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Professor Philippa Middleton (Independent Chair) &
Dr Natasha Reid (Content Chair)
Australian FASD/ND-PAE Guidelines Development Group

Submitted via email: fasdguidelines@uq.edu.au

Dear Professor Middleton, Dr Reid, and Guideline Development Group Members,

Consultation draft Australian clinical practice guidelines for the assessment and diagnosis of fetal alcohol spectrum disorder or neurodevelopmental disorder associated with prenatal alcohol exposure (FASD/ND-PAE).

The Australian Psychological Society (APS) is pleased to be part of the public consultation regarding the development of the Australian clinical practice guidelines for the assessment and diagnosis of FASD/ND-PAE. As an evidence-based organisation, we commend the comprehensive and rigorous approach to the development of the guidelines. Although there are many components of the guidelines which are outside the scope of the APS, we would like to draw a few matters regarding psychological aspects of FASD/ND-PAE to the attention of the Guideline Development Group.

The APS is the peak professional body for psychologists in Australia. We advocate on behalf of our members and the community for the implementation of evidence-informed prevention, intervention and systemic reform approaches that deliver health and wellbeing for all Australians. The APS embeds social impact and sustainability in our operations, advocacy, and initiatives guided by the United Nations global Sustainable Development Goals (SDG)[1]. We consider the reduction of and mitigation of the impacts of FASD/ND-PAE to be an important healthcare challenge in Australia, which can affect all sectors of society. Given this, the development of the Guideline goes some way toward SDG 3: *Ensure healthy lives and promote well-being for all at all ages*[2].

Firstly, we would like to commend the inclusion of a Cultural Advisory Group and *FASD Indigenous Framework (The Framework)* which represents a significant change from the 2016 guide. It is essential that the implementation and evaluation of the guidelines is also genuinely co-developed with First Nations Peoples[3] to ensure that all Australians can access appropriate care and support post-diagnosis. As acknowledged in *The Framework*, this is particularly important for a number of reasons including:

- The unique impact of colonisation means that there must be deep recognition of the intergenerational trauma and ongoing disenfranchisement that has been created in Australian society.
- Acknowledging that many of the social determinants of high alcohol use are not uniform across communities. Interaction with the criminal justice system,[4] racism and discrimination,[5] service inequalities, disconnection from country, education outcomes, health outcomes, and substance use are some of the many factors that may contribute to alcohol misuse in Indigenous communities as well as poor mental health. These inequalities must be addressed appropriately in order to see tangible progress.
- Recognising that access to mainstream services is not equitable. When dedicated services are not available, some initiatives need to be adapted to become more responsive to the particular needs of Aboriginal and Torres Strait Islander peoples.

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Similarly, we also commend the inclusion of lived experience voices throughout the different components of the development, including the 'Actionable Statements'. Incorporating lived experience voices into the development and implementation of guidelines enhances empathy, tailors services to patient needs, and fosters inclusive, culturally competent care. It brings valuable insights, improves decision-making, reduces stigma, and ultimately leads to better health outcomes and patient satisfaction.

In consideration of *the Main Guidelines Document*, in particular the Actionable Statements, the APS notes:

1. **A holistic approach** – The APS commends the inclusion of a holistic approach which considers a diversity of social determinants of health. As discussed in *the Main Guidelines Document*, it is vitally important to consider that FASD/ND-PAE occurs as a result of multifactorial and interacting circumstances and often intersectional disadvantage. We commend the thorough holistic approach to assessment undertaken by the Guidelines team.

2. **Shared decision-making, including yarning** – an approach which should be central to all healthcare, the APS commends the inclusion of shared decision making as an underlying principle to the guidelines.

3. **Gender inclusive language** – the APS commends the use of gender-inclusive language (for example, use of parent/caregiver) however, recommends that more inclusive language could be extended to the forms in the appendices (for example, page 109) as not all birthing parents identify as mothers.

4. **Greater focus on prevention and early intervention** – first and foremost, given the lifelong impacts of FASD/ND-PAE [e.g. 6] it is essential that the guidelines are embedded withinin a context of prevention and early intervention [see also 7,8]. Although *the Main Guidelines Document* is clear, that public messaging regarding FASD/ND-PAE is outside the scope of the document, not focussing on prevention represents a lost opportunity to: (a) reduce future incidence, (b) increase awareness and potentially early intervention, and/or (c) reduce stigma (see below).

5. **Taking a lifespan approach** – consideration of the impact of early experiences and challenges throughout the entire lifespan is a central tenant to psychologists, in particular Educational and Developmental Psychologists. We commend the Guidelines not limiting the focus to purely be on children but also incorporating downstream impacts and repeating assessments as necessary, however, this should also include a greater recognition of the increased risk of suicide and related behaviours and cognitions in people who have PAE[9].

6. **Elevation of the role of psychologists** – Given the psychosocial influences on alcohol use and the developmental, neuropsychological, and mental health impacts of FASD/ND-PAE[6], psychologists can play an important role in the holistic approach to healthcare. Psychologists are able to provide any behavioural and/or developmental support and mental health care to individuals affected, as well as interventions to reduce problematic drinking in parents [see also 10] to prevent further incidence of FASD/ND-PAE. For example, there are opportunities to elevate the importance and role of psychologists when discussing referral pathways.

7. **Importance of stigma reduction -** We commend the inclusion of providing 'non-stigmatising support' in the Lived Experience Actional Statements (page 14) and suggest that psychologists may be able to assist in the reduction of perceived (or self) stigma for individuals and contribute to related public health stigma-reducing initiatives.

8. **Greater consideration of support for Australians in regional and remote communities –** Although FASD/ND-PAE occurs in every sector of society, it is important that adequate support is given to Australians outside of metropolitan regions. We commend the flexibility in the guidelines regarding reusing previous assessments and clinical judgement, however, this is no replacement for well-funded health services in rural and remote Australia. In keeping with our ongoing advocacy, we advocate for greater funding and support to ensure that every Australian with FASD/ND-PAE has the best possible care, regardless of their geographical location.

9. **Importance of interdisciplinary teams –** the APS commends the transtheoretical ethos underlying the Guidelines which includes multiple inter-professional approaches (page 28).

10. **Expectations of the use of the document –** it is important to acknowledge that many health practitioners are time-poor and have to balance many competing demands and priorities [see 14,15]. Introduction of the guidelines will not be the "magic bullet[16(p. 530)]" for every patient and practice and should not replace appropriate training and a strong interdisciplinary approach. Given the lengthy and detailed nature of the guidelines, it is likely that some practitioners will only refer to the summary on an ongoing basis. It is essential, therefore, that the holistic, biopsychosocial and interdisciplinary approaches be integrated into an Executive Summary or abridged version in an easy to digest, accessible format.

Thank you for the opportunity to respond to this consultation. If any further information is required from the APS, I would be happy to be contacted through my office on (03) 8662 3300 or by email at z.burgess@psychology.org.au

Yours sincerely,

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Chief Executive Officer

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