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House Standing Committee on Social Policy and Legal Affairs
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Submission to Inquiry into Foetal Alcohol Spectrum Disorder

1. I have considerable senior executive experience in community development and social policy, particularly in the Indigenous sector, and foetal alcohol syndrome was one of my research and policy interests over a decade ago. My interest was sparked by talking to women in Cape York Aboriginal communities who attended the only FAS education program available in the country back then. They cried about all the 'grog babies' in their communities, and were angry that no-one had told them before of the dangers to babies of drinking while pregnant.
2. My conclusions at the time, after reviewing international literature, programs, data etc, and extrapolating to Australia's situation, was that our Indigenous population, particularly those in remote communities, was likely to have a very high incidence of undiagnosed in-utero alcohol damage, and that the negative effects would be apparent in years to come via persistently poor educational achievement, in over-representation in the criminal justice system and in unemployment statistics, in higher mental illness rates, in a crisis in Indigenous leadership whereby the mission-educated leaders have no-one to pass the baton to, and social and familial difficulties that would continue to have effects throughout the sufferers' lives. Sadly, there was little political interest in FASD at that time. Hence my interest in this inquiry.
3. I have read the 80 submissions published on your website and am writing this to fill in some gaps. I agree with much of the content and recommendations of existing submissions, with a few provisos. I will therefore confine my remarks to filling in some information gaps and additional recommendations.

Diagnoses and data:

4. There have to be reliable diagnostic and screening tools developed and widely used by educators, the medical profession, health workers, youth workers, child protection workers, and detention intake officers.
5. Increase and improve timely access to diagnostic testing/assessment.

6. Need to establish State and national data collection systems, perhaps including questions in NATSIS, the Census and other national surveys.

Prevention measures:

7. More targeted education strategies for high risk groups, including Indigenous-specific strategies implemented by Indigenous workers.
8. Public education campaign including warning labels on alcohol and posters at point of sale, recognising that labels and posters alone will likely be ineffective in changing behaviour in the short term – the aim is to create a widespread cultural attitude change over time whereby it becomes widely accepted and normal not to drink alcohol during pregnancy. It is possible to do this without making criminals of offenders, as the anti-smoking campaign has been able to do.
9. General alcohol consumption reduction strategies, especially in the NT and in Indigenous communities. Australia needs culture change to reduce alcohol consumption across the board.

Management:

10. Most submissions have paid little attention to management strategies, in particular, to the need for teachers to be trained in understanding FASD effects, recognising FASD behaviours, and adapting teaching practices to maximise learning outcomes. There is a plethora of good information about such teaching practices from other countries, particularly Canada and the USA, and I have attached one summary example for your information. I also note the details given in Paul and Kerryn Harper's moving story about their journey with Debbie, and fully endorse the observations they made about the elements of supportive education practices.
11. In a similar vein, this kind of information and training needs to be available for child protection officers, youth workers, parents and foster parents of FASD-affected children and young people. I note the comprehensive submission by Ms Prue Walker on the prevalence of FASD children in child protection systems and endorse her observations and recommendations. I also attach an example of parenting tips by a USA group that can benefit Australian carers.
12. Continue to educate police, detention officers and the legal profession about FASD effects so that they can recognise likely FASD-affected people, make referrals for diagnosis, and modify their approaches to dealing with FASD-affected people.
13. Some submissions wrote about the prevalence of FASD-affected people in the criminal justice system, and made recommendations about screening and management in the prison and juvenile detention populations, but the risk of a FASD-diagnosed person being placed in indefinite detention with no treatment is injustice heaped on injustice. Other, more humane, solutions need to be developed. The Queensland government funds some

excellent (though small) programs facilitating the transition of people with mental illnesses from prisons and psychiatric wards back into the community, which have a proven record of reducing recidivism and readmission and thus generating considerable savings – this kind of holistic support model should be available for FASD-affected adults.

14. Enable access of FASD-affected children, young people and adults to appropriate disability services and support programs, including through the new National Disability Insurance Scheme. I note the plea from the Aboriginal Disability Justice Campaign's submission that such access not be conditional on an unequivocal diagnosis of FASD, but on assessment of cognitive and behavioural difficulties. Given the current lack of FASD awareness and diagnostic expertise amongst Australia's medical profession, and the Darwin Paediatricians' submission about current assessment delays, it will be some time before swift diagnoses can occur, but treatment and support should be available as early as possible to gain maximum benefit for sufferers and their families.
15. Establish new community-based services to treat and support FASD-affected people and their families.
16. Some submissions, notably from the alcohol industry and Family Planning Association NSW, claim that there is insufficient evidence that occasional drinking during pregnancy causes harm to the foetus. However, they cannot possibly deny that foetuses consume whatever their mother is consuming. The irony is that these same people would undoubtedly say 'No' if asked whether it was okay to feed alcohol to infants and children, yet somehow it's okay to feed alcohol to a developing foetus!

In conclusion, it is unusual for so many submissions to an Inquiry to be so similar in views and recommendations, but I think that underlines how concerned we all are about this issue and the Australian government's failure to tackle it effectively before now. I therefore urge this committee to make it a national bipartisan goal to eradicate new FASD cases within one generation, and fully support the development of a National FASD Action Plan (and evaluation method) as advocated by some of the submission writers, with the content drawn from the recommendations listed in these submissions.

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