



Submission to the House of Representatives Standing Committee on Indigenous Affairs

Inquiry into the harmful use of alcohol in Aboriginal and Torres Strait Islander communities

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INTRODUCTION

This document responds to the Terms of Reference of the House Standing Committee on Indigenous Affairs *“Inquiry into the harmful use of alcohol in Aboriginal and Torres Strait Islander communities”* which follow:

1. Patterns of supply of, and demand for alcohol in different Aboriginal and Torres Strait Islander communities, age groups and genders.
2. The social and economic determinants of harmful alcohol use across Aboriginal and Torres Strait Islander communities.
3. Trends and prevalence of alcohol related harm, including alcohol-fuelled violence and impacts on newborns, e.g. Foetal Alcohol Syndrome and Foetal Alcohol Spectrum Disorders.
4. The implications of Foetal Alcohol Syndrome and Foetal Alcohol Spectrum Disorders being declared disabilities.
5. Best practice treatments and support for minimizing alcohol misuse and alcohol-related harm.
6. Best practice strategies to minimize alcohol misuse and alcohol-related harm.
7. Best practice identification to include international and domestic comparisons.

Our submission draws on expertise of the *Lililwan Project* Collaboration to specifically address Terms of Reference 2, 3 and 4. The *Lililwan Project* is Australia’s first population-based prevalence study of alcohol use in pregnancy and Fetal Alcohol Spectrum Disorders (FASD) in remote Aboriginal communities (Latimer 2010; Elliott 2012; Fitzpatrick 2012, 2013; Lucas 2013, 2014). Initiated by Aboriginal communities in the Fitzroy Valley (Kirby, 2012), this project is a collaboration between the University of Sydney Medical School (The Discipline of Paediatrics and Child Health and The George Institute for Global Health) and community-based organisations in Fitzroy Crossing (Nindilingarri Cultural Health Services and Marninwarntikura Women’s Resource Centre). While recognising it is important to progress a national agenda with specific focus on Aboriginal and Torres Strait Islander people, we acknowledge that alcohol misuse is a major problem throughout Australia with significant health, mental health, social and economic consequences (Parliament of Australia, 2012). The harms caused by alcohol, including FASD impact all Australians (Elliott 2008, 2012a). Our experience suggests leaders of Aboriginal and Torres Strait Islander communities are often better informed and more highly motivated than non-Indigenous Australians to prioritise and find solutions to the enormous challenges of alcohol misuse (Gooda 2010, Clark 2011, Elliott 2012a).

RESPONSE TO THE TERMS OF REFERENCE

The social and economic determinants of harmful alcohol use across Aboriginal and Torres Strait Islander communities. (TOR:2)

Background:

The following comments relate to alcohol use in pregnancy by Aboriginal and Torres Strait Islander women, which is where our specific experience and expertise lies. We draw on our experience working with Indigenous women including our participation in the *Lililwan Project*.

Data from the *Lililwan Project* suggests that more than half of the women living in the remote Fitzroy Valley drank alcohol during their pregnancies in 2001 and 2002. Most of the women who drank alcohol did so at high risk levels, posing significant risk to the unborn child (Elliott 2012a).

Prevention of alcohol use in pregnancy and FASD requires an understanding of the social and economic factors that determine why Aboriginal and Torres Strait Islander women drink alcohol during pregnancy. D'Antoine (Personal communication 2014) conducted focus group work with Aboriginal women in three different regions of Western Australia, including the Fitzroy Valley. She identified a number of reasons why women drink alcohol during pregnancy. These include lack of knowledge about potential harms to the fetus and stresses such as unemployment and the need for women from remote communities to travel long distances and live far from their homes and families during the final stages of pregnancy. Other reasons reported by women for drinking alcohol in pregnancy included having a partner who drinks and the stresses associated with domestic violence, loss of traditional land and culture, and the legacy of the 'stolen generation', when children were forcibly removed from their mothers by government authorities. Unresolved historical trauma has been recognised as a major determinant of stress and alcohol use in Indigenous communities worldwide.

Data from the *Lililwan Project* support this work. Of the women in the Lililwan cohort, 100% live in very remote communities and all had to travel over 250kms to give birth. The *Lililwan Project* also provides evidence in this cohort of overcrowded living conditions, low educational attainment, poor access to health care, unemployment, exposure to violence and alcohol use in the home and community and anxiety associated with a shortage of food and money. Children were universally exposed to early life trauma. The *Lililwan Project* thus provides strong evidence of a range of social and economic determinants associated with harmful alcohol use in women, including during pregnancy (The Lililwan Project, Unpublished data).

These findings also support previous work identifying the causal pathway to Fetal Alcohol Syndrome (Elliott & Bower, 2004) and suggest that prevention of FASD will not be achieved without attention from multiple government portfolios to the social and economic determinants of harmful alcohol use across Aboriginal and Torres Strait Islander communities.

Any response directed at reducing the harmful use of alcohol during pregnancy and FASD must have community support, must be developed in true collaboration with Aboriginal communities, and must only be implemented with consent and co-operation of those communities. In 2007 senior Aboriginal women in the Fitzroy Valley prioritised addressing the problems caused by alcohol and identified that:

“The ones who drink are a small group, but the impact is devastating. We are the ones who live with the violence, the suicides. It is our children who are born with Fetal Alcohol Spectrum Disorders. We women and children want a future. We want to move on. Restricting alcohol is the circuit breaker we need.” (Hope 2008; Gooda 2010, Latimer 2010)

Successful research such as the Lililwan Project, government programs and policy involving Aboriginal and Torres Strait communities require that non-Indigenous individuals and organisations form:

“a genuine partnership..with the community, guided by a relationship underpinned by meaningful, respectful engagement and collaboration” (Gooda 2010).

Recommendations:

In order to reduce alcohol use in pregnancy in communities across Australia, including Aboriginal and Torres Strait Islander communities, we must address the social and economic determinants of harmful alcohol use.

We recommend:

1. Introduction of evidence-based strategies to reduce *access* to alcohol.

These include:

- Restricting access to alcohol through limiting the number and restricting the opening hours of alcohol outlets
- Restricting access to alcohol through pricing, including volumetric taxation and minimum pricing
- Reinforcing legislation relating to responsible service of alcohol
- Limiting advertising and promotion of alcohol.

Specifically for **Aboriginal and Torres Strait Islander** communities we recommend:

- Support of community-led interventions to decrease *access* to alcohol, which may include:

- *Restrictions* such as those introduced by the WA Director of Liquor Licensing in Fitzroy Crossing in September 2007 on the sale of full strength take-away alcohol, such that “the sale of packaged liquor, exceeding a concentration of ethanol in liquor of 2.7% at 20 degrees Celsius is prohibited to any person other than a lodger.” (Section 3 WA Liquor Control Act, 1988).

This resulted in a reduction in the sale of pure alcohol from the Crossing Inn (Fitzroy Crossing) from 104 litres/day to 23 litres/day (Hope, 2008). Additionally, there were immediate benefits to the community, including a 36% reduction in alcohol-related presentations to hospital, 28% reduction in alcohol-related offences and a 14% increase in school attendance (Kinnane 2009).

- *Legislation* declaring an Aboriginal community ‘dry’ relevant to states and territories. For example, in 2008 the Wangkatjungka Community in the Fitzroy Valley was the first to be declared an alcohol free community under section 175 of the WA Liquor Control Act (1988). They asked the government to zone it a restricted area, giving police the power to fine people for bringing in alcohol.
2. Urgent provision of funding to support readily accessible, affordable, and culturally appropriate health and mental health services to address drug and alcohol misuse and dependency. For Aboriginal communities, the education and training of local Aboriginal drug and alcohol workers should be a priority.
 3. A whole of government approach to address disadvantage, including through improved housing, health, adult education and training, employment and health literacy.
 4. Support for safe places and refuges to provide accommodation, support and safety for women, including pregnant women and their children.

Trends and prevalence of alcohol related harm, including alcohol-fuelled violence and impacts on newborns, e.g. Fetal Alcohol Syndrome and Fetal Alcohol Spectrum Disorders. (TOR:3)

Background:

Alcohol is a teratogen that may cause a range of lifelong physical and central nervous system (CNS) abnormalities termed Fetal Alcohol Spectrum Disorders or FASD (Astley 2011, Chudley 2005, Elliott 2008).. The most identifiable diagnoses on the spectrum are characterized by a recognisable pattern of facial features, growth failure, and problems with learning, behaviour and development. These include Fetal Alcohol Syndrome (FAS) and partial FAS (pFAS). Alcohol can also damage the developing brain without causing physical or facial abnormalities. These children have learning and behavioural problems and are referred to as having a neurodevelopmental disorder - alcohol exposed or alcohol related neurodevelopmental disorder (Chudley 2005, Fitzpatrick 2012).

The prevalence of alcohol use in pregnancy and harm to the next generation has not been documented in Aboriginal and Torres Strait Islander communities in Australia (Elliott & Bower 2004, Elliott 2008). The most accurate method for establishing FASD prevalence is the use of an active case ascertainment approach and an interdisciplinary health and development assessment in a population based sample (Fitzpatrick 2012). Active case ascertainment is achieved when clinician researchers assess an entire population of children, rather than assessing only children for whom there is some concern regarding alcohol exposure *in utero* or a diagnosis of one of the FASD. Conduct of these studies is extremely difficult requiring highly trained assessors and significant funding and resources.

In 2008, in the Fitzroy Valley of Western Australia, The *Marulu Strategy* was developed by Aboriginal community leaders to address the prevention, diagnosis and management of FASD (Latimer 2010, Gooda 2010, Elliott 2012). As part of this strategy they invited Australian and international researchers to collaborate in Australia's first population-based prevalence study of FASD, known as the *Lililwan Project*. *Marulu* is an Aboriginal word meaning "precious, worth nurturing". *Lililwan* is a Bunuba word meaning "all the little ones".

The *Lililwan Project* is Australia's first population-based study of the prevalence of Fetal Alcohol Spectrum Disorders (FASD) in children living in remote Australia. The *Project* was initiated in the context of findings from a Coronial inquest: (Hope, 2008)

- (i) Increasing concern, as identified in the WA State Coroner's Inquest in 2007, of the harm caused or contributed to by alcohol misuse in the community, in particular, the harm done to Aboriginal children
- (ii) The potential impact of FASD on the continuation of Aboriginal culture
- (iii) Recognition of the lack of community awareness of FASD, in particular, lack of understanding of the lifelong impact these conditions may have on behaviour and learning of children.

- (iv) Recognition of the lack of culturally appropriate service options available for children living with FASD and their carers
- (v) Recognition of the lack of expertise within the community to diagnose and manage children living with FASD and their families.

The *Lililwan Project* was undertaken to provide data to inform the community and state and federal governments to make evidence-based policy decisions, in order to better meet health and service needs of children living with FASD in remote Australia. It will also inform prevention programs urgently needed in remote communities seeking to minimise the harm caused by alcohol to future generations. The Project commenced in 2009 and data on FASD prevalence are currently being analysed.

The high rates of alcohol use documented in women living in the Fitzroy Valley suggest that rates of the prevalence of FASD will be amongst the highest in the world.

Recommendations:

Data from the *Lililwan Project* are likely to be applicable to other remote Aboriginal and Torres Strait Islander communities throughout Australia, in which there has been sustained high level alcohol use. These data support the urgent need for diagnostic and management services for FASD, prevention programs and support for parents and carers. There is also need for education of communities and professionals including in health, justice, education and disability.

With regard to prevention of FASD we recommend:

- Measures to decrease access to alcohol and to address the social and economic determinants of alcohol misuse (see response above to TOR 2 and 3).
- Community-wide public health initiatives to raise awareness of the potential harms of alcohol use in pregnancy including the risk of FASD. These should include both men and women and should commence in school age children. The value of film for education and advocacy has been demonstrated in the *Lililwan Project* and should be considered for use in Aboriginal and Torres Strait Islander communities. Films made in association with the project, including *Yajilarra* (Hogan & Latimer 2008), *Marulu* (Hogan & Latimer 2009), *Tristan* (Hogan & Latimer 2012, Kirby 2012) and the educational DVD, *The Story of Alcohol Use in Pregnancy and Fetal Alcohol Spectrum Disorders* (Hogan & Elliott 2014), have been widely shown and applauded nationally and internationally.
- Targeted education of women of child bearing age.
- Education and support for women who are planning pregnancy and women who are pregnant. Educational materials must be developed in collaboration with Aboriginal and Torres Strait Islander communities to ensure that they are culturally relevant and language specific.

With regard to diagnosis and management of FASD we recommend:

- Improved access to early diagnosis and appropriate management as this has been shown to improve outcomes for children with FASD.
- Routine questioning and documentation of alcohol and drug use during pregnancy.
- Education and training of health professionals working in remote communities regarding the diagnostic criteria for FASD and the health and developmental assessment required to confirm the diagnosis.
- Use of culturally relevant, standardised diagnostic tools for history taking, physical examination and assessment of central nervous system (CNS) dysfunction (Fitzpatrick, 2013).
- Use of an interdisciplinary approach to assessment, diagnosis and management of FASD, as was used in the *Lililwan Project* (Fitzpatrick, 2012). This enables a child to be assessed by a paediatrician and allied health professionals concurrently. It allows for allocation of a FASD diagnosis if appropriate, and exclusion of alternative diagnoses, and for development of an individualised management plan informed by case conferencing involving the entire clinical team. This coordinated approach provides a supportive environment for clinicians and is time and cost efficient.
- A diagnostic and clinical approach that is child-centred, is conducted in a familiar environment such as the community school or health centre, and which enables provision of immediate feedback to families, and with their permission, teachers and local health workers.
- Standardised reporting and recording of diagnoses to enable evaluation of prevalence trends over time and the ability to contribute to state and national registers as they become available.
- Evidence-based treatments for the health and development problems associated with FASD.
- Evidence-based educational and behavioural interventions for use in schools to support children living with a FASD.
- Consideration of alternate pathways of education for children with significant cognitive and behavioural difficulties that focus on a child's strengths as well as their needs.
- Increased availability of paediatric, allied health, psychology, community and remedial education services in order to meet the demands identified in the Lililwan Project. There is evidence that current services are unable to meet the urgent needs of the high numbers of children living in the Fitzroy Valley with chronic and complex health and developmental needs.

With regards to support for parents and caregivers we recommend:

- Evidence-based programs to assist parenting skills, that are tailored to meet the needs of children with a FASD and are feasible for use in remote Aboriginal communities.

- Support of a collaborative community circle of care model, similar to that developed for support of families living with FASD in the Fitzroy Valley communities.
- Maintenance of peer support groups for parents and caregivers that are operating from Aboriginal controlled organisations.

The implications of Fetal Alcohol Syndrome and Fetal Alcohol Spectrum Disorders being declared disabilities. (TOR:4)

There is no doubt that children and adults with FASD may have a range of physical, learning and developmental disabilities. Although all children with FASD will have functional impairment in at least three domains of Central Nervous System function (e.g. communication, cognition, memory, executive function, ADHD) many will not meet the criteria for intellectual disability (IQ \leq 70).

Thus, a person with FASD who has an IQ of >70 , does not have a diagnosed mental illness, but has behavioural and other impairments resulting from alcohol exposure, may not be eligible for income support and services supplied or funded by government.

Lack of recognition of FASD as a disability may also significantly disadvantage individuals who come in contact with the legal system. It may impair the individual's success in the education system and their opportunities for employment (Blake Dawson, 2012).

Our work in the Aboriginal communities of the Fitzroy Valley suggests that families and caregivers are currently receiving inadequate support to care for the chronic complex health, learning and emotional problems faced by children with FASD. Few children receive additional support in the classroom, few receive a government disability allowance and few receive caregiver's allowance.

The implications of declaring FASD as a disability include:

- Better support for families and caregivers.
- Better access to educational and health supports.
- Better understanding of the capabilities of individuals with FASD and their ability to function normally and negotiate the justice and education systems.

Financial and educational support is particularly needed by Aboriginal and Torres Strait Islander children and families living in remote, or otherwise disadvantaged communities.

The issue regarding declaration of FASD as a disability is complex, in light of differing criteria and legislation applicable in different Australian states and territories. The relevance of the National Disability Insurance Scheme in relation to FASD is not clearly articulated.

We support the recommendations made by Blake Dawson in their submission to the HOR Standing Committee on Social Policy and Legal Affairs: people with Fetal Alcohol Spectrum Disorder in the Disability Regime and the Criminal Justice System. Submission No 49, 25th January 2012 (Blake Dawson, 2012).

We recommend that the Commonwealth:

Ensure that the range of disabilities that may be associated with FASD are recognised and clearly described, such that documentation of functional impairment is regarded as sufficient grounds for application and award of disability support even in the absence of intellectual impairment.

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