Commissioner for Children and Young People
Western Australia

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Committee Secretary
Standing Committee on Social Policy and Legal Affairs
House of Representatives
PO Box 6021
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CANBERRA ACT 2600

Dear Sir/Madam

Submission to the Standing Committee on Social Policy and Legal Affairs

Inquiry into Foetal Alcohol Spectrum Disorder

Thank you for the opportunity to provide comment in relation to the above Inquiry.

This submission is made on behalf of the South Australian Guardian for Children and Young People, Northern Territory Children's Commissioner, Australian Capital Territory Children and Young People Commissioner, the Queensland Commissioner for Children and Young People and Child Guardian, Tasmanian Commissioner for Children, NSW Children's Guardian, NSW Commissioner for Children and Young People, the Victorian Child Safety Commissioner and the Western Australian Commissioner for Children and Young People. These Commissioners and Guardians have a legislated responsibility to promote and protect the rights and wellbeing of children and young people under the age of 18 in their respective jurisdictions[1].

The Commissioners and Guardians recognise the significant impact of Foetal Alcohol Spectrum Disorder (FASD) on the health and wellbeing of children and young people, their families and the broader community and welcome the Standing Committee on Social Policy and Legal Affairs' Inquiry into the issue.

Australia has an obligation as a signatory to the *United Nations Convention on the Rights of the Child (CRC)* to ensure children have the highest attainable standard of health care, including prenatal care, and access to appropriate treatment where needed. Article 23 of the CRC specifically identifies the rights of children with a

[1] The legislated roles and responsibilities of Commissioners and Guardians vary across jurisdictions

disability to be afforded the appropriate services that ensure they are able to lead a full and decent life.

There is an urgent need to invest in appropriate prevention, screening and treatment services to respond to FASD at a national, state and local level if Australia is to meet its international obligations.

Summary of key points

It is imperative that a national strategy to provide a comprehensive and coordinated approach to the prevention, identification and management of FASD be developed to ensure that this wholly preventable disability is effectively addressed and that those currently affected by FASD get the treatment and support they need.

Prevention strategies need to include a range of strategies targeted at reducing excessive alcohol use across the community in addition to targeted strategies for women considered at increased risk of alcohol consumption during pregnancy.

FASD requires a multi disciplinary response and the capacity of existing child health services to implement screening and diagnostic processes is likely to require additional resourcing.

Support for families caring for children with FASD is essential. Formal recognition of FASD as a disability and access to resources to care for these children is paramount.

Alcohol consumption in pregnancy

The consumption of alcohol during pregnancy is known to be responsible for a range of adverse outcomes including miscarriage, premature labour, growth restrictions and birth defects.[1] The term FASD is commonly used to refer to the range of adverse clinical outcomes for the foetus that may result from alcohol exposure during pregnancy and includes Foetal Alcohol Syndrome (FAS).

Whilst adverse outcomes have been particularly associated with chronic or intermittent, heavy alcohol consumption, from the currently available evidence, it is not possible to accurately determine the impact of lower levels of alcohol consumption on foetal development. Consequently the National Health and Medical Research Council's guidelines recommend that for women who are pregnant, breastfeeding or planning a pregnancy, not drinking alcohol is the safest option.[2]

The excessive consumption of alcohol in the Australian community is cause for concern. In 2010 national data indicates that 1 in 5 people drank alcohol in a way that put them at risk of alcohol-related disease over their life time and 2 in 5 consumed enough alcohol on at least one occasion in the previous 12 months to put themselves at risk of an alcohol-related injury.[3] Whilst women have traditionally consumed less alcohol than men this gap has narrowed in the last two decades.[4] This is of particular concern given women are more susceptible to the effects of alcohol than men.

This data also identified that approximately a third of women in the 18 to 29 years age group drank at risky levels (more than 5 standard drinks on any one occasion) at some time in the previous 12 months with two thirds of these drinking at risky levels at least monthly. There is considerable variation across states and territories in the percentage

of women drinking at risky levels ranging from more than 40 per cent in the Northern Territory to 27 per cent in New South Wales.[5]

At present there is no consistent data collection on alcohol use in pregnancy in Australia. From the limited data available it appears that the percentage of women who did not drink alcohol during their pregnancy increased from 40 per cent in 2007 to 48 per cent in 2010.[6] However, as nearly 50 per cent of pregnancies are unplanned,[7] and, given the association between unplanned pregnancy and 'binge' drinking,[8] the potential for foetuses to be exposed to alcohol prior to the mother realising she is pregnant is high. Evidence has also indicated that women with university education and women with current high risk drinking behaviour are at increased risk of continuing to drink when pregnant.[9]

The paucity of evidence regarding the prevalence of FASD, coupled with factors that contribute to the under diagnosis of FASD, make it difficult to accurately determine the extent of FASD in Australia however, estimates of the prevalence of FAS are reported to be between 0.06 and 0.68 per 1,000 live births in Australia and 2.76 to 4.7 per 1,000 live births in Aboriginal women.[10]

Identified 'at risk' populations

It is important that FASD is recognised as a community wide problem if preventative, diagnostic and treatment strategies are to be undertaken effectively. However, bearing in mind the paucity of data, there are two specific populations in which the elevated risk profile would also warrant specific attention for prevention, intervention and management strategies.

Aboriginal children and young people

Whilst there are more non-drinkers in the Aboriginal population than in the Australian population generally, it has been estimated that the burden of alcohol-related disease in the Aboriginal population is almost double that of the general population.[11] Of particular concern for FASD is the high rate of risky or high risk drinking that peaks in the 25 – 34 year old age group for Aboriginal women.[12] Preliminary data from recent research with one Aboriginal community has indicated that approximately 50 per cent of women drank during pregnancy, similar to the non-Aboriginal population, however, *'as many as nine in ten of those women who do drink in pregnancy do so at high-risk levels.'*[13] Given the increased burden of alcohol-related disease in the Aboriginal population generally, this finding may be replicated in other Aboriginal communities.

Children in out-of-home care

The current research into the prevalence of FASD in children in out-of-home care by the Telethon Institute of Child Health Research (WA) is noted and it is anticipated that this research will provide valuable information in regard to this population of particularly vulnerable children.

The reasons children are placed in out-of-home care are often based on multiple and complex issues. For example, excessive alcohol consumption is estimated to be involved in up to 77% of child maltreatment cases. [14] Given the complex histories of disadvantage of children in out-of-home care, it is suggested that not only is there likely to be a higher prevalence of children with FASD in this group than the general population, but their experiences may also have led to them being at higher risk of not

having received the assistance and support they need and of their symptoms of FASD having been exacerbated before coming into care.

The particular needs of these groups will be further addressed later in this submission.

Reducing the impact of FASD in Australia

FASD is recognised as the single, biggest, preventable source of intellectual disability. It is associated with a range of social and economic impacts both to the individual and the broader community, with a lifelong impact and '[affected] *individuals often not achieving independent living*'.[15] In addition to primary disabilities arising from differences in brain structure and function, often children affected by FASD also have a range of secondary disabilities as a result of the damage caused by prenatal alcohol exposure including, learning difficulties and disrupted education, unemployment, increased mental health problems, higher rates of juvenile crime and alcohol and drug problems.[16]

FASD requires a national response that addresses the preventative, diagnostic and management issues in a comprehensive and coordinated manner. We draw attention to the work already being undertaken by the WA Department of Health in the development and implementation of the FASD Model of Care as an example of a comprehensive approach to FASD.

The sensitive nature of FASD and the shame, stigma and guilt associated with a FASD diagnosis require careful management in the development of strategies to ensure that they are effective and those affected by FASD are adequately supported.

The high rates of alcohol consumption across the community, particularly in women of child bearing age, indicate that strategies are required at a population based level. The importance of a whole-of-community approach is also demonstrated through the impact of other people's drinking on a woman's alcohol consumption during pregnancy, with one study showing that a third of women would modify their alcohol consumption during pregnancy if their partner also stopped drinking or was encouraging them to stop during pregnancy.[17]

Targeted strategies to populations considered to be at greater risk of alcohol consumption during pregnancy are also required to ensure that prevention, intervention and management strategies are culturally appropriate and effectively reaching those most in need.

A number of excellent examples of targeted strategies to Aboriginal communities already exist including the WA Drug and Alcohol Office, *Strong Spirit Strong Future* program, the Ord Valley Aboriginal Health Service (OVAHS) FASD project and the Lililwan Project in the Fitzroy Valley. Importantly these strategies have been developed in consultation with the relevant community to ensure they are culturally secure and effectively meeting the needs of the community.

It is also important to recognise that alcohol consumption can be part of a complex picture with other issues such as poverty, mental health problems, alcohol and drug dependency child abuse and neglect and strategies need to be mindful of this and respond with appropriate adjunct services and supports to address FASD issues in this context. The impact of community-initiated liquor restrictions, and other community development activity, in the Fitzroy Valley as a precursor to the development of the

Lililwan Project is noted here as an example of the benefit of addressing broader issues at a community level.

Given the paucity of data about the consumption of alcohol in pregnancy, FASD and the effectiveness of strategies across all aspects of the prevention and response to FASD, investment in further research into FASD to strengthen the evidence base and guide strategy development and implementation should be a national priority. Additionally the development and implementation of strategies should be monitored and evaluated to ensure that they are achieving the intended outcomes and effectively reducing the impact of FASD in the community.

Bearing these factors in mind the following provides further comment on the prevention, intervention and management strategies relevant to reducing the impact of FASD on both affected individuals and the community.

Prevention strategies

Prevention strategies need to include a range of strategies targeted at reducing excessive alcohol use across the community. In particular, education strategies, such as national public health campaigns, to raise awareness in the general population of the impact of alcohol consumption during pregnancy are required. Targeted education campaigns for high risk groups and communities should also be developed and implemented. Further, compulsory school-based education on alcohol that aims to modify behaviour and involves parents and the wider community is required and should include information on the effects of alcohol in pregnancy. With the development of the Australian school curriculum currently underway, opportunities to explore the inclusion of alcohol education in the curriculum should be considered as a matter of priority.

It is recommended that strategies such as health warning labels on alcohol products should be implemented. Warning labels have been compulsory in a number of countries for several years including France, South Africa and the United States of America. A number of factors influence the impact of warning labels, such as size, however, 'adding warning labels to alcohol containers has a longer term social utility in helping to establish social understanding that alcohol is a special and hazardous commodity.' [18] However it is important that such education is based on evidence of what works in changing behaviour as, whilst knowledge is important, research has found high rates of alcohol consumption during pregnancy amongst women with tertiary level education and stated that, '*awareness of the effects of alcohol in pregnancy alone is not sufficient to change women's behaviour.*' [19] Further, the message about alcohol abstinence throughout pregnancy needs to be carefully managed to reduce the possibility of inadvertent negative outcomes, such as women not disclosing alcohol consumption out of fear and shame.[20]

Strategies to improve the knowledge and skills of the health and welfare workforce to adequately deliver effective preventative information and to identify and support women who are at risk of continuing to drink during pregnancy, should also be a priority and should include the importance of advice about effective contraception for women who continue to drink, particularly at risky levels. *The Grog Brain Story*[21] resources provide an example of tailored resources for health professionals to provide appropriate preventative information to specific populations. The importance of developing resources to ensure cultural relevance to particular groups cannot be over

emphasised. In order for health and welfare workers to impart relevant knowledge and information it will also be important to ensure appropriate and affordable health care and support services are accessible to all pregnant women, and particularly those with alcohol problems.

At a broader level, a World Health Organisation (WHO) international review of alcohol-related research found that regulating the physical availability of alcohol (e.g. the trading hours and density of liquor outlets) and taxation and pricing were the top two most effective types of intervention for reducing alcohol-related harm. [22] Strategies such as the introduction of volumetric taxation and a minimum floor price for alcohol to reduce the availability of cheap discounting of alcohol may therefore be particularly effective in addressing excessive alcohol consumption in the general community. Such strategies have also been shown to reduce alcohol-related harm in young people.[23]

Intervention needs

The earlier FASD is identified and intervention strategies put in place, the more likely adverse outcomes will be minimised.[24] As such, early intervention strategies will provide considerable cost savings to the community and substantial improvements in the quality of life for the individual.[25] [26] Development and implementation of a national screening and diagnostic tool is essential. The Australian FASD Collaboration project has submitted its report to the Commonwealth Department of Health and Ageing[27] with its recommendations for the development of such a tool. The consideration of the recommendations of this report and the development of such a tool should be progressed as a matter of priority.

FASD requires a multi disciplinary response[28] and the capacity of existing child health services to implement screening and diagnostic processes will require additional resourcing. Implementation will also require a comprehensive workforce development strategy to ensure relevant health professionals are conversant with the tools and their application.

Eligibility for support for those affected by FASD and their families to access health and other required services will also need to be addressed – particularly for those in rural and regional areas where access to health care services is often severely limited. Provision of services at a local level where possible, including the use of 'telehealth' services, should be investigated and methods resourced where shown to be effective. However, as outlined above, the need for multidisciplinary assessment combined with the vast distances familiar to many regional areas of Australia and the shortage of skilled professionals, means that considerable resourcing to meet the needs of children in regional areas will inevitably be required.

Children in out-of-home care face some particular challenges and, as a high prevalence group for FASD, it is important that they receive access to relevant services and continuity of care in the assessment and management of their health needs. Foster families will also require appropriate resourcing to facilitate this access. We note the current research into FASD and children in the child protection system being conducted by the Telethon Institute of Child Health Research[29] that will provide important empirical data on the prevalence of FASD in this cohort of children and their health care needs. Other research is also planned in this area through the Northern Territory Department of Children and Families.

Management issues

FASD, as an umbrella term, covers a range of disabilities and these vary significantly across affected individuals. An individualised management plan would be required to address the specific needs of each affected individual.

This may also change over time as the nature of the damage caused by foetal alcohol exposure often impacts on the affected individuals' ability to undertake more complex cognitive tasks and *"these children may be more and more challenged the older they get by the demands placed on them within the school system and within their day-to-day social interactions."*[30] This highlights the need for ongoing systems of support for affected individuals and their families.

There is a need for considerable across agency collaboration and involvement in the management of affected individuals to ensure that those with suspected FASD can be referred to and receive appropriate assessment and intervention services. Health, education, justice, child protection and employment and training staff need to be educated in strategies to best identify and manage issues associated with FASD. We note the research underway at the National Drug and Alcohol Research Centre (NDARC)[31] regarding the care needs of families who raise children affected by FASD and also the Telethon Institute for Child Health Research[32] on FASD and the criminal justice sector. Such research will provide important insight into how best to support judicial staff to improve the outcomes for people affected by FASD who come into contact with the justice system.

Importantly educational resources that support the learning of children with FASD are urgently required. Maintaining engagement with the educational system is an important protective factor in children's lives and has significant bearing on their life outcomes.[33]

Similarly, the need for children to grow up in a supportive and stable family environment is essential to maximising their potential and minimising the adverse outcomes of FASD. Support for families caring for children with FASD is therefore essential so that families can provide appropriate support to affected children. Formal recognition of FASD as a disability and access to resources to care for these children is paramount.

Summary

In summary, since it was first recognised in the late 1960s there has been a growing understanding and recognition of the impact of foetal alcohol exposure and the spectrum of disabilities and adverse outcomes that can result from such exposure. There is considerable good work being done in research institutions, health facilities and local communities to progress understanding and improve responses to the prevention and treatment of FASD.

Of particular note is the work being undertaken by Aboriginal communities to address the issue of FASD at a community level and much can be learned from projects such as the Lililwan Project in the Fitzroy Valley. Further investment in existing effective projects and expansion into other communities should be supported.

Consistent with the priorities of Australia's Preventative Health Taskforce[34], strategies to address the widespread, excessive consumption of alcohol in the Australian community will not only help to reduce the incidence of FASD but will also reduce many other harms related to alcohol consumption which are now well documented. It is imperative that a national strategy to provide a comprehensive and coordinated approach to the prevention, identification and management of FASD be developed to ensure that this wholly preventable disability is effectively addressed and that those currently affected by FASD get the treatment and support they need.

We welcome the opportunity to provide comment to this Inquiry and look forward to continuing to advocate for what is in the best interests of all children and young people in the Australian community.

Yours sincerely

MICHELLE SCOTT

Commissioner for Children and Young People (WA)

26 March 2012

Signed on behalf of:

Howard Bath, Children's Commissioner (Northern Territory)

Pam Simmons, Guardian for Children and Young People (South Australia)

Alasdair Roy, Children and Young People Commissioner (ACT)

Elizabeth Fraser, Commissioner for Children and Young People and Child Guardian (Queensland)

Aileen Ashford, Commissioner for Children (Tasmania)

Kerryn Boland, Children's Guardian (NSW)

Megan Mitchell, Commission for Children and Young People (NSW)

Bernie Geary, Child Safety Commissioner (Victoria)

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