

NOFASD Australia Submission

“NOFASD is the oldest, dedicated FASD organisation in Australia with a 20-year history as an incorporated charity and many years of grass roots work which preceded incorporation. NOFASD was founded by parents and carers and continues to be the national voice for parents and carers of people living with, and affected by, FASD.”

“Currently, in Australia knowledge of the risks of alcohol consumption during pregnancy is not adequate. Research demonstrates that approximately 60% of Australian pregnancies are exposed to alcohol, most in the period before identification of the pregnancy.”

“Women of child-bearing age who are sexually active and not using birth control effectively contribute to the 50% of pregnancies which are unplanned in Australia. Australian pregnancies are being alcohol exposed at alarming rates, very often in the early stages from conception to pregnancy identification. This places many children at risk of being born with FASD.”

“Everyone has responsibility for prevention of alcohol exposed pregnancies. It is not just the responsibility of women themselves.”

“Culturally appropriate initiatives for people from Aboriginal backgrounds are essential. However, FASD must not be type-cast as an Aboriginal issue. In many cases Aboriginal communities have led the way on FASD and recognised the harm it is doing and taken action to prevent it.”

“An Australian study in the Banksia Hill Youth detention centre determined that 36% of sentenced young offenders had FASD. These compelling statistics should lead to insistence across State Government jurisdictions that screening is undertaken when children enter care or the justice system - at a minimum.”



“There is no doubt that FASD is present and frequently missed. Overseas research confirms this.

A prevention campaign and FASD informed education initiatives are critical to address this. As many as 80% of people diagnosed with FASD were previously diagnosed incorrectly with another disability/disorder.”

“One illuminating comment made by a Judge at a Vancouver conference was “you don’t see people with Down’s syndrome before the courts” highlighting the ‘invisibility’ of FASD and the harm caused by this invisibility.”

The lack of availability of adult diagnosis and lack of recognition that adults need this, contributes to the perception that FASD is a disorder which affects childhood and disappears in adulthood.”

“Australia was relatively late in engaging with FASD but the efforts made in recent years have contributed to a closing of this gap. Australia is beginning to be recognised as a leader in all aspects of response to FASD.”

Recommendations

- **“Initiatives to combat the perception that diagnosis will label a person and that because there is no “cure” there is no value or benefit to diagnosis.** This is a widely held viewpoint and denies those living with FASD their basic human rights, opportunities, services and support.”
- **“Engagement with all of Australia’s state and territory-based education systems is essential.** Many children with FASD are excluded from school because their disability is not understood.”
- **“There has been some outstanding work in Indigenous cultural settings which has embedded consultation and community engagement strategies to produce positive outcomes.** This work can inform ongoing work in at-risk communities.”
- **It will be beneficial to Australia to ensure that FASD is formally recognised in health and services systems and treated as a mainstream disorder,** rather than a problem in Indigenous communities.”

Read the quoted senate submissions here:

https://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/FetalAlcoholSpectrumDi/Submissions

