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Summary of Fetal Alcohol Spectrum Disorder (FASD) among Aboriginal and Torres Strait Islander people

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Australian Indigenous Health/InfoNet

The mandate of the Australian Indigenous Health/InfoNet (Health/InfoNet) is to contribute to improvements in Aboriginal and Torres Strait Islander health by making relevant, high quality knowledge and information easily accessible to policy makers, health service providers, program managers, clinicians and other health professionals (including Aboriginal and Torres Strait Islander Health Workers) and researchers. The Health/InfoNet also provides easy-to-read and summarised material for students and the general community.

The Health/InfoNet achieves its commitment by undertaking research into various aspects of Aboriginal and Torres Strait Islander health and disseminating the results (and other relevant knowledge and information) mainly via Australian Indigenous Health/InfoNet websites (<https://healthinfonet.ecu.edu.au>), The Alcohol and Other Drugs Knowledge Centre (<https://aodknowledgecentre.ecu.edu.au>), Tackling Indigenous Smoking (<https://tacklingsmoking.org.au>) and WellMob (<https://wellmob.org.au>). The research involves analysis and synthesis of data and other information obtained from academic, professional, government and other sources. The Health/InfoNet's work in knowledge exchange aims to facilitate the transfer of pure and applied research into policy and practice to address the needs of a wide range of users.

Recognition statement

The Health/InfoNet recognises and acknowledges the sovereignty of Aboriginal and Torres Strait Islander people as the original custodians of the country. Aboriginal and Torres Strait Islander cultures are persistent and enduring, continuing unbroken from the past to the present, characterised by resilience and a strong sense of purpose and identity despite the undeniably negative impacts of colonisation and dispossession. Aboriginal and Torres Strait Islander people throughout the country represent a diverse range of people, communities and groups, each with unique identities, cultural practices and spiritualities. We recognise that the current health status of Aboriginal and Torres Strait Islander people has been significantly impacted by past and present practices and policies.

We acknowledge and pay our deepest respects to Elders past and present throughout the country. In particular, we pay our respects to the Whadjuk Nyoongar peoples of Western Australia on whose Country our offices are located.

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Further information

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The summary, FASD review and more information about FASD among Aboriginal and Torres Strait Islander people can be viewed at: aodknowledgecentre.ecu.edu.au/fasd

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Cover artwork

Feeding the Family Pets by Brian Robinson

Featured icon artwork

by Frances Belle Parker



The HealthInfoNet commissioned Frances Parker, a proud Yaegl woman, mother and artist, to produce a suite of illustrated icons for use in our knowledge exchange products. Frances translates biomedical and statistically based information into culturally sensitive visual representations, to provide support to the Aboriginal and Torres Strait Islander workforce and those participating in research and working with Aboriginal and Torres Strait Islander people and their communities. Frances came to prominence winning the Blake Prize in 2000, making her the youngest winner and the first Indigenous recipient over the 65 year history of the prize.

“Birrinda is the Yagirr name for the mighty Clarence River (NSW). It is this river that is the life giving vein for the Yaegl people. And it is this river which inspires much of my artwork. I am deeply inspired by my Mother’s land (Yaegl land) and the Island in the Clarence River that my Mother grew up on, Ulgundahi Island. The stories which are contained within this landscape have shaped me as a person as an artist and most recently as a Mother. This is my history, my story and it will always... be my responsibility to share this knowledge with my family and my children.”

Introduction

Fetal Alcohol Spectrum Disorder (FASD) is a condition caused by alcohol exposure before birth. During pregnancy, alcohol freely crosses the placenta ^[1]. The baby cannot process the alcohol and this may result in damage to the baby's brain and body. Not all babies exposed to alcohol during pregnancy will develop FASD, but there is no safe level of alcohol use during pregnancy ^[2,3]. FASD is a lifelong condition that results in cognitive, physical and behavioural disabilities ^[2].

FASD occurs everywhere in Australia where people drink alcohol. Many women drink during pregnancy before they know they are pregnant and there is a lack of awareness about how alcohol use during pregnancy can affect the developing baby ^[2,4]. While alcohol use is generally less common among Aboriginal and Torres Strait Islander women than non-Indigenous women, for those who do drink, alcohol use is more likely to be at a risky level ^[5,6].

The National Health and Medical Research Council alcohol guideline for pregnancy recommends that 'To prevent harm from alcohol to their unborn child, women who are pregnant or planning a pregnancy should not drink alcohol' ^[2].

This summary is based on the *Review of Fetal Alcohol Spectrum Disorder (FASD) among Aboriginal and Torres Strait Islander people*. The review summarises the evidence from journal publications, government reports, national data collections and national surveys accessed through the Australian Indigenous HealthInfoNet's database of publications.



The context for FASD among Aboriginal and Torres Strait Islander people

Pre-colonial alcohol consumption

Before colonisation, there was limited alcohol production in Aboriginal and Torres Strait Islander communities. The use of alcohol for medical and ceremonial purposes was governed by strict cultural lore ^[7,8].

Impact of colonisation

Colonisation introduced recreational alcohol use to Aboriginal and Torres Strait Islander people and alcohol began to be used as a payment for labour ^[9]. In the face of introduced diseases and death, colonial violence, and increasing dispossession from Country and communities, alcohol became increasingly available to Aboriginal and Torres Strait Islander people and for many, offered an escape from ongoing trauma and pain ^[10,11].

FASD has emerged as an issue for Aboriginal and Torres Strait Islander people from a combination of factors some of which are related to historical violence, dispossession and intergenerational trauma ^[12].



Women

Drinking during pregnancy is a concern for all Australians. In the 2019 National Drug Strategy Household Survey ^[4]:



55% of respondents indicated that they had consumed alcohol while pregnant before they knew they were pregnant



15% continued to drink once they knew they were pregnant

Most Aboriginal and Torres Strait Islander women do not drink during pregnancy. In the 2018-19 National Aboriginal and Torres Strait Islander Health Survey ^[5]:



Around one in ten Aboriginal and Torres Strait Islander women reported alcohol use during pregnancy

However, high rates of alcohol use have been reported in some communities in remote areas ^[13].

Factors that appear to increase the likelihood of women drinking during pregnancy are diverse and complex ^[14-16]. They include ^[15]:



Ease of access to alcohol in communities, particularly if there is limited cultural leadership or resources to manage problems associated with alcohol



Pregnancy at a young age

Factors that assist women to not drink alcohol during pregnancy include ^[15, 17]:



A strong connection to culture



availability of social supports



supportive partners and family members



Men

In some Aboriginal and Torres Strait Islander communities, pregnancy and alcohol use during pregnancy, may be seen as 'women's business'. However, men can play an important role in influencing women's choices around drinking ^[18, 19]. Participants in one Western Australian study described wanting to stop drinking during pregnancy, but felt pressure from their partner to drink and experienced relationship issues if they tried to leave the drinking environment ^[18].

In a program run in the Kimberley region of Western Australia (WA), Elders requested that Aboriginal men be involved in FASD prevention, with positive results. Men could attend education workshops and brief interventions. These raised awareness about FASD and promoted the responsibilities of being a father from conception, and encouraged fathers to take an active, supportive role throughout the pregnancy by reducing or stopping their drinking ^[18]. The health outcomes of babies have been found to be better when fathers are supportive of mothers during pregnancy and help to make changes at home to minimise stress and alcohol use ^[20].



FASD prevalence

It is not known how many people in Australia have FASD. It is likely that FASD has been underdiagnosed and under-reported, and there is evidence of an increase in diagnoses over time, as clinicians become more familiar with the issue and its importance. There is limited information about the prevalence of FASD in the Aboriginal and Torres Strait Islander population (Table 1). WA is the only state or territory to have published data from population registers of birth defects by Indigenous status ^[21, 22]. Medical record reviews provided a population prevalence estimate for the Top End of the Northern Territory (NT) ^[23] and for Far North Queensland (Qld) ^[24]. A national study through the Australian Paediatric Surveillance Unit provided the only Australia-wide estimate of Fetal Alcohol Syndrome (FAS) ^[25].

Table 1. Prevalence of FAS/FASD among Aboriginal and Torres Strait Islander people

Location	Method of data collection	Prevalence
WA ^[21]	Population register, multiple sources; up to 6 years of age; births 1980-2004	2.76 per 1,000 births (FAS)
WA ^[20]	Population register, multiple sources; up to 6 years of age; births 1980-2010	4.08 per 1,000 births (FASD)
WA remote communities ^[25]	Comprehensive, active assessment of all children in communities born 2002-2003	194 per 1,000 children (FASD)
WA youth detention ^[26]	Comprehensive, active assessment of all young people (10-17 years of age) sentenced to detention 2015-2016	466 per 1,000 young people assessed in detention (FASD)
Top End, NT ^[22]	Medical record review Royal Darwin Hospital; 1990-2000	4.7 per 1,000 live births (FASD)
Far North Qld ^[23]	Outreach paediatric clinics; 2001-2006	15 per 1,000 Aboriginal children <18 years (FASD) 2 per 1000 Torres Strait Islander children < 18 years** (FASD)
National ^[24]	Active reporting by paediatricians through Australian Paediatric Surveillance Unit; 2001-2004	1.5 per 1,000 children <5 years at diagnosis (FAS) 0.81 per 1000 children <15 years at diagnosis (FAS)

** these are the only data available for Torres Strait Islander children separately from Aboriginal children.



Screening and diagnosis

Gaps in health knowledge and practices for recognising and diagnosing FASD were highlighted in 2009 ^[27]. In 2016, the *Australian guide to the diagnosis of FASD* was developed to support clinicians. The guide was updated in 2020 ^[1, 29].

For someone to be diagnosed with FASD:

- it needs to be known that alcohol was consumed by their mother during pregnancy and
- they must have severe impairment to at least three areas of the central nervous system structure or function ^[1].

Someone may also be diagnosed with FASD if they have three facial features that indicate they may have been exposed to alcohol before they were born. These features are:

- small eye openings
- small or absent ridges between the upper lip and nose
- a thin upper lip ^[1].

Early diagnosis of FASD and culturally secure resources and services are vital

to supporting young Aboriginal and Torres Strait Islander people with FASD to build on their strengths and develop strategies to respond to the challenges of living with FASD [26, 30]. Early diagnosis is more likely to prevent or reduce problems that may be associated with FASD such as contact with the justice system and issues with engagement in the community, school and employment [31]. Research has found that accessing diagnosis, support and resources can be affected by stigma and shame [30]. Developing culturally relevant resources with and for communities is important to encourage Aboriginal and Torres Strait Islander families to seek support [26, 30].

Impacts



Health

Aboriginal and Torres Strait Islander people with FASD have been found to experience poorer health and high rates of mental disorders than people without FASD. People with FASD may experience difficulties in many different areas of development, including [32]:

- motor skills
- academic achievement
- impulse control
- cognition
- memory
- controlling emotions
- language
- attention
- social skills.

There is also a range of other conditions that are more common among people with FASD than the general population. These include [32]:

- vision impairment
- chronic ear infection (otitis media)
- hearing loss
- mental health and behavioural conditions due to alcohol and other drug use
- problems with language.



Education

A survey by the National Organisation for FASD (NOFASD) about the education of children with FASD, although not specific to Aboriginal and Torres Strait Islander people, found that young people with FASD experienced discrimination, prejudice and exclusion. They were also more likely to be suspended or expelled from school [33].

There is no known Australian research which looks at the impact of FASD on the educational outcomes for Aboriginal and Torres Strait Islander students, despite the fact that FASD has been recognised as one of the major barriers to a successful education for young people [26].



Justice system

Undiagnosed FASD has been recognised as a major problem facing the Australian criminal justice system and as one of the causes for increasing offending behaviour and incarceration among young Aboriginal and Torres Strait Islander people ^[34]. The Banksia Hill FASD prevalence study in WA, which is so far the only study of FASD in the Australian justice system, found the highest recorded rates of FASD among young people in a justice setting anywhere in the world (see Table 1) ^[27].

There are concerns for people with FASD who come in to contact with the justice system. These concerns include that they may:

- have a lack of understanding about investigative procedures and court processes
- be more prone to impulsive behaviours
- be subject to indefinite detention.

To reduce imprisonment rates in the Aboriginal and Torres Strait Islander population, routine screening for FASD in the child protection system (given the known connections between children in care and youth detention) and on first contact with the criminal justice system is needed ^[30,35].



Community and culture

Community leaders have expressed concern about the effects of FASD on memory, language and communication ^[36,37], and on being able to remember and pass on cultural knowledge. This has been viewed as a threat to the preservation culture due to the impact on the communities' children and young people ^[38].

Aboriginal and Torres Strait Islander individuals with FASD have poorer health ^[26,39], high rates of mental health disorders ^[40,41], poorer education and employment prospects, and are prone to early disengagement from school ^[42]. Individuals with FASD are much more likely to be involved with the criminal justice system and be incarcerated ^[43,44] and to live away from their families, through adoption, or out-of-home care.

FASD prevention and management

FASD is completely preventable. There is no known safe level of alcohol use during pregnancy ^[1].

Primary prevention approaches include:

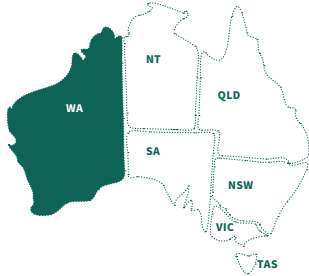
- liquor restrictions initiated by the community
- universal education messages directed towards both the public and health professionals about the dangers of drinking alcohol when pregnant or when planning a pregnancy
- adding the assessment of alcohol use into routine health checks
- supporting pregnant women who are alcohol dependent ^[45-47].

Among Aboriginal and Torres Strait Islander adults there are no known studies on the extent of FASD, the experience of FASD, or programs to manage FASD.

In 2021, the Australian government reported on a Senate inquiry into approaches to preventing, diagnosing and supporting FASD ^[48]. The Committee recognised the importance of community-led approaches and were impressed by the initiatives of Aboriginal and Torres Strait Islander communities to prevent and manage FASD.

FASD research and programs

Australian states and territories have a range of strategies related to the prevention and treatment of alcohol use during pregnancy and FASD [49]. State and territory approaches can vary greatly and until the National FASD Strategic Action Plan 2018-2028 there was no framework for a consistent approach.

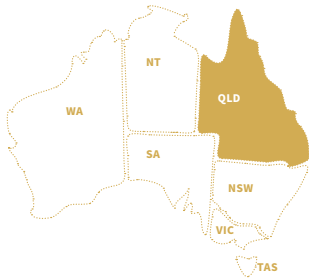


Western Australia: the Marulu Strategy

Following the introduction of community-led alcohol restrictions in 2008 in the remote Kimberley region of the Fitzroy Valley in WA, Aboriginal leaders developed the Marulu (precious, worth nurturing) Strategy to address FASD and early life trauma.

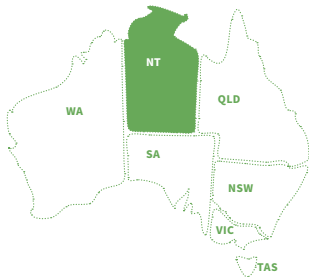
The Marulu Unit:

- provides multi-level advocacy and support for families
- influences policy and service delivery (particularly health, education, justice and child protection services)
- raises awareness about FASD and its prevention [50, 51].



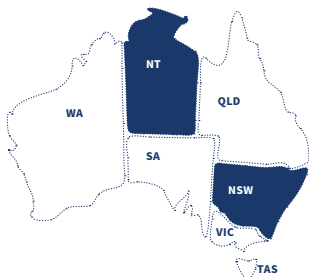
Queensland: the Yapatjarrathati Project

In Qld, a protocol for the first culturally developed tiered FASD assessments for the Yapatjarrathati project has been described [52]. Co-designed by the local community and researchers, the project involves a number of tiers in the process including using culturally relevant materials to explain the project and seek informed consent; a culturally sensitive interview; and a brief developmental assessment [52].



Northern Territory: Anyinginyi Health Corporation

The Anyinginyi Health Aboriginal Corporation in the NT have provided FASD prevention and early intervention in communities since 2011 [53]. They continue to provide education and prevention sessions on FASD with various community groups [54].



Northern Territory and New South Wales

A FASD prevention program in Newcastle, NSW and Alice Springs, NT has been developed, based on the Marulu Strategy [50]. This research program, which is guided by the community, develops and implements health promotion materials, workforce training, and targeted prevention programs primarily to pregnant women to address drinking during pregnancy. It also provides support to young people with FASD who are involved with the justice system [55].



Policies

National Fetal Alcohol Spectrum Disorder (FASD) Strategic Action Plan 2018–2028

The National Fetal Alcohol Spectrum Disorder (FASD) Strategic Action Plan 2018–2028 (the Plan) has been released and is a call out to all levels of government, non-government organisations, communities and individuals to prioritise the prevention of FASD and the support of those living with FASD ^[49].

The Plan identifies four national priorities:

- prevention
- screening and diagnosis
- support and management
- priority groups and people at increased risk ^[49].

NT action plan 2018-2024

Building on the national plan, the NT has an action plan for 2018-2024 which is focused on the prevention of FASD, by increasing public awareness about the risks of consuming alcohol during pregnancy and increasing health literacy in the community to understand more about these risks ^[56].

The NT action plan will upskill workers in Aboriginal Community Controlled Health Organisations to coordinate community responses and raise awareness about FASD ^[56].

Future directions

To increase understanding that FASD can affect the whole community, more work is needed to improve public awareness and assessment in both non-Indigenous and Aboriginal and Torres Strait Islander communities. This would include comprehensive prevalence surveys in addition to collection of information on cases of FASD diagnosed and notified to the national FASD Australian Registry (FASDAR).

Programs that work best for Aboriginal and Torres Strait Islander communities are those that are done with, for and by the communities and their leaders. Where possible, federal and state governments should choose to invest in Aboriginal and Torres Strait Islander community organisations to develop their own evidence-based, fit-for-community FASD prevention, intervention, and management strategies.

Given the impact of FASD on memory and communication, and the importance of both these factors to passing down cultural knowledge, work should be done with Aboriginal and Torres Strait Islander young people with FASD, to support the development of cultural knowledge ‘banks’ to store and pass on cultural knowledge to future generations.

Men are largely absent in FASD interventions. Aboriginal and Torres Strait Islander men need to be involved in research to understand the role they can play in the prevention, treatment and management of FASD.

Children and young people who are involved with the justice system and the child protection system are more likely to have undiagnosed issues associated with FASD. Routine culturally responsive screening and diagnosis are needed for young people when entering the criminal justice and child protection systems.

Moving forward, national coordination, collaboration, evaluation and dissemination of strategies to prevent, diagnose and manage FASD would assist in reducing unnecessary duplication and allow benefits from successful programs to be implemented more broadly and efficiently.

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