To the Secretariat,

Senate Standing Committees on Community Affairs.

Effective approaches to prevention, diagnosis and support for Foetal Alcohol Spectrum Disorder.

Submission

Dr Sharman Stone

When I moved a private members motion in the House of Representatives about 7 years ago calling for a national response to FASD, it referred to the lack of diagnosis, community understanding, information and education, the impacts on those with FASD and their carers. In November 2012 our committee's report "Hidden Harm" was tabled. Since then there has been bi-partisan support for a national strategy to address the problem of foetal exposure to alcohol, the number one cause of non-genetic brain damage in the newborn in Australia.

Alcohol consumption during pregnancy continues to be a hidden harm in this country, with anecdotal evidence and the occasional survey finding that significant numbers of the community, including some health professionals, educators and workers in policing and the courts are not fully aware of the condition and its varying impact on the individual. FASD cannot occur if no alcohol is consumed during pregnancy. However given the lack of comprehensive public awareness, children continue to be born with the incurable condition. Many are never diagnosed or misdiagnosed (eg as having ADD or "Autism"). Either way individuals and families too often receive little support, understanding or appropriate therapies.

This not only an Indigenous problem

Much has been achieved in the last decade, including greater professional awareness in the medical services and the development of an Australian Tool to support diagnosis, however the incidence of FASD is unlikely to have diminished in the population, whether indigenous or non indigenous. I say "unlikely", given one of the underlying problems we have in properly targeting

programs or adequately resourcing them within Australia is due to a lack of accurate and current prevalence data. We can extrapolate from other country's data, eg from Canada and the USA, but we need accurate data to identify the extent of the injury in the community, who and how people are disabled, and the location and demographic of the most at risk populations or cohorts.

There is a tendency in some Australian and international conversations to claim that the greatest foetal exposure to alcohol is within the indigenous communities. This may be a consequence of the first and most significant Australian prevalence research being undertaken in an indigenous community, Fitzroy Crossing, where the findings revealed some of the highest rates of FASD ever reported globally.

Health and Corrections professionals are also aware that significant numbers of Indigenous prisoners in Northern, Central and Western Australia have FASD. This does not mean however that the incidence of FASD is not significant in the non indigenous communities, and self evidently, the incidence of one child born with disabling FASD is one too many, given it is an avoidable condition.

The changing culture of alcohol consumption

Over the last 40 to 50 years alcohol consumption behaviour in Australia has changed. While women were once excluded from hotel bars, young women now binge drink in similar patterns and at the same venues as men. Given any women having unprotected sex may not have an unintended pregnancy confirmed for several months, and if their binge drinking continues, foetal exposure to alcohol is a high risk. Older women are also more likely to regularly consume alcohol and too many continue to drink during pregnancy, in particular where they are not sufficiently informed of the risks to the foetus.

There is also evidence that when a woman's partner supports her in not drinking alcohol during a pregnancy and breast feeding then that women is more likely to abstain.

We do not have sufficient supports in the community for women who are pregnant and have an addiction to alcohol. Australia needs to offer women in this situation intensive support to reduce or illuminate their alcohol

consumption in order to reduce or illuminate the risk to the foetus. There is currently little support for alcoholic women who are pregnant.

Targeted and national communication and information strategies.

A failing of the first FASD national strategies was a lack of a comprehensive generally targeted information/education campaign that aimed to ensure every Australian was aware of the NHRC guidelines in relation to alcohol consumption and pregnancy.

Australia has been at the forefront globally in promoting widespread and accurate community understanding about the health impacts of tobacco smoking, yet we have failed to address this other legally consumed harm to the unborn.

Assessing the cost of FASD to the Australian community

When a system has been established for the annual collection of accurate new-case and prevalence data it should be possible to calculate the human and financial costs to the nation of brain and other injuries acquired as a result of alcohol exposure in the womb.. This calculation would need to include the estimated per capita costs of incarceration, unemployment, special services for victims and carers, counselling support, welfare support, health and education support.

This calculation would allow a comparison with the costs to the nation of nicotine addiction and the resources expended to reduce that harm. It may then be easier to gain the support to mobilise resources to fill the gaps in community awareness- building campaigns, communications and training programs with the health, education, corrections policing, diagnosis and prevention professionals.

Alcohol's promotion to the public and the young

The messages surrounding alcohol consumption as portrayed in the industry's advertising continues to associate wine, beer and spirits with victory and celebration, sporting prowess, sophistication, relaxation, properity and personal popularity. In particular young children are exposed to alcohol advertising as they watch live or rerun sporting events. Players' clothing, the fences around the grounds or tracks and stencils on the field itself promote the close association between being a sporting champion and alcohol consumption.

Again, we need to mirror the multi pronged campaign which led to tobacco advertising being removed from the constant viewing and the false but positive associations of the product for the protection of children and adults who do not know the harms or who cannot drink alcohol responsibly.

I believe the most powerful message for the Australian community is: "None for Nine". This avoids the labelling of the messenger as a "wowser" (with its negative connotations in Australian culture) and helps the community to see not drinking during pregnancy is to do with the baby's development, and is not a reflection on choices made by others (who are not pregnant).

When mandated health warnings are finally included on every alcohol container, the size, colour, location and message needs to be more visible and coherent than the labelling currently to be found voluntarily placed on alcohol bottles and cans.

The Need for more Diagnostic Centres

Adequate multi disciplinary diagnostic centres need to be readily accessible with reasonable wait times across Australia. Adults also need access to diagnoses. Resources must follow diagnosis and be sufficient for appropriate therapies and support.

NDIS

The capacity for the NDIS to provide treatment and support to victims of FASD appears to be inadequate at this time. This may reflect the paucity of other data, specialist FASD services, and in particular diagnoses with adequate support and follow up across the Australian medical and mental health, education and employment sectors. Adults with FASD are particularly likely to miss out on diagnosis or support. The interface between the NDIS and those with FASD needs to be reviewed.

Dr Sharman Stone

Member, National FASD Advisory Group

Member Vic FASD Special Interest Group

Ambassador NOFASD

Patron RFFADA