



Aboriginal Leadership in the proactive treatment of Fetal Alcohol Spectrum Disorder

Not all disabilities look the same

Fetal Alcohol Spectrum Disorder (FASD) is a neurodevelopmental disorder caused by prenatal exposure to alcohol. It may impact multiple areas of development and can lead to a range of physical, behavioural, and intellectual difficulties that may continue into adulthood.

Fetal Alcohol Spectrum Disorder (FASD) is the leading cause of non-genetic/non-inheritable intellectual disability in the world.¹ FASD is a lifelong disability, and like any disability, it requires a whole of community response that includes a “No shame, no blame” approach. NACCHO is committed to supporting families and communities in prevention efforts and interventions to support children and adults living with FASD.

For decades, the Aboriginal community has demonstrated leadership in responding to FASD, from the pioneering work undertaken by Dr Lorian Hayes and the late Dr Jan Hamill and the ongoing work by Aboriginal communities and Health Services, including Fitzroy Crossing, Anyinginyi Health Aboriginal Corporation, Ord Valley, Danila Dilba, Derbarl Yerrigan, Mt Isa, Congress, and other Aboriginal communities around Australia. NACCHO acknowledges the strength and leadership within Aboriginal families and communities, which has been critical in advocating for improved resources and services for people with FASD and undiagnosed disabilities.



What we know

- No alcohol during pregnancy is the best choice.
- Globally, women with tertiary qualifications are reportedly more likely to consume alcohol during pregnancy.ⁱⁱ
- In Australia, approximately 50% of pregnancies remain unplanned, and alcohol consumption may occur before pregnancy is identified.ⁱⁱⁱ
- Most Aboriginal and Torres Strait Islander people do not consume alcohol; however, those that do often consume alcohol at risky levels. Binge drinking is one of the most harmful forms of drinking.
- FASD is not an Aboriginal and Torres Strait Islander problem and remains a serious global health concern for all communities where there is the consumption of alcohol during pregnancy.
- The ongoing impact of colonisation, including systematic racism, has impacted the disproportionate rates of disability amongst Aboriginal and Torres Strait Islander people in Australia and globally.

Best Practice and culture as care

A child born with FASD can thrive despite the challenges of the disability. Individuals with FASD have many strengths, and it is critical to recognise the capacity and resiliency that exists within each person. With early support and ongoing supportive interventions across the lifespan, individuals with FASD can lead successful lives. Achieving good quality of life is critical for all our children and youth. Those living with FASD require support from family, community, human services and the health sector across their lifespan.

The lives of individuals living with FASD can be impacted by stigma. Stigma must be addressed through knowledge and education about FASD, increasing community awareness and offering interventions to help the person live their best life possible.

Early intervention means intervening early in a child's life—from birth to six years. It is crucial to provide diagnosis and support as early as possible, when a child's brain is still developing, to avoid adverse outcomes during childhood and transitioning to adulthood. Children benefit from play, socialisation and stimulation that helps them grow. Children's early years are the critical time when the foundations for healthy development across the lifespan are laid.

Advice for the health workforce

FASD is known as a whole-of-body disorder. Alcohol exposure in the womb affects both the brain and the body. Individuals with FASD will experience some degree of challenges in their daily living and may need support with motor skills, physical health, learning, memory, attention, communication, emotional regulation, and social skills to reach their full potential.^{iv} Support for individuals with FASD may be required from a range of teams within a health service including primary healthcare, disability, allied health, child and maternal health, youth and SEWB.



Whilst most Aboriginal and Torres Strait Islander children are developing typically, Aboriginal and Torres Strait Islander children are at higher risk of developmental and behavioural problems. In the Australian population, about 20% of children start school without the necessary developmental skills for success. This figure is estimated at 40% for Aboriginal and Torres Strait Islander children^v recognising there are higher rates of disability for Aboriginal and Torres Strait Islander children and adults.^{vi}

NACCHO recognises the need to increase confidence and competency in Aboriginal and Torres Strait Islander primary health care for FASD as part of best practice. Resources can be found on the NACCHO website at naccho.org.au/fasd/strong-born.

Download the Strong Born information booklet for multidisciplinary clinic staff at naccho.org.au/fasd/strong-born



References

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- ⁱⁱ Muggli, E., O'Leary, C., Donath, S., Orsini, F., Forster, D., Anderson, P. J., ... & Halliday, J. (2016). "Did you ever drink more?" A detailed description of pregnant women's drinking patterns. *BMC Public Health*, 16(1), 1-13.
- ⁱⁱⁱ Lang, A. Y., Hall, J. A., Boyle, J. A., Harrison, C. L., Teede, H., Moran, L. J., & Barrett, G. (2019). Validation of the London Measure of Unplanned Pregnancy among pregnant Australian women. *PLoS One*, 14(8), e0220774.
- ^{iv} (Basic Information on FASD. Canada FASD Research Network. <https://canfasd.ca/topics/basic-information/>)
- ^v Chando, S., Craig, J. C., Burgess, L., Sherriff, S., Purcell, A., Gunasekera, H., ... & Woolfenden, S. (2020). Developmental risk among Aboriginal children living in urban areas in Australia: the Study of Environment on Aboriginal Resilience and Child Health (SEARCH). *BMC pediatrics*, 20(1), 1-13.
- ^{vi} DiGiacomo, M., Davidson, P. M., Abbott, P., Delaney, P., Dharmendra, T., McGrath, S. J., ... & Vincent, F. (2013). Childhood disability in Aboriginal and Torres Strait Islander peoples: a literature review. *International Journal for Equity in Health*, 12(1), 1-18.