout NSW.* This media campaign should respect the cultural norms associated with engagement of media and should not identify communities or individuals in an inappropriate or adverse way.
- *That funds be made available immediately from government to further consolidate the development of the Network.* Several positions are required to move the Network forward. Furthermore, funds should be made available to enable the creation of a systemic advocacy position to continue to lobby relevant stakeholders and advocate effectively changing the system that discriminates against Aboriginal people with disability.
- *That provision be made to support the Aboriginal Disability Network NSW to lead the further development of the National Indigenous Disability Network.* The National Indigenous Disability Network has suffered from a lack of meaningful support from both government and the private sector in its evolution.
- *That a independent review be undertaken into the crisis in Aboriginal housing focusing in particular on the jurisdictional conflicts that are resulting in incidences of favouritism.* Furthermore, the review should identify the quality of housing, the shortage of accessible housing stock for Aboriginal people with disability and the incidence of homelessness within Aboriginal communities. Such a review should be undertaken with the support of key Aboriginal community members who must be used as the facilitators of such consultations.
- *That an independent review be undertaken into the crisis in service provision for Aboriginal people with disability.* The review should consult directly with Aboriginal people with disability and be conducted by respected Aboriginal

community members in an environment where Aboriginal people with disability feel safe to talk openly.

- *That the Department of Ageing, Disability and Home Care review and monitor non-Indigenous disability service providers to investigate their lack of provision to Aboriginal clients particularly in remote and rural settings throughout NSW.*
- *The Department of Ageing, Disability and Home Care make it a requirement of all funded services that all staff be trained in culturally appropriate practices.*
- *That an independent review be undertaken into the lack of accessible transport services for Aboriginal people with disability across NSW.*
- *That a thorough investigation be undertaken into the crisis amongst Aboriginal carers of Aboriginal people with disability in NSW.*
- *That a thorough investigation be undertaken into the health status of Aboriginal people with disability.*
- *That relevant anti-discrimination authorities undertake a regularly concerted outreach approach to their service delivery.*

## References

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SCRGSP (Steering Committee for the Review of Government Service Provision) 2005, *Overcoming Indigenous Disadvantage: Key Indicators 2005*, Productivity Commission, Canberra.

Gething, L., *Aboriginal and Islander Health Worker Journal*, Volume 18 No.3, May/June 1994.

Smeaton T., *A Voice for All; Advocacy for Aboriginal and Torres Strait Islander people with disability*, Disability Services Aboriginal Corporation, Sydney 1996

## Appendices

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### Appendix 1: About the Aboriginal Disability Network NSW

On December 3 1999 the then Commonwealth Minister for Family and Community Services, Senator the Honourable Jocelyn Newman and the then Minister for Aboriginal and Torres Strait Islander Affairs, Senator the Honourable John Herron, jointly announced the formation of a Working Party to provide advice to the government on establishing a National Indigenous Disability Network.<sup>6</sup> The Working Party brought together Aboriginal and Torres Strait Islander people with disability from around Australia including representation from the Torres Strait. The delegates representing Aboriginal and Torres Strait Islander people with disability in New South Wales were Ms Roslyn Sackley and Mr Steve Widders.

The Working Party agreed that one of the fundamental ways that the National Indigenous Disability Network could move forward was to encourage the establishment of networks in each state and territory of Aboriginal people with disability. The strategy chosen to take this forward in New South Wales was to organise a conference that would bring together Aboriginal and Torres Strait Islanders with disability living in New South Wales. Ms Ros Sackley, the New South Wales delegate to the National Indigenous Disability Network, sought the support of People with Disability Australia Inc. (PWD) to help organise the conference. PWD is a leading non-government cross disability rights and advocacy organisation of and for people with disability in Australia.

In November 2002 a Conference of and for Aboriginal and Torres Strait Islanders with disability was held at Gibba Gunyah Stone Quarry Lodge, a conference facility administered by the Tharawal Aboriginal Land Council on the southern outskirts of Sydney. Aboriginal people with disability and Aboriginal service providers who attended came from throughout the state. As the event provided a unique opportunity for Aboriginal people with disability to come together, the Conference had a strong focus on providing information, particularly on services that are relevant for Aboriginal and Torres Strait Islanders with disability. Participants committed to actively working toward the formal establishment of the Aboriginal Disability Network NSW. Various non-government and government agencies were also represented at the Conference.

Delegates at the Conference made a number of recommendations, one of which was the proposal to establish the Aboriginal Disability Network New South Wales with the ongoing support of People with Disability Australia Inc. (PWD). Another key recommendation was the importance for the Network to engage directly with Aboriginal communities from throughout NSW and that funds should be sought to enable this. The Conference also confirmed the selection of a Management Committee of Aboriginal people with disability to oversee the consolidation of the Network.

People with Disability Australia Inc. offered to support the Network's development by bringing to the Network its skill and expertise particularly around funds

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<sup>6</sup> Aboriginal and Torres Strait Islander Commission and National Disability Advisory Council Joint Working Party; *Report on the Establishment of a National Indigenous Disability Network*, December 2000, page 2.

acquisition. PWD in partnership with the Management Committee of the Aboriginal Disability Network New South Wales (ADN) developed a number of funding applications. The focus of the funding submissions was to seek enough funds for the Network to be able to visit communities and gauge from consultations what the priorities and needs are for Aboriginal people with disability in their communities. This information would then be tabulated with a view to firstly publicly raising the profile of disability within Aboriginal communities, secondly to highlight the gross violations of the human rights of Aboriginal people with disability and thirdly to get an understanding of the prevalence of disability within Aboriginal communities.

The Aboriginal Disability Network was successful in accessing funds from the private sector namely the Rio Tinto Aboriginal Foundation and the Westpac Foundation. The funds enabled the Aboriginal Disability Network to engage an Aboriginal consultant to facilitate community consultations. Consultations were held in 30 different Aboriginal communities throughout NSW. The issues identified and prioritised by Aboriginal people with disability who participated in these events make up the content of this report.

## Appendix 2: Consultation Flyer

The Aboriginal Disability Network brings together Aboriginal and Torres Strait Islander people with disability to:

- tell our stories
- give each other support
- to create a voice for positive change
- speak for ourselves

The Network is coming to Moree. We would like to meet with Aboriginal people with disability, their carers and any other interested community members and Aboriginal community workers to talk about the Network.

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### MOREE

**When: Wednesday June 2<sup>nd</sup>, 10am to 3pm**

Free Lunch and Afternoon Tea provided

And

**Thursday June 3<sup>rd</sup>, 10am to 12pm**

An advocate will be available to meet with to discuss any individual matters.

**Where: Moree District Services Club**

**Albert St, Moree**

**Contact:** Damian on Freecall 1800 422 015 or (02) 9319 6622

**Venue is wheelchair-accessible with accessible toilets. Information in other formats is available on request. If you have any special dietary requirements please let us know before the event.**

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**Interpreters:** If you require a sign language interpreter please tell us at least 2 weeks before the event so we can make the necessary bookings.

Supported by



## Appendix 3: The funders



The Rio Tinto Aboriginal Foundation focuses upon improving education and health for Aboriginal people. The Foundation focuses on four key areas: Health, Education, Cultural Development and Sport (where it has a positive effect on one or more of the first three areas).<sup>9</sup> The Foundation has a number of prominent Aboriginal people as trustees.



The Westpac Foundation is a charitable trust, independent from Westpac Banking Corporation. The Foundation provides grants to non-profit organisations. Funding is directed towards early intervention programs and projects that aim to address the causes of social problems in disadvantaged communities, with a focus on literacy/numeracy and the advancement of social and community welfare. Priority is given to initiatives that are innovative, educational, and preventative in approach, replicable, scalable, collaborative and sustainable in the long term.<sup>10</sup>

Insert Westpac Foundation Logo

<sup>9</sup> Source: Information brochure on the Rio Tinto Aboriginal Foundation.

<sup>10</sup> Source: Information on the Westpac website at <http://www.westpac.com.au/internet/publish.nsf/Content/WIWCWF+Funding+priorities>



people with disability

People with Disability Australia (PWD) is a leading non-government cross disability rights and advocacy organisation of and for people with disability. PWD conducts its work at state, national and international level and has significant expertise in projects that focus upon capacity building and community development. Since its creation in 1981 PWD has had an association with the Aboriginal community that has culminated in ongoing representation on the PWD board by an Aboriginal person with disability. Mr Lester Bostock a prominent member of the Aboriginal Disability Network NSW was recently awarded a life membership of PWD.

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