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

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1. Executive Summary

The advent of the NDIS presents an opportunity for Aboriginal and Torres Strait Islander people with disabilities to engage for many for the first time with the disability service system. Currently most Aboriginal and Torres Strait Islander people with disabilities remain at the periphery of the disability service system. This continues to occur for a range of reasons some of which are well established however one factor that remains little understood is the reluctance of Aboriginal and Torres Strait Islander people with disabilities to identify as people with disability. This preference to not identify presents a fundamental barrier for the successful implementation of the NDIS. The First Peoples Disability Network (Australia) (FPDN) argues that it has a central role in addressing not only this fundamental barrier but also in facilitating the roll out of the NDIS more broadly.

The FPDN argues passionately that for positive change to happen in the lives of Aboriginal and Torres Strait Islander people with disabilities the change must be driven by community itself. It cannot be imposed, implied, intervened or developed with well meaning intention from an external service system that the vast majority of Aboriginal and Torres Strait Islander people with disabilities have little or no experience of in the first place.

Throughout many communities across the country Aboriginal and Torres Strait Islanders with disabilities are supported and accepted as members of their communities. However it is the resources to support Aboriginal and Torres Strait Islanders with disabilities that many communities lack. Furthermore the service system tends to operate from a ‘doing for’ as opposed to ‘doing with’ approach which only further disenfranchises communities because they simply do not feel that they can self-direct their future. However the NDIS does have the potential to address some of these concerns by giving Aboriginal and Torres Strait Islander people with disabilities the opportunity to self-direct their funding for instance.

It must be remembered that in many ways the social movement of Aboriginal and Torres Strait Islander people with disabilities is starting from an absolute baseline position. This is reflected in this submission by the fact that very few Aboriginal and Torres Strait Islander people with disabilities have an understanding of the language of the disability service system for example. So it is the view of the FPDN that the application of the NDIS in Aboriginal and Torres Strait Islander communities will need to have a different look and approach to what is advocated for with regard the rest of the Australian population. It may be that the application of the NDIS in Aboriginal and Torres Strait Islander communities takes a longer process. But the FPDN argues that it is critical to get it right as it is the experience of many Aboriginal and Torres Strait Islander people that they are usually the first to be blamed when new programs are not taken up by Aboriginal and Torres Strait Islander people.

The FPDN remains nervous of a scenario down the track whereupon the ‘system’ finally recognises disability as a major issue and acts in an interventionist way that includes the rapid roll out of a program without adequate lead in and consultation. This type of scenario will only further disempower Aboriginal and Torres Strait Islanders with disabilities.

There are currently state based networks existing in NSW, Queensland, Victoria and South Australia and the national body of the FPDN. These networks exist to represent the views of Aboriginal and Torres Strait Islander people with disabilities their families and carers. Each of these networks are the experts in this area yet they all remain seriously under resourced. The FPDN argues that it is these networks who will be the conduits for change not the ‘system’ which in many ways is completely abstract to many Aboriginal and Torres Strait Islander people with disabilities their families and carers.

2. 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 allocate funds 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's vision and objectives are

(a) Representing Aboriginal Persons and Torres Strait Islander Persons with a Disability at a national and international level including:

- being an active member of national organisations relevant to Aboriginal Persons and Torres Strait Islander Persons with a Disability;

- working in partnership with other cross disability national peak organisations and fostering communication and cooperation with these organisations;
- maintaining and establishing partnerships with various Commonwealth authorities;
- representing Aboriginal Persons and Torres Strait Islander Persons with a Disability at international forums and conventions;
- being a member of international networks of organisations representing Aboriginal Persons and Torres Strait Islander Persons with a Disability;
- maintaining a strong political presence by lobbying effectively with Federal Parliamentarians; and
- presenting at industry conferences and other relevant conferences raising the profile of the unmet needs of Aboriginal Persons and Torres Strait Islander Persons with a Disability.

(b) Assisting in the provision of advocacy services for individuals and families of Aboriginal Persons and Torres Strait Islander Persons with a Disability through:

- referring individuals and families to appropriate advocacy organisations;
- providing timely and effective interventions to support individuals and families at their request; and
- providing advice and support to advocacy organisations in relation to Aboriginal Persons and Torres Strait Islander Persons .

(c) Supporting the establishment, development and co-ordination of state, territory and regional Member networks, organisations and bodies corporate with similar objects to the Company through:

- providing advice and training (including advice and training targeted at building capacity); and
- disseminating relevant information to member organisations.

(d) Providing and facilitating advice and training relating to Aboriginal Persons and Torres Strait Islander Persons with a Disability across the disability sector and the wider community sector (including the Aboriginal and Torres Strait Islander sector).

(e) Promoting an understanding and awareness of the rights and issues of Aboriginal Persons and Torres Strait Islander Persons with Disability in communities through actions such as conducting community forums.

(f) Providing expertise to research organisations, and lobbying to include the needs of Aboriginal Persons and Torres Strait Islander Persons of Australia with disability in any relevant research being undertaken by government or tertiary institutions.

(g) Raising funds to further the aims of the Company.

(h) Undertaking all such things as are lawful and conducive to the attainment of the objects of the Company.

(i) assisting in the protection and development of the cultural and spiritual beliefs of the first peoples of Australia with disability;

(j) promoting greater tolerance and respect of the culture of the first peoples of Australia with disability;

(k) helping improve the economic, social and cultural status of the first peoples of Australia with disability;

(l) promoting to government and non-government service providers the needs of the first peoples of Australia with disability;

(m) promoting to government and non-government service providers the medical and healthcare needs of the first peoples of Australia with disability;

(n) advocating on behalf of the first peoples of Australia with disability particularly where their rights have been infringed;

(o) promoting access to proper and adequate representation of the first people of Australia with disability on all bodies which make decisions that affect their lives;

(p) supporting the development and co-ordination of local and regional and state and territory networks of first peoples of Australia with disability;

(q) providing information, advice and practical assistance to any first Australian with disability whose personal circumstances require such services. The services shall not be limited to Members of the network;

(r) fostering communication and cooperation with other community organisations with similar aims;

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**; in partnership with several academic institutions and other relevant research authorities;
- **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 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.

2.1 Current status of Networks across all jurisdictions

Across the country different jurisdictions are at different stages of development in terms of creating and consolidating networks of Aboriginal and Torres Strait Islander people with disabilities their families and carers.

New South Wales

In New South Wales there exists a formally constituted organisation that in 2010 was recognised by the NSW Government as a state peak organisation representing Aboriginal people with disability their families and carers living in NSW known as the Aboriginal Disability Network NSW (ADNNSW). The ADNNSW has been in operation since 2002 and incorporation occurring in 2006. It is currently staffed by 2 people.

Queensland

In Queensland there exists the Aboriginal and Torres Strait Islander Network Queensland (ATSIDNQLD). The ATSIDNQLD is currently auspiced by Queenslanders with Disabilities Network (QDN). The ATSIDNQLD has a part time coordinator to undertake a number of functions but in particular to increase membership of the ATSIDNQLD.

Victoria

In Victoria there is network of Aboriginal people with disability that is still in its infancy. It has a part time coordinator with responsibility for further developing the Network.

South Australia

South Australia has had an active network of Aboriginal people with disability for at least the past ten years. It currently operates primarily as an advisory committee to the South Australian government.

Western Australia

Western Australia has had a loose network of health professionals and other service orientated individuals in operation however it does not operate as a network of Aboriginal people with disability.

Northern Territory

There is no network in existence in the Northern Territory and there remains no political will to support its development despite extraordinary unmet need in the Northern Territory.

Tasmania

In early 2011 the first community consultations were held in northern Tasmania to begin the development of a Tasmanian network.

ACT
There has been no activity undertaken at the time of writing to facilitate the development of network based in the ACT.

Torres Strait Islands
It is the intention of the FPDN to facilitate a stand alone network of Torres Strait Islanders with disabilities. At the time of writing there has been no opportunity to progress it.

3. Endorsement of other submissions

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.

The FPDN also supports and endorses submissions made by People with Disability Australia and Motivation Australia in their entirety.

4. The Lived Experience of Aboriginal and Torres Strait Islander people with disability

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]

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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

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 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. 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.[4]

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.

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

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per 1000 children in the population aged 0 – 17 years) than for non-indigenous children (4 per 1000 children). Pg 9.5

[4] 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.

'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. 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.

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. Furthermore disability is more an impairment based discussion in communities. For example statements like 'does Aunty or Uncle have trouble getting around?' or 'does cousin having trouble understanding?' or 'can't brother hear me properly?' are more likely the ways in which disability is described. That is there is no label of disability but instead a statement on how a person is able or not able for that matter to interact with their own community and the wider community. Describing disability in this way is not done in an offensive or insensitive way but a matter of fact way.

In recent years through the work of such organisations as the Aboriginal Disability Network NSW and other state networks in Queensland, Victoria and South Australia as well as the First Peoples Disability Network (Australia) 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 for instance, 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 wholistic 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.

As this submission demonstrates, 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 which themselves invariably have needs of their own that are not being met. It is a situation that is distressing and inexplicable in such a wealthy country.

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.

Case Study 1

A 25 year old Aboriginal man living in a remote Aboriginal community located approximately 100kms from the nearest regional centre (which itself is a small centre with a population of about 5,000 people). The young man has cerebal palsy. He lives with at least five other family members in a two bedroom dwelling. He lives of the floor that is he eats of a plate on the floor. He crawls around the floor of his house. This occurs not due to abuse and neglect on the part of other family members but because they are simply unaware that there may be technical aids available to assist to enable the young man to join his other family members at the table for meals. There is also reluctance on the part of other family members to seek outside help because they fear that the young man will be taken away to Perth and institutionalised.

Case Study 2

A 47 year old Aboriginal woman with physical disability as well as a long term health condition is admitted to hospital in a large regional centre. She complains about being racially discriminated against with at the hospital. She is not provided with information that she can understand. She is heavily sedated whilst in hospital. She feels that she is not receiving the same level of support as other patients at the hospital. Whilst she feels seriously disempowered to complain she continues to feel discriminated against because of her Aboriginality whilst in hospital. She is eventually discharged from hospital. She returns to her home which she shares with several family members including a family member who is in his early 20's who has a serious mental illness. The nephew continues to be unsupported by the mental health system and his mental health deteriorates. Some six weeks after returning from hospital she is murdered by her mentally ill family member.

Case Study 3

A 23 year old award winning Aboriginal film maker from a small regional centre is a wheelchair user. He has a wheelchair that he was provided with by the government authority four years ago. Due to combination of erosion from the dusty environment he lives in as well as the lack of footpaths his wheelchair is virtually broken to the point where he uses a Coke bottle as a brake. He has been waiting 3 years for his new wheelchair which when it arrives is unlikely to be appropriate for the conditions in which he lives in any case.

5. Violations of the human rights of Aboriginal and Torres Strait Islanders with disability.

It is clear that Australia is in direct violation of virtually all articles contained within the *United Nations Convention on the Rights of Persons with Disabilities* with regard the situation for Aboriginal and Torres Strait Islanders with disabilities. The violations range form the most fundamental of human rights such as the right to shelter and the right to education for example to other articles related to the right to liberty or the right to equal status before the law. Too many Aboriginal and Torres Strait Islanders with disability live in overcrowded or inaccessible housing for instance. Many Aboriginal and Torres Strait Islanders with disabilities have to resort to making their own modifications to their housing in order to make it accessible. Or Aboriginal and Torres Strait Islanders with disabilities are simply homeless. In the area of education it is still the case that Aboriginal and Torres Strait Islanders with disabilities may simply not be attending school. This continues to occur for a range of reasons including that the school system is not able to adequately accommodate the disability needs of some Aboriginal and Torres Strait Islander students particularly those living in regional and remote parts of the country.

Recommendation

- Urgent audit of the lived experience of Aboriginal and Torres Strait Islander people with disabilities against the articles of the UNCRPD.

6. Wholistic and Flexible Approach

To improve the human rights of Aboriginal and Torres Strait Islanders with disabilities will require a concerted wholistic approach on the part of all governments across Australia. A whole of life truly person centred approach that incorporates all aspects of the life of an Aboriginal and Torres Strait Islander person with disability will be fundamental to creating positive change. It is not enough to provide a wheelchair when the community in which an Aboriginal person with physical disability lives in is inaccessible in that it does not have footpaths for instance. Or it is not enough to develop well meaning education programs for Aboriginal and Torres Strait Islanders people with disabilities yet there is not accessible transport available to transport people.

Enabling a truly wholistic approach will often mean that service delivery will have to operate well outside the current parameters of the service system. For example service providers will need to be resourced to be able to provide a transport service in addition to their accommodation or community support service. Furthermore there will need to be a significant 'on call' component for effective service delivery for Aboriginal and Torres Strait Islander people with disabilities. Successfully run programs for Aboriginal and Torres Strait Islanders with disabilities often share a common theme of flexibility. These programs often have individuals who work well beyond what they are funded to do. For example the government worker who transports people to hospital and doctors appointments because they know that they are the only possible way that the individual can access the health system. This will often be occurring outside the parameters of their job description.

The rigid nature of the disability service system across many parts of the country is a further fundamental barrier for many Aboriginal and Torres Strait Islanders with disabilities. The idea that the worker clocks off at 5 or that the services only operates strictly within the remit of its funding contract only serve to reduce the confidence of Aboriginal and Torres Strait Islanders with disabilities in accessing in particular the non-Aboriginal service system be it government or non-government.

7. Current Access to the Service System across Australia

The serious under representation of Aboriginal and Torres Strait Islanders with disabilities within the disability service system is a well established fact. This continues to occur for a range of reasons including one’s already outlined such as the lack of self-identification as a person with disability and the preference for communities themselves to be responsible for providing support to Aboriginal and Torres Strait Islander people with disabilities. Access to disability services will only improve if the following occurs:

1. Non-Aboriginal and Non-Torres Strait Islander services become more culturally aware;
2. Aboriginal and Torres Strait Islanders with disabilities, their families and carers become confident in using the service system including developing an understanding of the language of the disability service system.
3. Aboriginal and Torres Strait Islander with disabilities are fully cognisant of their rights and entitlements and are able to assert their rights.
4. And disability services have Aboriginal and Torres Strait Islander working within them.

7.1 Regional and remote access to Services

Access to disability services varies wildly across the country. It is true however that the provision of disability services in remote parts of the country remains a major challenge for service providers. There are the well known challenges involved with sheer distance but in many remote communities there are also issues that are often unique. For many remote communities do not have the most basic of infrastructure such as accessible footpaths. Or some remote communities encounter particular challenges when the wet season arrives. It is not uncommon to hear of stories where Aboriginal people with disability remain housebound for long periods during the wet season because they simply cannot get out of their homes. Or homes may have to be built on stilts to deal with flooding however they are not made with portable ramps. Or many remote communities have to rely on charter planes for instance that are not accessible. Furthermore it is true that there are inevitably greater costs associated with the provision of services in remote communities. However the FPDN believes that with greater investment and recognition of the skills and the roles that many people in remote communities already play many of these impediments can be addressed. That is valuing the work of people within community who by any other definition would be considered qualified support workers.

7.2 Access to services is metropolitan settings

It should be that by definition access to disability services for Aboriginal people with disabilities living in metropolitan areas should be greatly enhanced. There are a number of well run and effective Aboriginal owned and operated organisations that are providing a service to Aboriginal people with disabilities living in metropolitan areas. It is important that the NDIS avoid the tendency to focus primarily on regional and remote communities for Aboriginal people with disabilities and pay limited attention to the needs of Aboriginal people with disabilities living in metropolitan areas. Striking a balance in this regard is a challenge for the NDIS when in many respects the needs of Aboriginal and Torres Strait Islanders with disabilities living in remote communities are so urgent and acute.

8. Systemic Barriers faced by Aboriginal and Torres Strait Islanders with disabilities.

The FPDN argues strongly that without addressing the systemic barriers faced by Aboriginal and Torres Strait Islanders with disabilities the NDIS will not be able to make any meaningful change for Aboriginal and Torres Strait Islanders with disabilities. The NDIS in isolation is not a panacea indeed it has the potential to only further disenfranchise Aboriginal and Torres Strait Islander people with disabilities as it could create another layer of bureaucracy on a system where the vast majority of Aboriginal and Torres Strait Islander people with disabilities are already at the periphery of.

From an Aboriginal and Torres Strait Islander people with disabilities perspective, systemic barriers must be addressed within the framework of the NDIS. These systemic barriers are best addressed by better resourcing the advocacy functions of existing networks of state and territory networks of Aboriginal and Torres Strait Islander people with disabilities. Furthermore the education function of existing and future networks needs to be better resourced to only be able to inform Aboriginal and Torres Strait Islander people with disabilities their families and carers about the NDIS but also crucially about Aboriginal and Torres Strait Islander people with disabilities their rights and entitlements.

Recommendations

- NDIS implementers need to recognise the multiple barriers that Aboriginal people with disability face in their meaningful participation in their own communities and the wider community.
- NDIS implementers need to appreciate that Aboriginal people are very reluctant to identify as having a disability because of the implications of such a label.
- NDIS implementers must respect the way Aboriginal communities discuss, understand and construct disability and be responsive to shape the service system accordingly.
- 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.

9. Interaction between *Closing the Gap* and the NDIS

Members of the FPDN remain thoroughly frustrated and confused as to why the *Closing the Gap* campaign is not addressing disability. Regrettably this is not a surprise however to members of the FPDN. This is because of the aforementioned dominance of a 'medical model of disability'. This is further entrenched by organisations like Oxfam who have no track record nor experience nor any inclination to address disability within their wider work let alone within the *Closing the Gap* campaign.

A couple of case studies that reflect the fact that in the strong opinion of the FPDN that the *Closing the Gap* campaign will be another abysmal failure relate to the following where only part of the job is being done:

Case Study 4

An elder presents at hospital with complications related to his diabetes. He has left it to crisis point before engaging with the hospital system. This is because he does not feel comfortable in hospital settings. As a result of the complications with his diabetes he ends up having an amputation of a leg. At the time of release from hospital he is simply wheeled out the front of the hospital and that's the end of it. He returns to neither a home he no longer get in and out of nor a community he can no longer access because he does not have the appropriate technical aids and housing modifications. He is dead within two years because of his isolation. He has had a medical intervention but nothing to support his resultant physical disability.

10. The critical role of education within the NDIS in creating positive change for Aboriginal and Torres Strait Islanders with disabilities

Education is a critical component of creating positive change for Aboriginal and Torres Strait Islanders with disabilities. Any effective roll out of the NDIS in Aboriginal and Torres Strait Islander communities will be contingent on an effective education campaign. The NDIS is potentially an extraordinary change for most Aboriginal and Torres Strait Islander communities. Indeed most Aboriginal and Torres Strait Islanders with disabilities have not been a part of the current service system in the first place. This perversely presents an opportunity if the roll out of the NDIS in Aboriginal and Torres Strait Islander communities is done properly.

Recommendation

The first step is a concerted nationwide education program run by existing networks of Aboriginal and Torres Strait Islander people with disabilities. This roll out cannot be done by government authorities if it is to be meaningful and truly successful. Visits to communities by government authorities armed with a disability jargon that the vast majority of Aboriginal and Torres Strait Islanders with disabilities simply do not understand will not work. To be effective this will require significantly greater funder for existing networks however with proper investment at the outset this will be cost beneficial in that there should be limited need to continue to re-engage communities if communities are well informed and are able to access the NDIS.

11. Access to Individual Advocacy and Information Services as Integral to a NDIS

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.

Recommendation

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 when 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.

12. It’s not always about service provision!

The FPDN remains seriously concerned that the NDIS will potentially create a ‘micro industry’ of service providers who seek to operate in Aboriginal and Torres Strait Islander communities. This will be culturally unsafe for many Aboriginal and Torres Strait Islander communities. Equally the FPDN remains concerned that there will remain a lack of meaningful targeted support only to result down the track in an ‘intervention’ type approach when the often well meaning bureaucracy catches up and recognises ‘disability’ as a major issue in Aboriginal and Torres Strait Islander communities.

The FPDN argues passionately that addressing the unmet needs of Aboriginal and Torres Strait Islanders with disabilities is not simply about providing or creating more services. It is instead about recognising the skills that already exist in communities and in turn building the capacity of communities including the provision of greater resources to effectively and appropriately address the needs of Aboriginal and Torres Strait Islander people with disabilities.

A case study that best illustrates this point

Case Study 5

A remote Aboriginal community with a population of about 80 people includes a number of people with disability including significant numbers of people with physical disability. When the Aboriginal Disability Network NSW visited this community and reported back to government the unmet need in this community the government response was to immediately plan a HACC program and a range of other government programs. Yet all the community needed and wanted was a wheelchair accessible bus. The accessible bus would enable people to get to the larger regional town some 120kms away to do their shopping and also enable travel further afield for people to attend doctor’s appointments etc. Furthermore there were already several community members who by any other definition were working as support workers. The provision of the wheelchair accessible bus would also easily by any cost analysis and the employment of community members as support workers be a hugely more cost effective approach then funding any number of services to work remotely.

13. Individualised funding and its application in Aboriginal and Torres Strait Islander communities

The FPDN is generally supportive of the principle of individualised funding for the well articulated reasons that many other organisations have advocated. However the FPDN would like to raise a caveat. Regrettably the FPDN is aware of situations particularly in circumstances where an Aboriginal person with disability has received a compensation payment for a motor vehicle accident only for all or most of their funds being 'humbugged' from them. The following case study best illustrates this:

Case Study 6

An Aboriginal woman in her 30's was severely injured as the result of a motor vehicle accident that took place in her remote community. She received a large compensatory payment for catastrophic injury under a motor vehicle accident insurance scheme. When members of the Aboriginal Disability Network NSW met her she was living permanently in a multi purpose health centre. All of her compensation payment had been spent by other family or community members, it was meant to be set aside for her to be able to build an accessible home for herself. Perversely the woman was viewed by most members in the community as someone who had wealth, this is a tragic example of the broader implications of poverty within Aboriginal communities and how a person with disability may at times actually be viewed as someone who has a higher income or potentially greater income then the vast majority of other people in the same community. This is symptomatic of general poverty as opposed to the abuse of the person with disability.

In many ways individualised funding may go against many cultural norms. This is potentially a major issue for the NDIS to resolve in relation to its application in Aboriginal and Torres Strait Islander communities. The 'collective' is often of greater importance in Aboriginal and Torres Strait Islander communities than the individual.

13.1 Co-operatives of Aboriginal and Torres Strait Islander people with disabilities their families and carers

One possible way of addressing some of the inconsistencies associated with individualised funding would be to support the establishment of co-operatives made up of Aboriginal people with disabilities their families and carers. This may have particular relevance in more regional and remote parts of the country where the choice of services may be minimal or even non-existent. Aboriginal and Torres Strait Islander people with disability could pool their funds and with appropriate guidance (say from existing networks of Aboriginal and Torres Strait Islander people with disability) have greater buying power because of greater concentration of funds to purchase services.

Recommendation

- That a feasibility study be undertaken into the establishment of co-operatives of Aboriginal and Torres Strait Islander people with disabilities

14. The role of Networks of Aboriginal and Torres Strait Islander people with disabilities;

Positive change for Aboriginal and Torres Strait Islanders with disabilities will occur through the leadership of Aboriginal and Torres Strait Islanders with disabilities themselves. It is self evident by the lack of uptake of services by Aboriginal and Torre Strait Islander people with disabilities that change led by services be they government or non-government will not be the conduits for change that many may still believe. This is because Aboriginal and Torres Strait Islanders with disabilities either do not understand the language of the disability service system or they do not have confidence in the service system. Those Aboriginal and Torres Strait Islanders with disabilities who are current users of the disability service system have accessed the system more by chance then design. To gain confidence in the service system communities need to learn the language of the service system.

The FPDN believes that the Networks both those currently in operation and other new networks due to come online within the next few years can be the educators when it comes to informing Aboriginal and Torres Strait Islanders with disabilities their families and carers. In addition the networks can be the educators of the wider disability service system particularly in the area of cultural awareness.

Networks critically must be funded also to undertake individual advocacy. Each of the networks also has the potential to act as brokers. That is they could operate as the first point of contact for Aboriginal and Torres Strait Islanders with disabilities. The way a potential brokerage model could work would be

Figure 1

Aboriginal and/or Torres Strait Islander with disability or advocate makes contact with their state based network requesting assistance

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The Network contacts a disability service provider/s on behalf of the Aboriginal or Torres Strait Islander with disability to discuss service options.

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Case Management Conference is undertaken between the Aboriginal and/or Torres Strait Islander person with disability, the service provider and the Network to determine the most appropriate way to proceed

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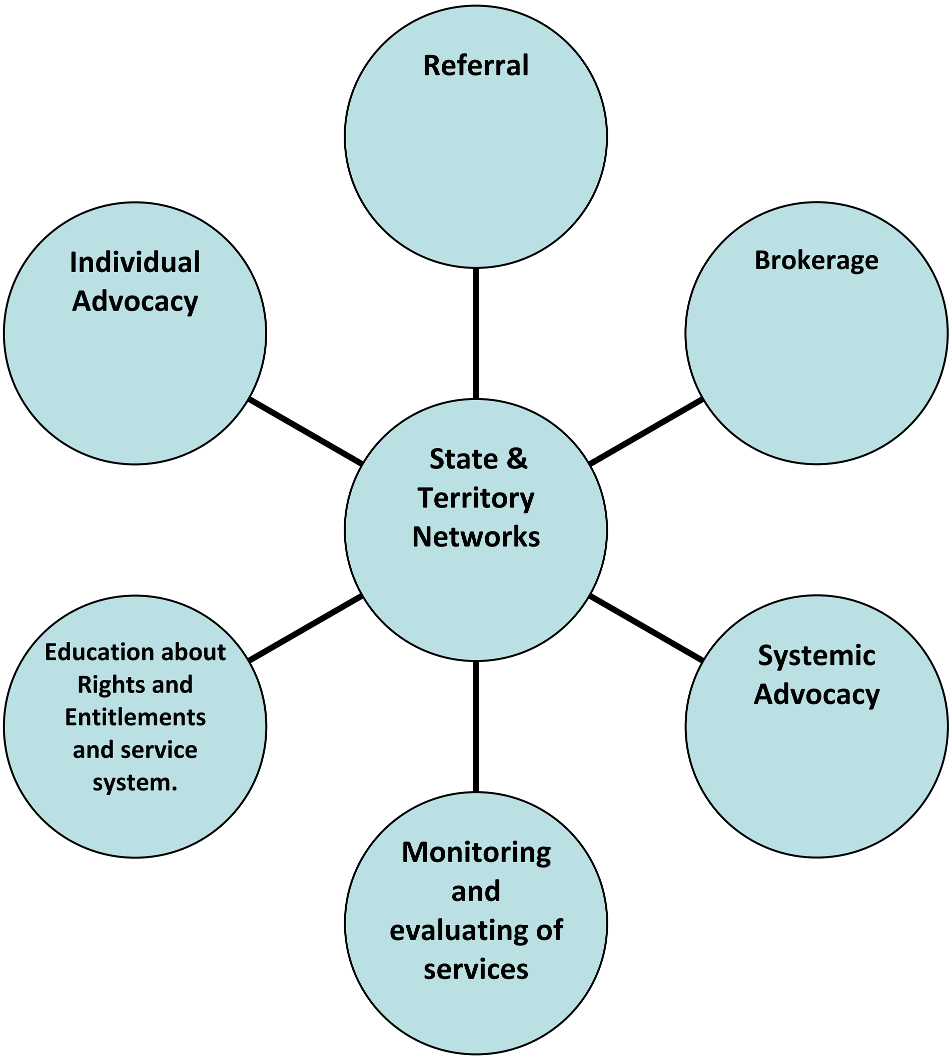
The Network plays an ongoing role in evaluating and monitoring the service delivery.

Figure 2

Role of State, Territory and Regional Networks of Aboriginal People with Disability



15. Building disability services capacity (cultural awareness training)

The FPDN advocates for compulsory cultural awareness training for all stakeholders with the disability service system. The cultural awareness must substantially address the consequences of contact history between white and black Australia including the discriminatory laws that were in place against Aboriginal people and Torres Strait Islanders.

Recommendation

- That the rollout of the NDIS includes compulsory cultural awareness training.
- Those existing and future networks of Aboriginal and Torres Strait Islander people with disabilities are the providers of cultural awareness training. This could be undertaken on a fee for service basis which could potentially create an additional funding source for the networks.

16. Creating a workforce

A major barrier for the successful rollout of the NDIS from an Aboriginal and Torres Strait Islanders with disabilities perspective is the lack of Aboriginal and Torres Strait Islanders who have a professional background in disability. It is a well known fact that Aboriginal and Torres Strait Islanders prefer to use services that have Aboriginal or Torres Strait Islander employees or that are Aboriginal or Torres Strait Islander owned and operated. Currently there are only very small numbers of Aboriginal and Torres Strait Islanders who work in the field of disability. Whilst creating a workforce is not the focus of the NDIS the FPDN believes that a parallel process of supporting the development of an Aboriginal and Torres Strait Islander workforce will be critical to the success of the NDIS for Aboriginal and Torres Strait Islanders with disabilities.

It is the experience of the FPDN that throughout the country those programs that are operate appropriately and successfully for Aboriginal and Torres Strait Islanders with disabilities are often dependent on the goodwill of individuals. In some cases individuals have committed a lifetime working in remote communities with their work often going largely unrecognised. They are often exceptional people who work flexibly outside the constraints of an often inflexible service system. This reliance on individuals is also of major concern to the FPDN and adds weight to the need for a comprehensive strategy to encourage more Aboriginal and Torres Strait Islander people to work in the disability field.

Recommendation

- That the FPDN be resourced to engage with National Disability Services to facilitate the development of a workforce strategy.

17. The Maori experience

The situation for Maori with disability appears to be in complete contrast to that experienced by Aboriginal and Torres Strait Islander people with disabilities. Putting aside the differences that the Treaty of Waitangi has facilitated for Maori there is a fundamentally different respect shown toward Maori with disability their families and carers. In particular great respect shown for their capacity to most appropriately meet the needs of their own people with disabilities. In New Zealand there is a substantial nationally focused organisation providing accommodation and community support programs for Maori with disability. The organisation took some 25 years to evolve but throughout is development it was never threatened with defunding nor did the program guidelines change depending on which political party was in power, instead their was a recognition and respect shown that logically Maori people are the most appropriate people to be providing and designing support for Maori with disabilities. This respect on the part of relevant authorities as well as the conviction of Maori with disability and their families to self-determine their future has seen the development of a Maori owned and operated service system that is the envy of those Aboriginal people with disability who have had the opportunity to witness its operation firsthand.

Recommendation

- That comprehensive comparative study be undertaken to analyse the difference between the experience for Maori with disability and Aboriginal and Torres Strait Islanders with disabilities.

18. Research

It is clearly evident that there remains a serious lack of research into disability in Aboriginal and Torres Strait Islander communities. With regard the NDIS the FPDN advocates for further research into how the NDIS will be applied for Aboriginal and Torres Strait Islanders with disabilities. The fact remains that the NDIS remains a largely abstract concept for the vast majority of Aboriginal and Torres Strait Islander people with disabilities their families and carers. Throughout the consultation process for this submission the NDIS was a difficult concept to describe too many Aboriginal and Torres Strait Islanders with disabilities. This was often for the simple reason that the vast majority of Aboriginal and Torres Strait Islanders with disabilities are currently outside the service system in any case.

19. Implementation of the NDIS for Aboriginal and Torres Strait Islander people with disabilities

For the purposes of this submission the FPDN provides comment on the Productivity Commission's recommendations on implementation of the NDIS as described in Chapter 17, Volume 2 of the Commissions Draft Report. The Commission's recommendations for implementation of the NDIS are broadly supported by the FPDN however the FPDN would like to make the following observations to ensure that the needs of Aboriginal and Torres Strait Islander people with disabilities are met appropriately.

The FPDN supports the proposal for a COAG taskforce to oversee the preparatory component of the NDIS. The FPDN however remains seriously concerned about the lack of expertise on the particularly needs of Aboriginal and Torres Strait Islander people with disability in such a taskforce.

19.1 Data

The Commission describes the need for data as a key feature of the preparatory stage. What concerns the FPDN in this regard is the lack of reliable data on the prevalence of disability in Aboriginal and Torres Strait Islander communities let alone any other relevant data.

Recommendation

- The FPDN must be consulted by the COAG taskforce to ensure that the particular needs of Aboriginal and Torres Strait Islander people with disabilities are understood including the most appropriate way to collect relevant data.

19.2 Assessment

Preparatory work on the assessment component of the NDIS is also an area of major concern to the FPDN. Many submissions have raised concerns about the assessment tool that may be activated for the NDIS. However the FPDN has some particular concerns regarding assessment these include:

- Many Aboriginal and Torres Strait Islander people fear being assessed. It has the potential to conjure memories of the days of the stolen generations or raise fears that of being 'checked up on' particularly by government authorities.
- Assessment must occur in community settings, particularly in remote and regional communities so that the sometime acute needs related to isolation can be best assessed.
- Ideally assessment should be undertaken by Aboriginal and Torres Strait Islander people particularly where there may be language issues

however there is a significant lack of enough Aboriginal and Torres Strait Islander people with a professional background in disability or in relevant allied health professions to undertake such assessments.

Recommendation

- That an assessment tool be devised in consultation with the FPDN and Aboriginal and Torres Strait Islander experts in relevant allied health fields.

19.3 Self-directed funding

The concept of self-directed funding will need to be described in an accessible way for Aboriginal and Torres Strait Islander communities. As outlined earlier in this submission the concept itself may be problematic in some communities particularly those that live in poverty whereupon a person with disability may actually considered to be someone who is in fact wealthier then other members of the community because they at least have access to funds to support their needs.

Recommendation

- That the FPDN be consulted to provide advice on how communities can be educated about self-directed funding.

19.4 Non-government intermediaries

The role of non-government intermediaries in relation to Aboriginal and Torres Strait Islander communities is critical. In fact NGO's are at an advantage for the very reason that they are non-government. Aboriginal and Torres Strait Islander NGO's are at an even greater advantage because they are not tarnished with the connotations associated with government. The best placed NGO's are the networks of Aboriginal and Torres Strait Islander. As described earlier they will need to be significantly better funded to be able to form a range of tasks relevant to the implementation and consolidation of the NDIS.

Recommendation

- Major increase in funding of all state and territory based networks and the FPDN so that they can perform the increased duties as identified by the Productivity Commission such as; informing Aboriginal and Torres Strait Islander people with disabilities about their rights and entitlements; case management and individual advocacy.

The FPDN welcomes the Productivity Commissions recommendations for a stand alone strategy for implementation in Aboriginal and Torres Strait Islander communities. This strategy must involve direct consultation with state and regional networks of Aboriginal and Torres Strait Islander people with disabilities.

19.5 Three Tiers of Support

The FPDN supports the Productivity Commission recommendation that the NDIS provide three tiers of support. However from an Aboriginal and Torres Strait Islander perspective it is likely in the opinion of the FPDN that significant time and investment needs to be applied to the first two tiers. The first tier relating to the promotion of opportunities for people with disabilities will require a concerted outreach approach nationwide for Aboriginal and Torres Strait Islander communities. This will be resource intensive and likely to take up to five years to complete. This is because for Tier 1 to be successful consultation with Aboriginal and Torres Strait Islander people with disabilities and their wider communities will need to be undertaken in community. The FPDN is concerned that there will be a temptation to shortcut this process by instead producing brochures for example that will be meaningless if they are not supported by in person consultation. Such consultations must be undertaken by existing networks of Aboriginal and Torres Strait Islander people with disabilities and not government authorities. Government authorities are not the appropriate body to be undertaking Tier 1 as Aboriginal and Torres Strait Islander communities for the well established reasons related to trust on the part of many Aboriginal and Torres Strait Islander communities.

The same principles apply to Tier 2 of the implementation process in particular the need to have a nationwide concerted outreach approach to information provision.

With regard Tier 3 related to the actual provision of individualised funding supports the FPDN supports the Productivity Commission’s proposal to undertake this component in a staged approach. The FPDN however recommends that an appropriate number of Aboriginal and Torres Strait Islander people with disabilities are included in this initial target group, this group however must include Aboriginal and Torres Strait Islander people with disabilities living in very remote, remote, large and small regional centres as well as metropolitan areas.

19.Summary of Recommendations

- Urgent audit of the lived experience of Aboriginal and Torres Strait Islander people with disabilities against the articles of the UNCRPD.
- NDIS implementers need to recognise the multiple barriers that Aboriginal people with disability face in their meaningful participation in their own communities and the wider community.
- NDIS implementers need to appreciate that Aboriginal people are very reluctant to identify as having a disability because of the implications of such a label.
- NDIS implementers must respect the way Aboriginal communities discuss, understand and construct disability and be responsive to shape the service system accordingly.
- 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.
- The first step is a concerted nationwide education program run by existing networks of Aboriginal and Torres Strait Islander people with disabilities. This roll out cannot be done by government authorities if it is to be meaningful and truly successful. Visits to communities by government authorities armed with a disability jargon that the vast majority of Aboriginal and Torres Strait Islanders with disabilities simply do not understand will not work. To be effective this will require significant greater funding for existing networks however with proper investment at the outset this will be cost beneficial in that there should be limited need to continue to re-engage communities if communities are well informed and are able to access the NDIS accessibly.
- 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 when 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.
- That a feasibility study be undertaken into the establishment of co-operatives of Aboriginal and Torres Strait Islander people with disabilities
- That the rollout of the NDIS includes compulsory cultural awareness training for service providers.
- Those existing and future networks of Aboriginal and Torres Strait Islander people with disabilities are the providers of cultural awareness. This could be undertaken on a fee for service basis which could potentially create an additional funding source for the networks.
- That the FPDN be resourced to engaged with National Disability Services to facilitate the development of a workforce strategy.
- That comprehensive comparative study be undertaken to analyse the difference between the experience for Maori with disability and Aboriginal and Torres Strait Islanders with disabilities.

- The FPDN must be consulted by the COAG taskforce to ensure that the particular needs of Aboriginal and Torres Strait Islander people with disabilities are understood including the most appropriate way to collect relevant data.
- That an assessment tool be devised in consultation with the FPDN and Aboriginal and Torres Strait Islander experts in relevant allied health fields.
- That the FPDN be consulted to provide advice on how communities can be educated about self-directed funding.
- Major increase in funding of all state and territory based networks and the FPDN of Aboriginal and Torres Strait Islander people with disabilities so that they can perform the increased duties as identified by the Productivity Commission such as; informing Aboriginal and Torres Strait Islander people with disabilities about their rights and entitlements; case management and individual advocacy.