nofasard

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Submission to: Senate Select Committee on Regional and Remote Indigenous Communities

Submission from: The National Organisation for Fetal Alcohol Syndrome & Related Disorders (prepared by Sue Miers)

Re: Terms of Reference

This submission will address the impact of Fetal Alcohol Spectrum Disorder (FASD)* in relation to the following Senate Inquiry Terms of Reference

> **The health, welfare, education and security of children in regional and remote Indigenous communities.**

NOFASARD makes this submission based on available evidence, our collective experiences of the impact FASD has on children and family's lives, as well as the responsiveness within communities.

*(**For further information on FASD please see Annexure A)**

Background & Introduction

The National Organisation for Fetal Alcohol Syndrome & Related Disorders (NOFASARD) is a collective of people and agencies with a shared concern about Fetal Alcohol Spectrum Disorder (FASD) and with experience and expertise with regards its prevention and intervention. We are proud to have: Her Excellency Ms Quentin Bryce Governor-General of the Commonwealth of Australia as our Patron.

The people who make up NOFASARD come from within families both Indigenous and non-Indigenous, who are living with a FASD as well as a wide range of professionals involved with health & disability, education, justice, social services and community-based organisations. Approximately 300 individuals currently make up the network, with many of whom disseminate FASD information widely through their own networks.

Our purpose is to connect and inform people and to work collaboratively on the prevention of Fetal Alcohol Spectrum Disorder (FASD) and improve the outcomes for those born affected.

NOFASARD is linked through an email information update service, face-to-face meetings, community and workforce educational activities and international affiliations with organisations including Fetal Alcohol Network NZ (FANNZ) and National Organisation for Fetal Alcohol Syndrome (UK). Further information about NOFASARD can be found on our website at www.nofasard.org.au

Philosophical Statement

The child who has been prenatally exposed to alcohol has the right to honest, diagnostic information that has not been corrupted by ego, social stigma or ignorance by our health professionals. Individuals with FASD and their families have the right to specifically targeted integrated support services implemented by professionals who have a sound understanding of the complex needs of children/adolescents and adults who have this (lifelong) disability.

At a time in history when people with more recognisable disabilities are demanding their rights to be fully participating members of their communities, people with Fetal Alcohol Spectrum Disorders FASD)are still struggling to be understood for the disabilities they have.

Epidemiology of FASD in Australia

To date, Australia has never carried out specific population based studies to ascertain the true prevalence of FASD. Retrospective and Prospective studies have all shown an over-representation of Indigenous children amongst the study cohorts.[i]

A study conducted by Bower et al in 2000 estimated the incidence of Fetal Alcohol Syndrome, (the most visible of the range of conditions captured by the term FASD), in Australia at 0.02 per 1000 live births for non-Indigenous children and 2.76 per 1000 for Indigenous children.[ii] Subsequent studies in the Northern Territory and nationally through the Australian Paediatric Surveillance Unit found similar or lower rates but all authors acknowledge under-ascertainment is likely given poor data quality and the difficulties associated with determining an accurate diagnosis of the full spectrum.[iii]

NOFASARD supports many, many families who are non-Indigenous

The essence of understanding individuals with FASD

Children, both Indigenous and non-Indigenous who are suffering the effects of prenatal exposure to alcohol are not just children whose behaviours are learned and reflective of a chaotic and or abusive home environment.[iv]

FASD is a medical condition. It is a chronic, life-long complex learning disorder with varying deficits in socialization and communication that will be compounded by psycho-social and environmental stressors such as physical abuse and neglect, sexual abuse and multiple foster home placements. In addition to learning disorders, prenatal exposure to alcohol can effect organ & system development and FASD is also linked with neuropsychiatric disorders i.e.– mood disorders, anxiety disorders and regulation disorders of sensory processing. [v]

Irrespective of their outward appearance and/or their IQ (IQ can range from 40-140[vi]) affected children have significant brain damage, are high maintenance and don't generally respond to accepted parenting and/or behaviour modification programmes. Thus, children with FASD are extremely difficult to raise causing stress, confusion and exhaustion for vulnerable parents adding a further burden to already volatile situations.

In the school setting many students with FASD have difficulty developing functional and adaptive living skills. These difficulties relate to limitations in cognitive and language capabilities that in turn reflect underlying neurological impairments. Students may have problems with social communication and complex thinking such as planning ,predicting ,organising and generalising.

Young people with FASD will never be candidates for independent living without intensive, comprehensive support. While empowering people with disabilities is the ultimate goal, sometimes the only way this can be achieved is by structuring their life within certain boundaries to allow the person to be "dependently independent". Support from early adolescence until the mid 20's at the very least is vital to successful transition to adulthood. Maturation is delayed for these young people without lifelong supports in place the affected individual goes into repeated predictable crises that sets them up for a life-time of failure.

We know from international evidence over the past 30 years that FASD is linked to a range of ongoing adverse health, disability and social outcomes, and that failing to address these early and appropriately leads to a wave of secondary disabilities or behaviours such as mental health problems, school failure, trouble with the law and alcohol & drug problems[vii]. These Secondary disabilities have implications across all sectors of government – finance, health, justice, education to name a few. Accordingly, rising numbers in prison population groups, children in care placements, the homeless, those with mental health problems, those experiencing problematic alcohol and other drug use are all indicators of undetected FASD.

We have a situation in Australia where Indigenous people are over represented amongst all of these groupings.

The situation in Australia

Currently in Australia we have a situation where the majority of children, Indigenous and non-Indigenous, who are suffering the effects of prenatal exposure to alcohol are unable to access the services of appropriately trained health professionals for diagnosis and ongoing support and management.

There is no ready access to specialist FASD centres or services and no clear policy direction to address this. The medical profession has received very little information about the disorder in their medical school training, there are no Australian Clinical Guidelines for diagnosing FASD and there are no specially trained multidisciplinary diagnostic teams. FASD doesn't appear on the Government list of registered disabilities and there is no Medicare number for rebate for the diagnosis.

> A recent survey of approximately 1,100 primary healthcare professionals in Western Australia, found there was insufficient knowledge about alcohol and other drug use during pregnancy and only 12 percent of the primary healthcare professionals interviewed were able to correctly identify all 4 criteria for an FAS diagnosis and only 2 percent felt prepared to deal with FAS and most wanted information for themselves and their clients.[viii]

NOFASARD does not believe the situation in any of the other states would differ from the WA findings.

To date, Governments have invested resources in ad hoc, limited public awareness campaigns. They have also relied too heavily on an overworked GP system, overstretched women's and children's hospitals and a limited number of FASD informed paediatricians.

There are few Australian training programs and toolkits to help the large number of NGO service providers which on a daily basis work with people with FASD. There are no special strategies or programs for the large number of people who care for someone with FASD. Population groups at high risk of FASD are not receiving FASD specific intervention strategies. There is no clear government allocation or spending on community based expertise, education and advocacy or FASD specific treatment**.**

FASD is rarely listed as an alcohol related harm and it is not mentioned in most major policy and discussion documents where it should be receiving priority attention e.g.

- AIHW – Report on Australia's Welfare 2007.
- ANCD Report 2007 Drug use in the family: impacts and implications for children) (FASD is not mentioned despite the report claiming that 451,000 children from birth to 12 yrs live in binge-drinking families.
- Health & Welfare of Australia Aboriginal & Torres Strait Islander Peoples 2008 (FASD is not listed under the risks associated with alcohol consumption).
- WA Department of Epidemiology - Impact of Alcohol on the Population of Western Australia (2008).

A recent Swedish study found that prenatal alcohol exposure was predictive of substantially reduced educational attainment, lower earnings and higher welfare dependency rates.[ix] Prenatal alcohol exposure for instance is shown to be predictive of alcoholism in adolescents and adults[x].

Sadly, studies also indicate that individual with FASD are over-represented in the criminal justice system and prisons. A Canadian study of 287 youths remanded for a forensic psychiatric/psychological assessment found 67 of the young offenders (23.3%) had an alcohol-related diagnosis[xi]. Children and youth with an FASD are at increased risk for maladaptive behaviour because of the constellation of brain based disabilities such as poor impulse control, poor reasoning and judgement, abstraction, adaptation, socialisation and their inability to alter behaviour.

However, in Australia, these consequential outcomes are failing to be recognised as disabilities in the wider community. Without efforts to transfer and update the knowledge base around FASD, its effects remain poorly understood by the general public and largely misunderstood or overlooked within the health, education, mental health, disability and justice sectors in Australia, compounding further the problems being experienced.

When acute and chronic needs go unmet, a ‘revolving door’ situation emerges whereby people present seeking help multiple times to multiple agencies. These agencies try to do their best but ultimately fail because the services they offer don’t fit the need and often exacerbate the problem.

Recent evaluative evidence of innovative interventions for children with a FASD, indicate they are effective at improving behaviour and skill levels.[xii] The status quo is costly and ineffective. To redress this will require resources, not to create more and more services but rather to reorient those already there so they can work more effectively for individuals with FASD who have high and complex needs.

Recommendation –

We cannot afford to underestimate the devastating lifelong impact FASD has on all sectors of our society. In order to

- ***Reduce the number of infants born prenatally exposed to alcohol***
- ***Improve quality of life for individuals and families affected by FASD and ensure the health, welfare, education and security of all children including those in regional and remote Indigenous communities***

and as a matter of urgency:

> ***The Australian Government must instigate culturally appropriate initiatives that recognise the importance of addressing Fetal Alcohol Spectrum Disorder at every level - i.e. public awareness and education, surveillance, early identification, diagnosis, intervention and management for both Indigenous and non Indigenous pregnant women and Indigenous and non-Indigenous individuals (of any age) affected by prenatal exposure to alcohol. Broad-based efforts are required, given that this is possibly the most serious and far reaching health problem ever faced by Indigenous and non-Indigenous Australians. Families/carers need training that is specific to FASD., extra support, guidance and respite. It is also imperative that support agencies inclusive of the health, welfare, education and judicial sectors have specific training in FASD issues so that they can provide an appropriate level of support to affected children, adolescents, adults and their families. Grassroots organisations and parents and caregivers who are already dealing with FASD must be given expert status as key informants.***

Failure to act on this recommendation will be in direct breach of **the Convention on Rights of Persons with Disabilities**

The Convention on Rights of Persons with Disabilities Article 25 (ratified by Australia) states:
States Parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. States Parties shall take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation. In particular, States Parties shall: (b) ***Provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities, including among children and older persons;***

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