



Secretary
House of Representatives Standing Committee on Social Policy and Legal Affairs
Inquiry into Foetal Alcohol Spectrum Disorder
PO Box 6021
CANBERRA ACT 2600

Dear Sir/Madam

About the First Peoples Disability Network (Australia)

The First Peoples Disability Network (Australia) (FPDN) is the new national peak organisation representing Aboriginal and Torres Strait Islanders with disabilities and their families. The FPDN performs a range of functions including:

- Systemic advocacy representing the views of Aboriginal and Torres Strait Islanders with disabilities in a range of forums including providing advice to government;
- Education – with a particular focus on educating both the government and non-government sectors about how to address the unmet needs of Aboriginal and Torres Strait Islanders with disabilities;
- Research – undertaken in a qualitative way on a range of issues impacting on the lives of Aboriginal and Torres Strait Islanders with disabilities;
- Individual Advocacy – this is an unfunded part of our work but relates to providing advice, support and referral for Aboriginal and Torres Strait Islanders with disabilities.

Recognition of FASD as a disability

The key message the FPDN wants to convey in this brief submission is that Foetal Alcohol Spectrum Disorder must be recognised as a disability. By doing so this will potentially afford those people with FASD the human rights protections that are currently prescribed under anti-discrimination law. But also it has the potential to enable people with FASD to access a range of potentially beneficial social programs

such as the proposed *National Disability Insurance Scheme*, particularly for those people with FASD who may have high support needs. The FPDN asserts that FASD is clearly a disability because it can impair the ability of a person to participate in their own community and the wider community. It is important to note that at the FPDN we include people who have a diagnosis of FASD and their family members as members of our organisation.

The FPDN fully supports the *Australian Human Rights Commission (AHRC)* submission particularly in relation to *7.1 Applying a social model of disability* paragraphs 27 to 31.

One of the major barriers facing Aboriginal and Torres Strait Islanders with disabilities more generally and as a result relates to people with FASD is the dominant medical model of disability approach that continues to have a seriously adverse effect on the lives of many Aboriginal and Torres Strait Islanders with disabilities. The dominant medical model approach is a source of significant frustration for the FPDN and is firmly entrenched when it comes to Aboriginal and Torres Strait Islanders with disabilities. This is most clearly evident by the *Closing the Gap* campaign that does not address disability in any meaningful way. So we would be very concerned if a medical model of disability approach was applied to FASD because we would expect that the same problems would present as currently plays out with regards disability more broadly. That is what we continue to encounter are situations where only part of the job is being done because only medical interventions are occurring and not a focus upon the whole of life needs of Aboriginal and Torres Strait Islanders with disability.

By any measure Aboriginal and Torres Strait Islander people with disabilities (including Aboriginal people with FASD) 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.

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

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

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 systems², and in the care and protection system (both as parents and children).³

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 (including the rights of Aboriginal people with FASD) 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.

Our Experiences related to Foetal Alcohol Spectrum Disorder

Over the past decade whilst the FPDN has been in development we have consistently encountered a range of issues related to Aboriginal people who have FASD. Whilst we have not had capacity to address their concerns in any substantive way we have been increasingly concerned about not only the prevalence of FASD but also the lack of a nationally focused approach to address prevention, intervention and management issues. We congratulate the *House Standing Committee on Social Policy and Legal Affairs* for taking this critical step in investigating this critical human rights issue.

From the FPDN perspective FASD has always been a story in communities across the country that people have shared with us. Our engagement invariably has commenced when a family or individual is at crisis point. This may be when a person with FASD has reached an age where they may be interacting adversely with the criminal justice system for example. Or it has occurred when we have met a family where there are a range of behaviours being exhibited by the person with FASD but the individual does not have a diagnosis. Or where a family has simply struggled on their own to best meet the needs of the individual with FASD often with no meaningful support.

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

Prevention Strategies

Clearly FASD is a preventable disability given that it is directly related to the consumption of alcohol during pregnancy. Therefore education is critical in reducing the incidences of FASD. The FPDN recommends several approaches. Firstly using Aboriginal people that have had personal experience of FASD to share their experiences in community settings in the experience of the FPDN would be likely to have a very significant impact. A second approach the FPDN would recommend involves a concerted outreach approach. It is not enough to simply produce brochures in this instance and send them out for distribution; a successful prevention campaign must involve direct consultation with Aboriginal and Torres Strait Islander people in the community in which they live. And thirdly the FPDN supports the advent of a national awareness raising campaign that seeks to inform woman but also importantly men of the dangers of drinking whilst pregnant. The FPDN would see it as a logical extension of the successful anti smoking campaign that there be warnings placed on alcohol labels for example.

Intervention

Intervention related to FASD must adhere to human rights principles as defined in the United Nations Convention on the Rights of People and the *Disability Discrimination Act (1992)*. Clearly the earlier the intervention the better the outcomes for individuals with FASD as has been articulated by several other submissions to this inquiry. The FPDN remains concerned however about how intervention strategies will be successfully implemented particularly in regional and remote parts of the country where the availability of relevant health professionals and therefore access to early intervention therapies is seriously compromised.

It is the understanding of the FPDN that ongoing support is critical to the success of early intervention. For example speech pathology requires ongoing intensive intervention, the FPDN from experience knows that is very unlikely that speech pathology could be provided intensively in regional and remote parts of the country because of a lack of availability. Therefore a critical strategy given the lack of availability of intervention services in regional and remote Australia is to provide families and other community members with knowledge and skills so that they can act as facilitators during the sometimes long periods when specialist services may not be available. The FPDN recommends investment in this sort of approach as a critical way of addressing unmet need in an innovative way.

Management Issues

The FPDN is concerned about access to services for people with FASD particularly in regional and remote parts of the country. The FPDN is aware that across many communities in regional and remote parts of the country there exist no services or very little service provision. This means that in many cases the person with FASD is entirely dependent on family and other community members for support. This often

proves very difficult for families and communities particularly if they lack resources themselves or respite options. The burden of care can often have a seriously adverse effect on family members and in some instances the wider community.

The FPDN is also seriously concerned about the interaction between people with FASD and the criminal justice system. Our evidence is anecdotal but in the experience of the FPDN it is not uncommon to meet Aboriginal people who are either in jail or are in contact with the criminal justice system who it would appear have some form of FASD. Yet it would appear that it is either undiagnosed or simply not identified or adequately supported by the criminal justice system. Invariably the stakeholders within the criminal justice system do not see it as their responsibility to deal with symptoms of FASD. The FPDN is not aware of any quantitative data on the prevalence of FASD amongst the Aboriginal prison population for instance which may serve to highlight the significance of FASD as an issue.

It is clear from our brief submission and from the detailed submissions received by the *House Standing Committee* that much needs to be done to address the unmet needs of people living with FASD. From an Aboriginal perspective this is an urgent social and human rights issue. From the perspective of the FPDN it is critical that people with FASD and the people who support them are afforded the full protections of relevant disability discrimination legislation including the *United Nations Convention on the Rights of Persons with Disabilities*. In addition the FPDN asserts that any response to this issue must firstly come from a person centred social model of disability perspective.

Yours sincerely



Damian Griffis
Executive Officer