First Submission to the Productivity Commission Inquiry into Disability Care and Support

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About the First Peoples Disability Network (Australia)

The evolution of the First Peoples Disability Network (Australia) as the national peak organisation representing Aboriginal and Torres Strait Islander people with disabilities can be traced as far back as 1999 when the then Department of Families and Community Services with the Aboriginal Torres Strait Island Commission (ATSIC) bought together Aboriginal and Torres Strait Islander people with disabilities from every jurisdiction to discuss the development of a national peak. Over the ensuring ten years the development of the national peak, (the National Indigenous Disability Network (NIDN) as it was then known) faced a number of challenges including the demise of ATSIC which significantly inhibited the further development of the network. Capacity to move forward amongst its leadership was also very difficult as there were no funds available for the NIDN to continue to communicate. As a result membership of the NIDN dwindled to the point where it was no longing functioning in any meaningful way. However with the election of the Rudd government in 2007, members of the Aboriginal Disability Network NSW (ADN) advocated directly to the new Parliamentary Secretary for Disabilities, Mr Bill Shorten MP at which point funds were made available to the ADN to investigate the feasibility of establishing a national peak organisation representing Aboriginal and Torres Strait Islander people with disabilities.

After holding a series of community consultations across the country and two face to face national gatherings of Aboriginal and Torres Strait Islander people with disabilities in April 2010 the First Peoples Disability Network (Australia) (FPDN) was officially named and endorsed as the new national peak organisation representing Aboriginal and Torres Strait Islander people with disabilities. (The FPDN has yet to be officially launched which is scheduled to occur in December 2010, and is currently having its constitution completed with pro bono legal advice).

The FPDN membership is made up of existing state networks of Aboriginal and Torres Strait people living in NSW, Queensland, Victoria and South Australia. As other networks in Western Australia, the Northern Territory and Tasmania continue to build their capacity they will achieve full membership status. The membership structure of the state and territory network differs to that of the national body in that their membership is made up of individual members who are Aboriginal and/or Torres Strait Islander persons with disability or a carer or family member that supports an Aboriginal and/or Torres Strait Islander person with disability.

The FPDN performs the following functions:

- **Systemic Advocacy** using a range of strategies including representation to Federal and state governments on a range of issues effecting the lives of Aboriginal and Torres Strait Islander people with disabilities;
- **Capacity Building**; a key role of the FPDN is support to build the capacity of existing networks as well as supporting the development of networks

of Aboriginal and Torres Strait Islander people with disabilities where they do no currently exist;

- **Research**; the FPDN undertakes much of this work in partnership with relevant authorities such as the Australian Institute of Health and Welfare or by undertaking its own qualitative research on a range of issues. The Executive Officer of FPDN is a current member of the Advisory Board to the University of New South Wales, Disability Studies and Research Centre for example.
- **Education and Training/Community Development**; the FPDN is regularly called upon to provide advice to the non-Indigenous disability services sector on how to provide culturally appropriate service delivery. In addition the FPDN regularly holds community forums throughout Australia on a range of issues as requested or as identified by Aboriginal and Torres Strait Islander communities.
- **Individual Advocacy**; the FPDN is increasingly seen by Aboriginal and Torres Strait Islander communities across the country as a provider of individual advocacy services. This is a major challenge for the FPDN as at the moment it is not currently funded to do such work. However as the profile of the FPDN grows the expectations on part of community that it will provide individual advocacy support also grows. Furthermore it would be negligent of the part of the FPDN for it not to respond to requests for individual advocacy support and it would also seriously effect the FPDN's reputation particularly as an emerging organisation were it to ignore such requests for support. Fundamentally Aboriginal and Torres Strait Islander people with disabilities prefer to engage an Indigenous organisation for support then seek out a non-Indigenous advocacy provider which they may not be aware even exists.

The FPDN currently undertakes it work through a single paid employee and a one-day a week accountant. It has a small pool of volunteers to call upon who largely have other commitments including other employment or issues related to their disability that makes it difficult for them to commit in a regular way.

Introduction

This submission presents the views of Aboriginal and Torres Strait Islander peoples with disabilities in general terms. As detailed consultation with Aboriginal and Torres Strait Islander people with disabilities, their families and carers will commence in September 2010 the First Peoples Disability Network (Australia) will be submitting our major submission at the conclusion of the nationwide consultations. From September 2010 to March 2011 the First Peoples Disability Network (Australia) (FPDN) will consult directly with Aboriginal and Torres Strait Islander people with disabilities their families and carers across all jurisdictions. The FPDN has identified four geographical areas for the consultations;

- Large Regional – general population greater than 5,000 people with a significant Aboriginal and Torres Strait Islander population.
- Small Regional – general population less than 5,000 people with a significant Aboriginal and Torres Strait Islander population.
- Urban – capital cities and other large centres such as Newcastle and Gosford.
- Remote – Communities located 300kms or more from a regional centre.

Schedule for National consultations

Date/s	Location	Large Regional Community	Small Regional Community	Urban	Remote
12th October	Moree	X			
13th October	Walgett		X		
14th October	Dubbo	X			
15th October	Condobolin		X		
25th October	Nyngan		X		
26th October	Wilcannia		X		X
27th October	Broken Hill	X			X
1st November	Yarrabah (Nth Qld)		X		
2nd November	Weipa (Nth Qld)		X		X
3rd November	Thursday Island (Torres Strait)				X
22nd November	Redfern			X	

23rd November	Blacktown			**X**	
24th November	Campbelltown			**X**	
6th December	Gosford			**X**	
7th December	Newcastle			**X**	
8th December	Taree	**X**			
13th December	Tamworth	**X**			
14th December	Armidale	**X**			
31st January	Tweed Heads	**X**			
1st February	Lismore	**X**			
2nd February	Ballina	**X**			
3rd February	Grafton	**X**			
21st February	Perth			**X**	
22nd February	Broome	**X**			
23rd February	Fitzroy Crossing				**X**
14th March	Mt Isa	**X**			
15th March	Dajarra				**X**
16th March	Doomadgee				**X**
17th March	Urandangie				**X**
28th March	Adelaide			**X**	
29th March	Murray Bridge	**X**			
30th March	Port Augusta	**X**		**X**	
4th April	Melbourne			**X**	
5th April	Shepparton	**X**			
6th April	Warrnambool	**X**			

Endorsement of Joint Advocacy Submission

The FPDN endorses all aspects of the joint advocacy submission tabled by the Australian Federation of Disability Organisations and endorsed by a number of state and national disability advocacy organisations. The FPDN in particular supports the seven key principles that the joint advocacy submission articulates. In addition the FPDN also supports the need for a rights based approach with the UN Convention on the Rights of Persons with Disabilities as the framework for any potential new national disability care and support scheme. Furthermore the FPDN supports the establishment of an independent statutory authority to oversee all aspects of the implementation of a potential national scheme, as well as the requirement for such a scheme to have people with disabilities themselves as both the evaluators and implementers.

However the FPDN makes the following general observations in relation to the often unique needs of Aboriginal and Torres Strait Islander people with disabilities.

Firstly, it is well established that Aboriginal and Torres Strait Islander people with disabilities continue to be at the periphery of all aspects of the disability sector. This continues to occur for a range of reasons including:

- A lack of culturally appropriate services;
- A different way in which 'disability' is currently considered in many Aboriginal and Torres Strait Islander communities;
- Lack of a concerted well constructed educative program that includes informing communities of what is meant by the term 'disability'.
- A serious lack of access to information related to all aspects of the disability service sector, including information about rights and entitlements and what the role of the service system is?
- A serious lack of trust of the service sector in general and the resultant lack of engagement with the service sector;
- Lack of targeted individual advocacy services

By any measure Aboriginal and Torres Strait Islander people with disabilities are amongst the most disadvantaged Australians. They often face multiple barriers to their meaningful participation within their own communities and the wider community. The vast majority of Aboriginal and Torres Strait Islander people with disabilities are at the periphery of all aspects of the disability services sector. In accessing individual advocacy services this is particularly acute, despite the fact that in many ways Aboriginal and Torres Strait Islander people with disabilities are the group within the Australian community who are most in need of individual advocacy support.

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.[1]

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[2], and in the care and protection system (both as parents and children).[3]

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.

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.

All of these factors contribute to the fact that disability rights from an Aboriginal and Torres Strait Islander perspective is an emerging social movement. In many ways this social movement is starting from a baseline position.

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[1] Commonwealth Steering Committee for the Review of Government Service Provision *Overcoming Indigenous Disadvantage Key Indicators 2005 Report.* Page 3.6

[2] 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.

[3] *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

Access to Individual Advocacy and Information Services as Integral to a National Disability Care and Support Scheme

It is well established that Aboriginal and Torres Strait Islander people with disabilities face serious disadvantaged, often facing the violation of the most fundamental of human rights such as access to shelter, access to adequate nutrition and access to education. As a consequence many Aboriginal and Torres Strait Islander people with disabilities are in urgent need of advocacy support.

Currently the number of Aboriginal and Torres Strait Islander people with disabilities accessing individual advocacy services is very small. One of the most basic reasons why this continues to occur is that many Aboriginal and Torres Strait Islander people with disabilities do not in fact indentify as people with disabilities. This occurs for a range of reasons including:

- Why would you indentify as a person with disability when you already experience discrimination based on your Aboriginality; i.e. why take on another negative label.
- In traditional language there was no comparable word to disability which suggests that disability may have been accepted as part of the human experience.
- Or in some communities particularly communities that continue to practice a more traditional lifestyle disability may be viewed as a consequence of 'married wrong way.' That is many Aboriginal people with disabilities and their parents and family members experience stigma related to a kind of 'bad karma' type view of disability.
- A predominance of the medical model of disability has had a profoundly negative impact on the lives of many Aboriginal and Torres Strait Islander people with disabilities. Much of the focus on contemporary Indigenous Australia relates to the *Closing the Gap* campaign. This campaign whilst essential often focuses heavily on primary health interventions. This does not address the whole of life needs of Aboriginal and Torres Strait Islander people with disabilities. An example of this includes recognition, rightfully of the high prevalence of hearing impairment amongst young Aboriginal children and a concerted campaign to address this. What tends to happen however is that many Aboriginal children are getting their hearing impairment treated however their accompanying learning disability which has occurred because of extended periods without proper hearing does not get addressed? This results in only part of the job being done, that is a medical intervention has taken place but a 'social model of disability' intervention around the more long term related impairment has not.

In many ways 'disability' is a new conversation in Aboriginal and Torres Strait Islander communities. Put simply in some ways the movement supporting Aboriginal and Torres Strait Islander people with disabilities is not unlike the way disability was viewed in the rest of Australian society some fifty to hundred years ago.

It is the experience of the FPDN that often Aboriginal and Torres Strait Islander people with disabilities require advocacy support for complex matters. What may present initially as a simple matter of supporting an individual to access the Disability Support Pension for instance invariably turns into a matter related to housing, education, employment, access to health services or any number of other more substantive issues.

A major barrier for many Aboriginal and Torres Strait Islander people with disability their families and carers and indeed the wider Indigenous community in which a person with disability may be living is access to information. Throughout Australia the disability system is overly complex. In NSW for example it is possible that a carer or parent of an Aboriginal child with disability may have to deal with as many as six or seven different government departments during the early years of the life of the child. The same sort of scenario is often replicated in other jurisdictions. Many Aboriginal parents and carers or the person with disability themselves may already be reluctant to engage the service sector particularly if it is government operated for reasons that are now well established such as a general distrust of government and this only exacerbated by an overly complex often cumbersome system.

The FPDN argues that the advent of a national advocacy and information program for Aboriginal and Torres Strait Islander people with disabilities is integral to beginning to address unmet need. All the service provision in the world will be rendered meaningless is Aboriginal and Torres Strait Islander people with disabilities their families and carers firstly don’t understand how to navigate it and secondly don’t trust it.

A Way Forward; a Model for Advocacy and Information Service Provision as a way to begin to address unmet needs

The FPDN has been tasked by the Commonwealth to help establish networks of Aboriginal and Torres Strait Islander people with disabilities around the country. At the time of writing there exist networks in Queensland, New South Wales, Victoria and South Australia with each supported to varying degrees with funding from their respective state governments. The FPDN is currently supporting to build capacity for networks to be established in Western Australia, Northern Territory and Tasmania.

Each network has Aboriginal and/or Torres Strait Islander people with disabilities their families and carers as their primary voting members. As a result they are unique organisations in an Aboriginal and Torres Strait Islander context as they are effectively consumer based organisations.

The FPDN argues for a three track approach to address unmet need with each of these functions to become core responsibilities for the FPDN and State and Territory networks.

Track One involves a concerted outreach approach. That is visits to communities to determine unmet need across the country.

Track Two is the development of partnerships with the disability service sector around the country by way of providing cultural awareness training. In addition an evaluation system is developed to determine a services cultural competency. And as a final step the development of Memorandums of Understanding between networks, communities and disability service providers that articulate the practicalities of the partnership in that particular region.

Track Three is to further build the capacity of the FPDN and the state and territory based networks as information providers. To consolidate a detailed database so that the national and state and territory networks can effectively become call centres for Aboriginal and Torres Strait Islander people with disabilities their families and carers to contact. Information provided could include details of an organisations cultural competency to the type of service provided. The FPDN argues strongly that this function must be one of the FPDN and state and territory networks and not a government function because of the well established reasons of distrust of government that still exist in much of Indigenous Australia still today.

Conclusion

To conclude the FPDN asks the Productivity Commission to recognise this submission as a preliminary one. It is not based on any substantive community consultations. A truer picture of unmet need and how it could be addressed through a possible National Disability Care and Support Scheme will be articulated in our major submission which the FPDN will submit by April 2011.