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Senate Community Affairs References Committee Inquiry Submission

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

This submission is authored by Evi Muggli and Jane Halliday from the Murdoch Children's Research Institute (MCRI).

Evi Muggli is a Senior Research Officer and Honorary Research Fellow with the Department of Paediatrics, University of Melbourne. She has a background in medical science & cell biology, now with 15 years' experience in epidemiological research and project management. Jane Halliday is an Honorary Professor, University of Melbourne, Department of Paediatrics, and Group Leader of Reproductive Epidemiology at the MCRI. She is an epidemiologist with over 200 peer-reviewed publications, designing and undertaking research that measures the impact of potentially harmful prenatal exposures, such as alcohol, on health and wellbeing of infants, children and young adults, integrating knowledge of genetics, epigenetics, environmental and psychosocial risk factors.

Over the past 10 years, Halliday and Muggli collectively led and/or actively contributed to many alcohol, pregnancy and Fetal Alcohol Spectrum Disorders (FASD) research projects, academic and government expert panels and working groups. Examples include the Technical Advisory Group of the FASD Research Australia Centre of Research Excellence and contribution to the development of the FASD Diagnostic tool guidelines (Halliday); the FASD Hub Technical Subject Matter Expert Panel (Muggli) and NHMRC funded project grants (2011-2014 and 2018-2021) for the longitudinal cohort, 'Asking Questions about Alcohol in Pregnancy' (the AQUA study) (Halliday & Muggli).

We have a specific interest and expertise in data collection in this field and, in recognition of this, were commissioned by the Australian Institute of Health and Welfare to investigate the best way of collecting national data on alcohol use in pregnancy.

Our acclaimed research in this field has led to many peer-reviewed publications, commissioned reports, invited commentaries and several fact sheets and patient advice statements, all of which have been highly cited in other publications. Some of our research is referred to below as evidence to support our submission.

As epidemiologists in the alcohol, pregnancy and FASD field, we particularly recognise the importance of prevention and early diagnosis and welcome the opportunity to provide a submission to this Inquiry.

This submission will be addressing reference points relating to **prevention approaches**, namely points a, b, c, d & o.

We would also welcome the opportunity to meet with members of the Senate Community Affairs References Committee and contribute to public hearings.

Key issues in prevention approaches

1. Alcohol use continues to be prevalent in the general antenatal population despite health messages advising abstinence and a widespread awareness that alcohol use in pregnancy could be harmful to the developing child.
2. FASD in the general population continues to be underdiagnosed, meaning that the extent of harm remains hidden and leading to the belief that occasional alcohol use in pregnancy is safe.

Supporting evidence

Prevalence

Data from our own research in Victoria, plus two large national surveys of Australian women aged 18 to 45 years, showed that 34 to 54% of women consumed alcohol in pregnancy [1-3]. Despite women's awareness that drinking alcohol in pregnancy can lead to lifelong disabilities in a child, nearly one third intended to drink alcohol in a future pregnancy [2]. There is no reason to believe that these data, collected 6-7 years ago, will have changed in the last few years. *Whilst knowledge of the potential harms of alcohol consumption during pregnancy is important, it is apparent that an awareness alone does not discourage some women from drinking when pregnant.*

Women's beliefs

Outcomes from our discussions with both Indigenous and non-Indigenous pregnant women revealed that women understood that drinking alcohol when pregnant was "bad", potentially causing harm to their developing baby [4]. However, they were often unsure about the nature of harm and believed that it was safe to drink some alcohol after the first 12 weeks or that some types of alcohol were more harmful than others. Women tended to base their beliefs around low risk of harm from occasional alcohol use on their personal observations of the behaviour of family and friends. They also felt there was a lack of convincing research evidence on harm from low consumption patterns [4]. *Consequently, beliefs about the benefits of abstaining from alcohol were low and the barriers to taking such action, for example when at a social event, were seen to outweigh any risks. Together, these perceptions permitted nuanced decisions by individual women about how much alcohol consumption was to be without risk of harm, despite receiving health messages advising complete abstinence.*

Reframing messages

In 2017, we published findings from the AQUA study showing that any prenatal alcohol exposure is associated with facial shape of one year-old children (using 3D photography), resulting in imperceptible, yet measurable, flattening of the midface and upturning of the nose [5]. These changes are reminiscent of those seen in Fetal Alcohol Syndrome, previously only associated with high level, chronic alcohol exposure. Our findings add weight to the

growing body of evidence on the influence of alcohol on all stages of fetal development. This paper was named the top 2017 publication in JAMA Pediatrics. *In light of this, it is now important to reframe discussions around harm prevention or whether there is a potentially 'safe' threshold. The message should emphasise the importance of alcohol abstinence in optimising health and cognitive outcomes for the unborn child.*

Diagnosis

Timely and accurate diagnosis of FASD is an important aspect of prevention efforts. The required specialist multidisciplinary diagnostic services currently remain few and far between, so that FASD in Australia continues to be underdiagnosed [6, 7]. More often than not, an affected child's difficulties are attributed to another cause. *This means that the true prevalence of harm from prenatal alcohol exposure remains hidden and its effects continue to be underestimated in all sectors of the community and within government.*

Monitoring and evaluation

We welcome the recent addition of maternal alcohol use items to the Perinatal National Best Endeavours Dataset. We, however, want to emphasise the need for accurate and consistent data on alcohol use in pregnancy to be incorporated into the mandatory National Perinatal Minimum Dataset as part of ongoing monitoring. An evaluation should be undertaken as soon as possible to determine if there is a need to upskill or assist midwives in any way in order to ensure this data collection is meaningful and useful.

Summary of our recommendations

Prevention strategies should include:

1. A national campaign to increase public awareness and understanding of how the consumption of alcohol during pregnancy can affect the developing fetus
2. Information on how the consumption of alcohol during pregnancy can affect the developing fetus to be included in the health education curriculum to educate secondary school students
3. A range of stakeholders, including researchers, health professionals, FASD support organisations and members of the community
4. Health professional education on FASD as part of their training and continuing professional development
5. Easily accessible sources of information for women and the community, that are visual, easy to understand, culturally relevant and available in different languages
6. Monitoring and evaluation through national mandatory perinatal data collection of maternal alcohol use

Prevention messages should;

1. Provide advice in line with current Australian Guidelines to Reduce Health Risks from Drinking Alcohol;
2. Include strategies to correct misinformation about supposed 'safe' timing, quantity and types of alcohol;
3. Develop a more accurate perception of FASD; emphasising brain damage and importance of diagnosis to improve management and outcomes for the child;
4. Emphasise that abstinence maximises outcome for all babies;

5. Reframe messages about 'harm' to messages about optimising the child's health and cognitive outcomes, as part of a broad paediatric approach to neurodevelopment;
6. Develop a holistic approach encompassing women's social and cultural context.

This submission has been read and endorsed by Prof John Christodoulou, Director, Genetics Research Theme, MCRI and Prof Vicki Anderson, Director, Clinical Sciences, MCRI.

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