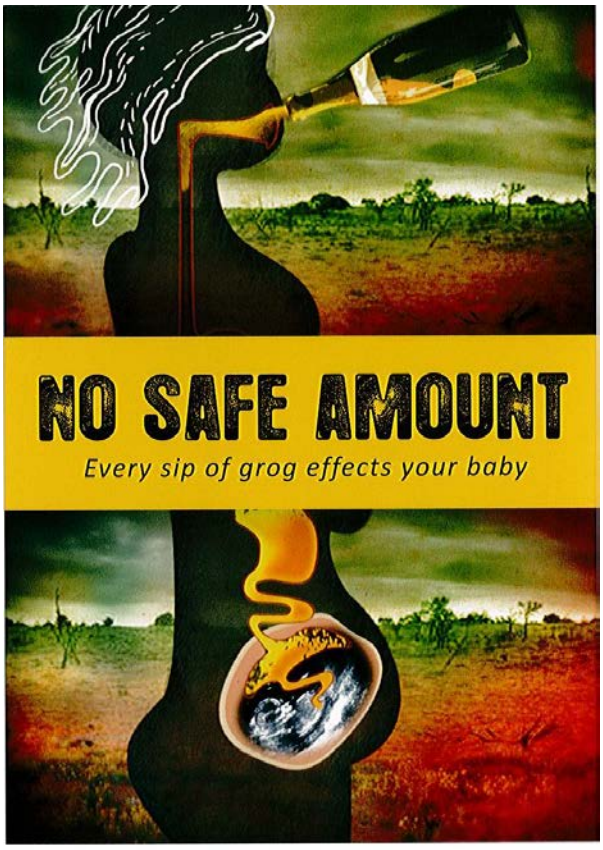
Ngaanyatjarra Pitjantjatjara Yankunytjatjara Women's Council –Aboriginal Corporation

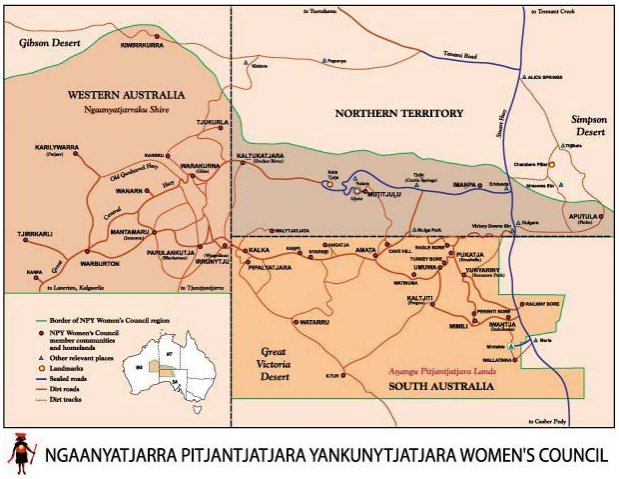
Submission to the House of Representatives Standing Committee on Social Policy and Legal Affairs: Inquiry into Foetal Alcohol Spectrum Disorders



ABOUT NPY WOMEN'S COUNCIL (NPYWC)

The **Ngaanyatjarra Pitjantjatjara Yankunytjatjara Women's Council** is an Aboriginal, community-controlled organisation dedicated to improving the health and well-being of approximately 6000 Anangu (Aboriginal) men, women, and children living in the Central Australian region. Its land covers 350,000 square kilometres of the remote tri-state area of Western Australia, South Australia and the Northern Territory.

NPY Women's Council was formed in 1980 to provide a voice for women in the remote tri-state central desert region and **the members' determination to improve the quality of life for families in the region continues to drive the organisation today**.



NGAANYATJARRA PITJANTJATJARA YANKUNYTJATJARA WOMEN'S COUNCIL

ABOUT NPYWC CHILD NUTRITION & WELL BEING PROGRAM

The NPYWC Child Nutrition and Wellbeing Program primarily aims to support indigenous families in the NPY region to increase their capacity to care for children. The Program provides support, education and early intervention to parents of children aged 0-5 years, and in particular addresses the needs of those children that experience or are at risk of 'failure to thrive'.

The Program focuses on the development and delivery of nutrition and parenting skills workshops to individual referred clients as well as larger community groups. This involves a combination of health promotion and health education strategies alongside intensive case management and support, aimed at providing young mothers with the skills and knowledge necessary to ensure optimum nutrition for their babies and young children. Thereby improving the quality of life within the family unit, building positive family relationships and overall enhancement of general family well-being.

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SUMMARY OF RECOMMENDATIONS

Prevention Strategies

Education and Awareness Campaign - The need to raise awareness of FASD and its lifelong consequences in Central Australia is urgent and must be addressed at both a local and National level. We recommend that the Australian Government as soon as possible invest in a health promotion campaign to highlight FASD as an urgent public health issue, and that any such campaign should include campaigns which are aimed specifically to Indigenous communities.

FASD education for health professionals – There is an urgent need for a greater awareness among health professionals about the effects of alcohol use during pregnancy, particularly about appropriate prevention strategies and ways of supporting a reduction in alcohol use during pregnancy.

Intervention Needs

Recognition of and Support Services for people living with FASD It must be acknowledged that people living with FASD are living with an organic brain injury. As such Governments must provide a greater investment in early intervention programs which provide individual support to people living with FASD and their families. As with other disabilities, early interventions are associated with belter long-term outcomes for those affected. FASD is a significant and permanent disability and as such recognition of and support services should be available for the duration of an affected person's life.

Management Issues

Diagnosis of FASD- resources to enable diagnosis of FASD in Australia are extremely limited and in remote Central Australia virtually non-existent, therefore the provision of diagnostic teams must be of high priority. Further, it is essential that culturally specific diagnostic services are made available.

Invest in community controlled; culturally relevant resources to support families – Severe lack of resources coupled with high levels of social disadvantage creates an overwhelming management burden for families already struggling with significant challenges. Government should urgently invest in resources and in building skills, using a community led approach, to enable communities to best manage FASD over the lifespan of those affected.

SITUATION ANALYSIS –NPY REGION AND ALCOHOL USE

Alcohol is associated with a significant burden of disease for Indigenous Australians compared with non-Indigenous Australians. One in six Indigenous adults report drinking in such a way as to pose long term high risk to their health and one in five report high risk drinking (or binge drinking) at least once a week (Boffa et al. 2009). Indigenous Australians are twice as likely to binge drink than non-indigenous Australians (17% and 8% respectively) (AIHW, 2011) and the pattern of drinking which is most harmful to the foetus is binge drinking (Jones et al. 2006, May et al. 2011).

NPY Women's Council has been concerned about the issue of alcohol consumption during pregnancy for many years. The misuse and abuse of alcohol continues to affect people across Ngaanyatjarra, Pitjantjatjara and Yankunytjatjara communities. The use of alcohol during pregnancy is an important public health and social issue in the NPY region. Amongst people living in the NPY region, binge drinking is often the norm which makes alcohol consumption difficult to quantify in terms of standard drinks. There are currently no or few formal community education initiatives surrounding FASD in NPY communities, despite an anecdotally reported high rate of FASD incidence in the NPY region.

The NPY Women's Council Child Nutrition Program records children born to mothers who are known to use alcohol excessively during pregnancy, and as such considers that there are currently 11 cases of FASD in children under the age of 5 within the NPY region out of our current 128 clients, children suffering with failure to thrive. This equates to 8% of the current client group who are known to have been prenatally exposed to alcohol. We believe this figure is likely to be a gross underestimation of the incidence of FASD given the extent of alcohol abuse in the region. The published rates of FAS in the Northern Territory are 4.7 cases per 1000 live births for Aboriginal women and 0.7 per 1000 live births for non-Aboriginal women (Hunt 2008) The highest FASD rates outside of Australia are in South Africa where the prevalence is 5 cases per 1000 live births (Rothstein J, 2007) (Rothstein, Heazelwood and Fraser 2007). This suggests that the NT has one of the highest incidences of FASD in the world and highlights that FASD is an extremely important

public health issue for the NPY region, and that the case for raising awareness of the dangers of alcohol use during pregnancy is urgent.

The secondary effects of FASD include mental health problems, disrupted school experience, trouble with the law, incarceration, inappropriate sexual behaviour, sexual assault and abuse, alcohol and drug misuse, dependent living and problems with employment, and parenting. These effects are seen widely throughout NPY communities and while FASD is certainly not the only contributor to such problems we believe that given the high levels of alcohol misuse and abuse in the region, FASD is potentially a significant contribution to the problems faced by many young people in the region. The NPYWC Child Nutrition and Wellbeing Program is also witnessing the intergenerational effects of alcohol use during pregnancy with increasing numbers of young people believed to have been exposed to high levels of alcohol in-utero now becoming parents themselves. As those affected by pre-natal alcohol exposure become parents we, having already observed this, anticipate that the need for case management providing intensive parenting support will increase significantly.

PREVENTION STRATEGIES

FAS and all other conditions incorporated under the FASD umbrella term are 100% preventable as long as pregnancies are alcohol free (Floyd, Webber, Denny and O'Connor 2009). Evidence suggests that the level of alcohol use prior to pregnancy is a strong predictor of alcohol use during pregnancy (Day et al 1993, Floyd et al 1999 as cited by Floyd, Webber, Denny and O'Connor 2009). Given the high rates of alcohol use in the NPY Region, alcohol use during pregnancy continues to be an import public health concern. There is an urgent and critical need for evidenced based and culturally appropriate prevention strategies to reduce alcohol-exposed pregnancies in the NPY region. Moreover, there is a great need for basic education of FASD in the local languages of remote NPY communities.

The need to raise awareness of FASD and its lifelong consequences in Central Australia is urgent and must be addressed at local, State and National levels of Government. We recommend that the Australian Government at all levels invest, as soon as possible, in a health promotion campaign to highlight FASD as an urgent public health issue and that any such campaign should include campaigns which are aimed specifically to Indigenous communities.

International research has found that prevention strategies effective in reducing the incidence of alcohol use during pregnancy include the use of screening tools and brief intervention and counselling (Floyd, Webber, Denny and O'Connor 2009). Given this, evidenced based education about alcohol use during pregnancy and about FASD for health professionals is essential in order that effective prevention strategies can be applied. Appropriate education for health professionals, highlighting in particular, the issues surrounding alcohol use in pregnancy in a remote Indigenous context, as well as highlighting ways of supporting families in remote communities who are affected in some way by FASD are required. Further, research is needed to identify effective and culturally specific methods of reducing alcohol use during pregnancy in a remote Indigenous context.

INTERVENTION NEEDS

It is well know that a protective factor for all children with developmental disabilities which improve their long-term developmental outlook is access to supportive interventions, and particularly early interventions. Therefore, considering that those living with FASD are living with an organic brain injury, interventions must be an important educational and public health concern (Streissguth, Barr, Kogan, & Bookstein, 1996 as cited by Bertrand 2009).

As noted in the situation analysis, the secondary effects of FASD are significant and are seen widely throughout NPY communities, and we believe FASD makes a significant contribution to the problems faced by many young people in the region. International research supports the fact that the "social skills deficits" of those prenatally exposed to alcohol continue into adulthood and given what we believe to be a significant percentage of individuals in the NPY region with prenatal exposure to alcohol, early intervention is essential to promote competence in social problem solving for these individuals (Bertrand 2009).Providing increased access to evidence based interventions is a critical action in the challenge of reducing the secondary effects of FASD both for those affected and for their families (Bertrand 2009).

Again, international evidence suggests that effective interventions which are individualised and specific to deficits among children with an FASD can be applied within the current framework of community services typically available rather than duplicating services which may already be available (Bertrand 20029). Whilst this finding is positive for policy making, particularly as interventions in this context could be fairly cost effective, significant investment will still be required in the NPY region given the current lack of services available.

A lack of resources and appropriate services in remote Central Australia seriously inhibits the possibility that people living with FASD in the NPY region will have the lifelong impacts of FASD minimised with early intervention strategies and services. The lack of quality, culturally specific research into FASD in the region also inhibits the kinds of services (which are very few to almost none) being offered to those affected by FASD in the region.

MANAGEMENT ISSUES

No diagnostic tools are being used for FASD in the NPY region; rather informal assessments are made by observation of physical abnormalities in addition to knowledge of mothers drinking heavily during pregnancy. The lack of diagnostic tools is reflected in the deficiency of published data of the incidence rates of FASD in Central Australia.

Management of FASD in a remote community context is a great challenge; already isolated from 'mainstream' services, the ability to divert families living with FASD to other support services is not possible. Management of children with FASD in remote communities falls completely within the family, and individuals with FASD often require more intensive assistance, according to age, than what would ordinarily be expected. The evidence suggests that people with FASD have the best outcomes when they experience a good quality caregiving environment, with supportive parental or caregiver presence and a stable, structured and consistent home (Grant et al. 2004 as cited by Olsen, Rudo-Stern, Gendler 2011). Within the context of NPY communities where people experience high levels of disadvantage and families already struggle with their significant unmet needs, the management of children and adults with FASD in the ways described above is both in contradiction to cultural styles of parenting and unmanageable given the severe lack of resources available in remote communities. Community controlled, culturally appropriate management strategies that address the social determinants of FASD must be developed and implemented using evidence based best practice (i.e. community led) models. Action in this area needs to be taken as soon as possible to ensure the best possible outcomes for all affected by FASD.

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