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

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

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About this review

The purpose of this review is to provide a comprehensive synthesis of key information on Fetal Alcohol Spectrum Disorder (FASD) among Aboriginal and Torres Strait Islander people in Australia to:

- inform those involved or who have an interest in Aboriginal and Torres Strait Islander health and, in particular, FASD
- provide evidence to assist in the development of policies, strategies and programs.

The review provides general information on the historical, social and cultural context of FASD, and the factors that contribute to FASD. It provides information on the extent of FASD. It discusses the prevention and management of FASD and provides information on relevant programs, services, policies and strategies that address FASD among Aboriginal and Torres Strait Islander people. It concludes by discussing possible future directions for FASD for Aboriginal and Torres Strait Islander people in Australia.

This review draws mostly on journal publications, government reports, national data collections and national surveys, the majority of which can be accessed through the Australian Indigenous Health*InfoNet*'s publications database: <https://healthinfonet.ecu.edu.au/keyresources/publications>.

Information specifically about FASD can be found at: <https://aodknowledgecentre.ecu.edu.au/learn/health-impacts/fasd>. This was not a systematic literature review in that not all articles were synthesised or assessed in the review. Rather, it was a scoping review, whereby the articles collected were used as the basis of the review, with further information sought during the drafting process.

The Health*InfoNet*, consistent with its nomenclature guide, prefers the term 'Aboriginal and Torres Strait Islander' rather than 'Indigenous Australian' for its publications. Also, some sources may only use the terms 'Aboriginal only' or 'Torres Strait Islander only'. However, when referencing information from other sources, authors may use the terms from the original source. As a result, readers may see these terms used interchangeably in some instances. If they have any concerns, they are advised to contact the Health*InfoNet* for further information.

Introduction

Fetal Alcohol Spectrum Disorder (FASD) occurs in all parts of Australian society where alcohol is consumed. Many women drink alcohol before they know they are pregnant and there is a lack of awareness of how alcohol use during pregnancy can affect the fetus at different stages of development in utero [1, 2]. 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 [3].

In Australia, gaps in health knowledge and practices for recognising and diagnosing FASD, and a lack of agreement on a diagnostic model and treatment for FASD were highlighted in 2009 [4]. Since 2016, Australian diagnostic guidelines have been available to support clinicians in screening and assessment for FASD [5, 6]. In March 2021, the Australian government reported on a Senate inquiry into approaches to preventing, diagnosing and supporting FASD [7]. Early identification 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 [8, 9].

FASD is preventable. The National Health and Medical Research Council recommends that, 'To prevent harm from alcohol to their unborn child, women who are pregnant or planning a pregnancy should not drink alcohol' [1]. However general messages about abstinence from alcohol consumption during pregnancy may not always be effective [10]. Individuals and communities require tailored approaches to inform their drinking choices and culturally relevant resources and services are important to encourage Aboriginal and Torres Strait Islander families to seek support.

Key facts

- FASD is preventable.
- An individual with FASD will have life-long challenges.
- Early assessment and diagnosis are key to mitigating negative impacts of FASD.
- FASD prevalence is known to be higher in the Aboriginal and Torres Strait Islander population than the non-Indigenous population.
- FASD prevalence is known to be high among children and young people in child protection and justice.
- More needs to be known about the prevalence of FASD in the Australian community, particularly in early childhood.
- An increased focus is needed on FASD education and prevention, and the management of FASD impairments and treatment options.
- A greater focus on the benefits of involving men in the prevention and management of FASD is required.

- Routine screening for FASD is required for all children and youth on entry to the criminal justice and child protection systems to support early diagnosis.
- FASD screening should consider cultural and neurodevelopmental needs for understanding assessment and diagnosis.
- Future FASD assessment, treatment and public health programs must consider the history of trauma incurred by Aboriginal and Torres Strait Islander communities as a result of colonisation.
- Future FASD prevention strategies and diagnostic assessment programs for Aboriginal and Torres Strait Islander people should be community identified, led, and driven and where required, implemented, in partnership with key stakeholders that are identified by the community.

What is Fetal Alcohol Spectrum Disorder?

Fetal Alcohol Spectrum Disorder (FASD) is a complex neurodevelopmental disorder caused by alcohol exposure before birth. Alcohol freely crosses the placenta, and 1-2 hours after maternal ingestion, fetal blood alcohol concentrations are nearly as high as maternal blood levels and remain higher for longer than in the mother's blood [11]. Alcohol can damage the developing fetus, and the developing brain is particularly susceptible. The degree of damage depends on the stage of pregnancy at which exposure occurs, the frequency and level of alcohol exposure, and maternal and fetal genetic and metabolic factors [12, 13]. Exposure in the first trimester can result in characteristic facial features and congenital anomalies, while exposure at any time in pregnancy can affect the developing brain. There is no known level of prenatal alcohol exposure that has been guaranteed as safe for the developing embryo and fetus. This is reflected in the National Health and Medical Council alcohol guideline for pregnancy, which states that 'To prevent harm from alcohol to their unborn child, women who are pregnant or planning a pregnancy should not drink alcohol' [1].

Identifying FASD: screening and diagnosis

Initially in Australia, FASD diagnostic guidelines were developed in 2010, and in 2013, a group of experts and community representatives reviewed the available international information on FASD screening and diagnosis and developed consensus recommendations for the diagnosis of FASD in Australia [14]. The *Australian guide to the diagnosis of FASD* was developed in 2016 and reviewed in 2020 [5, 6].

A diagnosis of FASD requires evidence of prenatal alcohol exposure and severe impairment in three or more domains of central nervous system structure or function, and exclusion of other causes that would account for the impairments [6]. Co-existing or alternative diagnoses, including genetic conditions (e.g. chromosomal anomalies, microdeletions or duplications¹), effects of other

1 A microdeletion or duplication refers to the absence or repetition of a small (submicroscopic) segment of a chromosome.

teratogens² and prenatal exposures, as well as the effects of postnatal exposures such as early life trauma and brain injury, should be considered [6]. The presence of three sentinel³ facial features is considered pathognomonic (specific characteristics) of alcohol exposure [6], so in this instance a diagnosis of FASD with three facial features can be made if prenatal alcohol exposure is unknown. The three sentinel facial features are: short palpebral fissures (small eye openings); a smooth lip philtrum (diminished or absent ridges between the upper lip and nose); and a thin upper lip that is without volume.

The *Australian guide to the diagnosis of FASD* [6] refers to FASD as a diagnostic term with two diagnostic sub-categories:

1. FASD with three sentinel facial features
2. FASD with less than three sentinel facial features.

These diagnostic terms are used in Australia, Canada and New Zealand [15]. The ten domains that are recommended to be assessed when considering a diagnosis of FASD are summarised in Table 1.

In Australia, FASD with three sentinel facial features replaces the diagnosis of Fetal Alcohol Syndrome (FAS), but without a requirement for growth impairment [6]. FASD with less than three sentinel facial features encompasses descriptors that may be used elsewhere or were previously in use, such as Partial Fetal Alcohol Syndrome and Neurodevelopmental Disorder-Alcohol Exposed [16].

At present, African American norms are used for lip philtrum measurements and Caucasian norms for palpebral fissure length measurements [6, 17]. Australian research has been published on measurement of facial features using two-dimensional digital technology, which may lead to better fitting norms for Aboriginal children [18].

The diagnosis of FASD requires multidisciplinary assessment, with a comprehensive physical and developmental assessment, as well as psychometric testing, preferably by a multidisciplinary diagnostic team, and typically led by a medical specialist such as a paediatrician, psychiatrist, or geneticist. A neuropsychologist, occupational therapist and speech pathologist are also usually involved in the assessment [6].

It is ideal for all 10 domains to be assessed, as management strategies can then build on those domains in which the individual has relative strengths while addressing domains with impairment.

The assessment process may be confronting for the individual or caregiver, who should provide informed consent beforehand, and receive appropriate support as required. For Aboriginal and Torres Strait Islander people, diagnosis should be provided in the presence of extended family members if possible, and where

2 A teratogen is a substance that causes damage to a developing embryo or fetus. Alcohol is a teratogen.

3 Sentinel refers to indicators associated with a disease or condition.

Table 1. Australian diagnostic criteria and categories for Fetal Alcohol Spectrum Disorder (FASD)

Diagnostic criteria	Diagnostic categories	
	FASD with 3 sentinel facial features	FASD with < 3 sentinel facial features
Prenatal alcohol exposure	Confirmed or unknown	Confirmed
Neurodevelopmental domains <ul style="list-style-type: none"> • Brain structure/Neurology • Motor skills • Cognition • Language • Academic achievement • Memory • Attention • Executive function, including impulse control and hyperactivity • Affect regulation • Adaptive behaviour, social skills or social communication 	Severe impairment* in at least 3 neurodevelopmental domains	Severe impairment* in at least 3 neurodevelopmental domains
Sentinel facial features <ul style="list-style-type: none"> • Short palpebral fissure • Smooth philtrum • Thin upper lip 	Presence of 3 sentinel facial features	Presence of 0, 1 or 2 sentinel facial features

* Severe impairment is defined as either a global score or a major subdomain score on a standardised validated neurodevelopmental scale that is <2 SD below the mean or < 3rd percentile.

Source: Bower et al., 2020 [6]

appropriate, in language. This is particularly salient when biological parents or family are involved. An assessment report outlining the individual's strengths and difficulties, and recommendations should be provided to the family and referring clinician or agency [6].

FASD screening and diagnosis: cultural perspectives

Qualitative studies have been conducted to ascertain the benefits and challenges of FASD assessments from multiple perspectives [8, 19]. In these studies, the participants were Aboriginal young people in detention (n= 38, Aboriginal participants = 27) and their caregivers (n= 17, Aboriginal participants = 12).

The researchers found that stigma and shame were important considerations when screening for and diagnosing FASD, including intergenerational shame that can be experienced by Aboriginal people at the interface of traditional and contemporary culture and institutions, as this can affect the uptake of diagnostic support and resources [8].

Ultimately, the aim should be to view FASD screening and diagnosis as a protective factor which can assist to develop the capacity of families to recognise that their child/ren may be struggling with neurodevelopmental impairments. By developing with and for communities, a range of culturally relevant and informed resources, and encouraging early diagnosis, there is potential to mitigate the impact of the secondary disabilities associated with FASD, and promote recovery and avoid exposure to adverse experiences that can lead to disengagement from school, mental health problems, alcohol and other drug (AOD) use and subsequent involvement with the youth and adult criminal justice system [8, 9].

Health impacts of FASD

Many of the health, functional and behavioural effects of FASD relate to the domains of neurodevelopmental impairment (see Table 2).

A systematic review has documented a wide variety of co-morbid conditions that are also associated with FASD [20], the most common of which were within the categories of congenital malformations and mental and behavioural disorders. Compared with the general population, conditions with the highest prevalence in individuals with FASD were:

- visual impairment
- chronic serious otitis media
- hearing loss (conductive and sensorineural)
- mental health and behavioural disorders due to AOD use
- expressive and receptive language disorders and
- conduct disorders.

Preterm birth is also more common among infants with FASD. In addition, human and preclinical studies suggest that prenatal alcohol exposure may affect other organ development and function. There have been systematic reviews of possible effects of prenatal alcohol exposure on immune, metabolic, cardio-renal, liver and reproductive functions [21, 22], although the evidence is limited.

Table 2. Domains and neurodevelopmental impairments

Domain	Impairments that may be present
Brain structure/Neurology	Microcephaly, structural brain anomalies, seizures or other functional neurological anomalies (with no other known cause)
Motor skills	Impaired fine motor skills (manual dexterity, precision), gross motor skills (balance, strength, co-ordination, ball skills and agility), graphomotor (handwriting) skills and visuo-motor integration
Cognition	Low IQ, impaired verbal and non-verbal reasoning skills, processing speed
Language	Impairment in expressive and/or receptive language
Academic achievement	Problems with reading, mathematics, and/or literacy (including written expression and spelling). Includes specific learning disorder according to DSM-5 criteria
Memory	Impairments in overall memory, verbal memory, and visual memory
Attention	Concentration, task focus and work organisation
Executive function, including impulse control and hyperactivity	Problems in organising and controlling one's own thoughts and behaviours in order to fulfil a goal with maximum efficiency. For the purposes of FASD diagnostic criteria, also includes impulse control and inhibition response, hyperactivity, working memory, planning and problem solving, shifting and cognitive flexibility
Affect regulation	Depressive and anxiety disorders meeting DSM-5 criteria
Adaptive behaviour, social skills or social communication	Impaired life skills which may affect how well an individual can live independently in a safe and socially responsible manner and how they cope with everyday tasks. Includes Autism Spectrum Disorder according to DSM-5 criteria.

Published evidence for co-morbidity associated with FASD in Aboriginal and Torres Strait Islander people specifically is currently limited. The Lililwan study in the Fitzroy Valley (n=108; 21 with FASD) found a greater occurrence of thought problems (including suicidal ideation) and post-traumatic stress problems in children with FASD compared with children without FASD [23]. Of the children in the Lililwan study, 40% were referred to child mental health services [24]. However, it is known that FASD is associated with high rates of psychiatric, emotional, conduct and sleep disorders that often present in childhood and continue through adolescence into adulthood [9, 25]. Studies have highlighted the high rates of attempted suicide and suicide by individuals where FASD is present [26-28]. There is no known research which has specifically examined the association of psychiatric disorders with FASD in the Aboriginal and Torres Strait Islander community. A few studies have collected data about mental health disorders in a range of FASD prevalence study settings [9, 19, 24, 29].

In a qualitative study of Aboriginal youth in detention, up to 90% who received a FASD diagnosis were identified by their caregivers as having an additional diagnosis of a mental health/conduct disorder [8, 19]. High rates of mental health conditions in the Aboriginal and Torres Strait Islander community reflect the complex relationship between history and multiple contemporary influences related to biological, social, community and environmental factors, and with living arrangements such as residential institutions, prisons and foster care [19, 30]. Early diagnosis is important, as it allows for intervention to begin when neurodevelopmental pathways are more plastic and is more likely to prevent or reduce secondary problems with engagement in the community, school, employment, and contact with the justice system [31].

FASD prevalence

FASD occurs in all parts of Australian society where alcohol is consumed. Although alcohol use is generally less common among Aboriginal and Torres Strait Islander women than non-Indigenous women in Australia, consumption is often at higher levels [3, 32].

The earliest reports of FASD in Australia appear in the late 1970s–early 1980s. In 1978, six children affected by maternal alcoholism were reported, followed by two further case series which included a total of 27 children, of whom six had an Aboriginal mother [33].

In Australia, gaps in health knowledge and practices for recognising and diagnosing FASD, and a lack of agreement on a diagnostic model and treatment for FASD were highlighted in 2009 [4]. It is acknowledged that there is likely underdiagnosis of FASD and under-reporting of FASD in Australia, and there is evidence of an increase in diagnoses over time, as clinicians become more familiar with the diagnosis and its importance. More than a two-fold increase was seen in notifications of cases to the Western Australian (WA) Register of Developmental Anomalies [34] for births in 2000-2010 compared with 1980-1989 and there was a significant increase in FAS over the study period in notified cases in the Australian Paediatric Surveillance Unit study [35].

The publication of the *Australian guide to the diagnosis of FASD* [6] has provided consistency about the diagnostic criteria for use in Australia. Training of clinicians in its application and the development and expansion of clinics undertaking multidisciplinary assessment will likely lead to increased estimates of FASD prevalence.

FASD prevalence: Aboriginal and Torres Strait Islander people

There are limited available estimates of prevalence of FASD in the Australian Aboriginal and Torres Strait Islander population (Table 3). WA is the only state or territory to have published data from population registers of birth defects by Indigenous status [34, 36]. Medical record reviews provided a population prevalence estimate for the Top End of the Northern Territory (NT) [37] and for Far North Queensland (Qld) [38] and a national, prospective study through the Australian Paediatric Surveillance Unit provided the only Australia-wide estimate of FAS [35]. A second FASD prevalence study through the Australian Paediatric Surveillance Unit is underway [39]. There have also been two studies that have actively estimated FASD prevalence in specific subpopulations: one, Australia's only population-based study, conducted in remote Aboriginal communities in the North West of WA [9, 40] which established a prevalence of 19% (all Aboriginal children); and one in youth detention in WA [29] (Table 3). This latter study was undertaken in WA to measure the prevalence of FASD in young people in Banksia Hill Detention Centre for youth [29, 41], in the only FASD prevalence study to be undertaken in an Australian corrections facility. The study established from assessments with 99 participants, a FASD prevalence of 36% which is the highest global estimate in a justice setting. Seventy five percent of participants were Aboriginal, and of these participants, 47% received a diagnosis of FASD [29]. While almost all eligible children or young people were assessed through a comprehensive physical and neurodevelopmental examination in both the Lililwan and Banksia Hill studies, and the prevalence of FASD was high, they are both small studies (around 100 young people in each) and special populations. Hence the findings may not be reflective of prevalence more generally in Aboriginal and Torres Strait Islander people.

There is wide variation in the estimates from the studies in Table 3, in part due to different methods and periods of ascertainment, differing populations and different diagnostic criteria [42]. Authors also acknowledge the high likelihood of under-reporting in studies based on retrospective review or register-based data.

The context for FASD among Aboriginal and Torres Strait Islander people in Australia

The social determinants of health have become known as 'the causes of the causes' [43] and have redefined global understandings of health. The social determinants of health are defined as 'the conditions in which people are born, grow, live, work and age' [44] and call for understanding the way individual problems relate to causes of broader population incidence and the way these

Table 3. Prevalence of FAS/FASD among Aboriginal and Torres Strait Islander people

Location and publication	Ascertainment method	Prevalence
Western Australia [36]	Population register, multiple sources; up to 6 years of age; births 1980-2004	2.76 per 1,000 births (FAS)
Western Australia [34]	Population register, multiple sources; up to 6 years of age; births 1980-2010	4.08 per 1,000 births (FASD)
Top End, Northern Territory [37]	Medical record review Royal Darwin Hospital; 1990-2000	4.7 per 1,000 live births (FASD)
Far North Queensland [38]	Outreach paediatric clinics; 2001-2006	15 per 1,000 Aboriginal children <18 years (FASD) 2 per 1000 TSI children < 18 years** (FASD)
National [35]	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)
Western Australian remote communities [9]	Comprehensive, active assessment of all children in communities born 2002-2003	194 per 1,000 children (FASD)
Western Australian youth detention [29]	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)

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

contexts then translate into how socio-economic and socio-cultural factors impact health [44, 45]. For Aboriginal and Torres Strait Islander people, health is understood as more than physical health, but includes the social, emotional and cultural wellbeing, where individuals can reach their potential and contribute to the wellbeing of the entire community [46]. Considering the way

Aboriginal and Torres Strait Islander people view health and contribute to their own wellbeing is critical to positive outcomes for individuals and communities.

Our understanding of FASD cannot be separated from an understanding of the historical context from which alcohol use in Aboriginal and Torres Strait Islander communities has emerged. There was limited alcohol production in Aboriginal and Torres Strait Islander communities prior to colonisation, with the use of a variety of plant-based fermentation for medical and ceremonial purposes, governed by strict cultural lore [47, 48]. With the arrival of the First Fleet and subsequent establishment of the colonies, recreational use of alcohol was introduced to Aboriginal and Torres Strait Islander people as it weaved its way into the social fabric of the nation and became a currency for labour [49]. As the colonies grew, Aboriginal and Torres Strait Islander people and communities were increasingly dispossessed from their country and moved to missions, children were taken away and placed in homes for the purpose of assimilation into 'white' society [50]. 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 the enduring trauma and pain incurred by these colonising forces [51, 52].

With deleterious effects, alcohol use was increasingly sanctioned and by 1929 all states and territories prohibited the sale of alcohol to Aboriginal and Torres Strait Islander people and prohibited the purchase or possession of alcohol by Aboriginal and Torres Strait Islander people [50]. They were excluded from the pubs and other social arenas that were shaping the post-colonial nation and were subject to heavy surveillance and punishment [48, 52]. As a result of these discriminatory and exclusionary legal controls, individuals and communities were increasingly targeted by illegal alcohol trading, with women particularly exploited for sexual labour [53]. The fear of being caught with alcohol resulted in large amounts of alcohol being consumed quickly, often without adequate nutrition [50, 54].

The impact of colonisation is generally well understood as connected to the dispossession of kin, culture and land [55-58]. The widespread destruction of kinship networks, the loss of cultural possessions, knowledge and language, the loss of place, and the loss of collective identity well explain the contemporary high rates of mental health problems and trauma, family violence, homelessness, and AOD problems [48, 59]. The over-representation of Aboriginal and Torres Strait Islander people in the child protection and youth and adult criminal justice system has long been attributed to this history [55, 60]. In relation to alcohol, the pattern of rapid heavy drinking for fear of being caught established drinking patterns which are still observed in many contemporary Aboriginal and Torres Strait Islander Australians [48, 61]. A small prevalence study identified one of the highest rates of FASD in Indigenous communities in the world, recognised firstly, due to the devastating social consequences of alcohol consumption in communities [9, 62, 63]. It is important to emphasise that FASD has not emerged due to poor drinking decisions by Aboriginal and Torres Strait Islander mothers; but rather from a confluence of

factors related to historical violence and colonial dispossession and subsequent intergenerational trauma [64]. The successful provision of education about, and interventions to identify and deal with the social impacts of FASD cannot be separated from these historical factors for Aboriginal and Torres Strait Islander communities and the social and economic determinants of alcohol use [65].

FASD: Women

Alcohol consumption during pregnancy is a concern for all Australians. In 2019, the National Drug Strategy Household Survey reported that 55% of respondents indicated that they had consumed alcohol while pregnant before they knew they were pregnant and 15% continued to drink after they knew they were pregnant [2]. In the 2018-19 National Aboriginal and Torres Strait Islander Health Survey, around 9% of Aboriginal and Torres Strait Islander women reported alcohol use during pregnancy [66]. High rates of alcohol use during pregnancy have been reported for vulnerable populations and some communities in remote areas [40, 67]. In one community, a study found of the 115 respondents with AUDIT-C⁴ scores, 60 (52%) reported alcohol use during pregnancy. Among the 60 women who drank in pregnancy, 57 (95%) did so at risky or high-risk levels [68].

The reasons for high levels of prenatal alcohol consumption among some Aboriginal and Torres Strait Islander women are diverse and complex [61, 69, 70]. One study identified that pregnancy, particularly at a young age is one determinant of social disadvantage, and both pregnancy and alcohol consumption can validate the assumptions of adult status, often in a way that was accepted and normalised [69]. Young women, who also have a high number of unplanned pregnancies, are more likely to drink during pregnancies due to peer pressure and the need to maintain social connections [10]. Moreover, ease of access to alcohol can be a considerable problem for communities especially if they have limited cultural leadership or resources to help manage problems associated with alcohol, and particularly prenatal alcohol consumption and resultant FASD.

Aboriginal women have led the way for increasing awareness about the devastating social impacts alcohol has had on communities. In WA's Fitzroy Valley Aboriginal community leaders raised concern about early deaths, self-harm and suicide, languishing grief and despair, children exposed to drinking and violence in communities, high rates of criminal involvement, low employment and school attendance rates, child protection concerns, and children suspected of being affected by prenatal alcohol exposure and undiagnosed FASD [71]. Highly relevant to community leaders, who advocated for liquor restrictions in the community, was concern about the effects on memory, language disorder and communication difficulties from FASD [72, 73], and the threat to retention, preservation and translation of cultural knowledge due to the impact on the communities' children and young people [74]. Further, information and messaging about alcohol related harm was inadequate [48, 75].

4 AUDIT-C is an assessment tool for identifying harmful drinking

General messages about abstinence from alcohol consumption during pregnancy may not always be effective [10]. Individuals and communities require tailored approaches to inform their drinking choices. One study found there was a need to correct the inconsistency in messaging, including misrepresentation about the quantity and types of alcohol considered, to present more accurate information and reframe messages of the harm of FASD and to develop an holistic approach to alcohol messaging which incorporated the social and cultural context of women's drinking [10]. In this study, the perspectives of Aboriginal and Torres Strait Islander women in the NT and Victoria, found that drinking decisions were often based on their own perceptions of their babies' growth 'inside them' and were influenced by listening to health workers, and witnessing children in the community born to drinking mothers [10]. Additionally, mental health issues, addictions, violence and homelessness or unsafe accommodation influenced drinking choices. Abstinence from drinking alcohol during pregnancy was assisted where culture is strong, social supports are available and where partners and family members are supportive [10, 69].

FASD: Men

In the Aboriginal and Torres Strait Islander community, there is potential for the notion of pregnancy, and thereby prenatal alcohol exposure to be perceived as 'women's business', despite the fact that men can hold significant power and have a strong influence on the drinking choices of women [76, 77]. Few studies have focused on the role of men and FASD [63, 76]. In one study in WA, women expressed a desire to stop drinking, but reported partner pressure to drink to show commitment to both their family circles and to their partners and attempts to move away from the drinking environment resulted in relationship problems, including violence and abuse [76]. This program is the only one found in Australia that, at the request of Elders, purposefully involves Aboriginal men in all aspects of their FASD work, with positive results. In addition to their work on FASD prevention with women and girls, they run education workshops and brief interventions that focus on men, raise awareness about FASD that promote the responsibilities of being a father from conception, and urge fathers to take an active, supportive role throughout the pregnancy by abstaining or cutting down their alcohol consumption [76].

There is research that supports an approach to include men in all aspects of FASD prevention, though none of the research is Aboriginal and Torres Strait Islander specific. These studies show that having a supportive male partner who alters their own diet and alcohol use as well as minimises stress on the mother can improve the odds of having a healthy child [78]. Pregnant mothers are also more likely to attend all medical and other appointments during pregnancy if they have a supportive partner [79, 80]. Infant health outcomes are better when fathers are supportive of mothers during pregnancy and assist in making changes at home to minimise stress and alcohol use [79]. Although there is an expanding awareness of the important role Aboriginal and Torres Strait Islander men can play in FASD interventions and an emphasis on the importance of strengthening family relationships, the role of men in the prevention, management and treatment of FASD requires a greater focus in future FASD initiatives [81].

Family and communities

There are various underlying factors that constitute an historical pattern of disruption involving Aboriginal and Torres Strait Islander systems of law, morals, authority and punishment that triggered the onset of widespread social and psychological problems which are now being passed from generation to generation. There are strengths in all Aboriginal and Torres Strait Islander communities, however, in some communities, high rates of violence and crime are widespread [82] and combined with factors such as the collapse of established family patterns and community structures, violence and dysfunction renew themselves over generations [83-85]. Some Aboriginal and Torres Strait Islander families are now trapped in environments where alcohol-related crime has become accepted as normal behaviour and, as such, is transmitted across generations [83, 86, 87]. FASD is one of the outcomes of this behaviour and without Aboriginal and Torres Strait Islander community identified and led interventions, will have significant social impacts for individuals, families and communities.

Social impacts of FASD

Aboriginal and Torres Strait Islander individuals with FASD have; poorer health [9, 65], high rates of mental health disorders [88, 89], poorer education and employment prospects, and are prone to early disengagement from school [23]. Individuals with FASD are much more likely to be involved with the criminal justice system and be incarcerated [90, 91] and to live away from their families, through adoption, or out-of-home care.

FASD: Educational outcomes

A survey undertaken by the National Organisation for FASD (NOFASD) into the education of children with FASD, although not specific to Aboriginal and Torres Strait Islander people, found children and young people with FASD experienced discrimination, prejudice and exclusion and were more likely to experience school suspension or expulsion [92]. The survey, which was undertaken with the caregivers of children with FASD, also found mixed experiences in relation to flexibility in education settings, and children lacked individualised support and planning. Further, children were unable to access culturally responsive education due to their disability, and teachers had limited training about FASD, the onus being on caregivers to educate staff about FASD. As a result, children were reported to be handled inappropriately with ineffective behaviour management and abusive practices such as being isolated, being restrained, the use of violence including abuse, verbal abuse, neglect and exploitation. Concerningly, there were few avenues for reporting these abuses. The report made a number of recommendations to improve the educational outcomes for students with FASD, including introducing an external complaints mechanism for reporting incidents of violence. Many of these recommendations have been previously highlighted in the literature about the experiences of Aboriginal and Torres Strait Islander children, and include: improving FASD training for all education sector staff [75]; engaging supports to improve school retention [93]; and developing a workforce culture of inclusion and respect to address discriminatory attitudes and practices [93-96].

The neurodevelopmental impairments in executive functioning and self-regulation skills which come with FASD can significantly influence educational outcomes and require specific management [23, 97]. Little is known about the effects of FASD for Aboriginal and Torres Strait Islander people on educational outcomes, particularly given that there are many other confounding factors which influence poorer educational outcomes: hearing impairments, learning in a western education system which uses Standard English and is often not their first language, or being assessed with culturally and linguistically biased testing [98]. Studies and interventions undertaken with Aboriginal children and youth with FASD have found that there are unique and complex educational needs that contribute to their learning styles and behaviours [69]. Education based intervention research has been undertaken to assist to develop the self-regulatory skills of remote-living Aboriginal children and youth living with FASD and neurodevelopmental impairments [97, 99]. The results of this research were mixed with some improvement for some of the children in their ability to moderate their behaviour and improve educational outcomes. However, the study sample was small and overall, the results against key measures were not statistically significant [99].

Students with FASD can struggle with learning, concentrating, managing their own behaviours [23], and difficulties with language and communication [72]. This can then lead to conflict with teachers and peers, school disengagement, and low academic achievement [23]. There is no known Australian research which examines 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 children and youth [9]. It has been recommended that FASD be recognised as a disability with the National Disability Insurance Scheme (NDIS), and that a FASD screening and management program for all students be developed, and training and professional development opportunities be provided for education staff [100]. In response, the Australian government has funded projects to develop resources for pre-school and school educators [101].

One study examined educational experiences in detained Aboriginal youth [19] undergoing assessment for FASD [29] and found that the social complexity in their lives combined with their neurodevelopmental challenges meant participants described irregular attendance and early disengagement from school. Qualitative research undertaken as part of the study [19] highlighted that although most of the participants said they liked school, they spoke of being negatively labelled or being 'given up on'. Yet, the research also found that school was an important source of social and sporting opportunities. Unrecognised FASD and associated neurodevelopmental impairments however, impeded the potential for different outcomes for the young people. Ultimately, the research highlighted a clear need for well-resourced neurodevelopmentally and culturally responsive education services both in the community and in youth detention centres [19].

FASD: Criminal justice system

Globally, research has consistently highlighted the high prevalence of FASD among Indigenous populations involved with the criminal justice system [20, 64, 102, 103]. Undiagnosed and untreated 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 in Aboriginal and Torres Strait Islander youth [102]. Individuals with FASD who come into contact with the criminal justice system raise serious concerns regarding fairness and equity from their first contact with the police. They may not understand investigative procedures and may not be fit to stand trial due to diminished responsibility, their capacity to testify, and the reliability of that testimony [64, 104]. When they come before the courts, they do not always understand court processes and present with language disorders and poor communication skills [19, 29, 72, 73]. An individual with FASD is prone to impulsive, petty crime where their neurodevelopmental impairments prevent them learning from consequences and they are more likely to be incarcerated. Once incarcerated, they can be susceptible to bullying and coercion by other inmates, are less likely to understand and respond appropriately to instructions or orders and be punished and managed by custodial and non-custodial workforces who are unaware of their needs [105]. They can also be subject to indefinite detention [106].

Given the complexity and cognitively demanding nature of legal proceedings, it is likely that processes at all stages of engagement with the criminal justice system (including police arrest and interviews, determining fitness to plead, court proceedings, sentencing, supervision orders and incarceration) will need to be adapted to appropriately consider the needs of an individual with FASD. Aboriginal and Torres Strait Islander peoples have an additional layer of need relating firstly to intergenerational trauma incurred as a result of past colonial policies, language diversity, and different cultural ways of being and knowing [106, 107]. Supporting the implementation of community led, designed and controlled diversionary programs for justice-involved children and adults with FASD has been recommended [75, 106].

The Banksia Hill FASD prevalence study in WA, which has to date been the only study of FASD in the Australian justice system, found the highest documented prevalence of FASD among youth in a justice setting internationally (see Table 3) [29]. For the majority, FASD and neurodevelopmental impairments had not previously been recognised, despite significant involvement with child protection, health and education services [8, 19, 29]. In order to reduce imprisonment rates in the Aboriginal and Torres Strait Islander community, routine screening for FASD in the child protection system (given the known intersections between children in care and youth detention) and on first contact with the criminal justice system is needed [8, 108]. The young people in this study, and in detention, were mostly Aboriginal youth who required recovery-focussed, coordinated support for trauma and neurodevelopmental impairments and resources which were culturally responsive to their needs and understandings [8, 19].

There is little research into the prevalence and effects of FASD among adults. Diagnosing FASD in adults is difficult for various reasons including confirming prenatal alcohol exposure [61], and other factors which may account for cognitive impairments such as complex trauma or acquired brain injury [29]. Of particular concern, is that it is well established that people with FASD are at much greater risk of involvement with the criminal justice system. The imprisonment rate for Aboriginal and Torres Strait Islander men was 41.94 per 1,000 population in December 2020 [109]. More research is needed to understand if FASD is part of the disturbing level of over-imprisonment of Aboriginal and Torres Strait Islander men and explore alternative options for support in a community setting and management, using a multidisciplinary approach across justice, health, education, and other relevant systems.

As a matter of human rights, people with cognitive disabilities should whenever possible be cared for in the community and not be in the prison system [110]. More choices for sentencing options, such as enhancing the capacity of Aboriginal communities to offer place-based, diversionary alternatives for people with FASD in the justice system has the potential to reduce rates of incarceration, especially for young people [111]. In addition, the state could save money by investing in community-based approaches to support people with FASD. The Productivity Commission estimated in a report on government services in 2020 the cost of keeping an adult in prison was \$231.39 per day [112]. This figure did not include capital costs, which include building maintenance and other related expenses which was an additional \$78.94 per adult in prison per day. This together puts the cost per adult in prison per day at \$310.33. It is not known how many adults in Australian prisons have FASD but given the high prevalence of FASD in juvenile detention it is quite possible the numbers are large. To reduce the number of people in prison who have FASD (and, in so doing, potentially reduce the cost of imprisonment), would require policy change and a long-term strategy toward improving the lives of people with FASD.

FASD interventions: prevention, management and resources

FASD is preventable. There is no known safe level of prenatal alcohol exposure and the recommendation in Australia is that ‘women who are pregnant or planning a pregnancy should not drink alcohol’ [6]. While knowledge of the need to avoid prenatal alcohol exposure and hence FASD is necessary, knowledge alone is not sufficient, and an understanding of behavioural, social and cultural factors supporting alcohol use, as well as barriers to abstinence, and circumstances such as unplanned pregnancy is important in any effective prevention program. Primary prevention approaches include; universal education messages directed towards public and professionals alike about the dangers of consuming alcohol when pregnant or when considering pregnancy, embedding the assessment of alcohol use into routine health checks, and supporting pregnant women who are alcohol dependent [113, 114]. Currently, a national campaign is being developed by the Foundation for Alcohol Research and Education to increase awareness of the risks associated with alcohol consumption; raise awareness of alcohol related conditions, including FASD; and reduce FASD prevalence by providing support and information to women

to enable healthy choices in pregnancy, and when planning a pregnancy [115]. Secondary prevention approaches target women at risk, in this instance women of reproductive age and/or who may be pregnant and who consume alcohol. Tertiary approaches target women at high risk of drinking during pregnancy and supporting families who already have a child/ren diagnosed with FASD [116].

An online scan exploring health promotion resources for Aboriginal and Torres Strait Islander communities for FASD prevention found 60 resources that met criteria for cultural appropriateness and targeted to a range of people, from pregnant women, family members and health professionals [117]. None were specifically designed for grandmothers or aunts, although many were considered suitable for use with these culturally important groups. There were three resources identified that were targeted at men. All three were limited in scope and aimed at men helping women to abstain from alcohol during pregnancy by changing their own behaviour including alcohol consumption. The online scan found that while there were resources there were difficulties accessing most of the resources. This was largely due to maintenance issues including broken web links and loss of funding [117].

A systematic review of international FASD prevention interventions in Indigenous communities was published in 2018 [118]. From 10 studies, only one was Australian [76]. This prevention program was conducted in Northern WA and consisted of five target groups: all antenatal clients, all women of child-bearing age, service staff, local men and the community [76]. The prevention strategies included providing education about FASD and information about contraception. The service, a local Aboriginal Community Controlled Health Service, conducted drug and alcohol assessments at three stages of the pregnancies of women who attended the antenatal clinic. The results, based on 78 pregnant women, showed a high level of alcohol consumption in pregnancy (over 80%). Following receipt of FASD education, 56% reported abstaining from alcohol and 14% reported a reduction in prenatal alcohol consumption [76]. Another WA study reported, since the systematic review was published, a comparison was undertaken to examine alcohol consumption reported to midwives [118]. Between 2008 and 2015, women reported significantly lower alcohol use during pregnancy where community-led prevention efforts took place. These community interventions involved; mass media attention to the dangers of alcohol use to an unborn child and the potential for FASD, health promotion messaging with an increased focus at times where alcohol use was known to be higher, the screening of all pregnant women for alcohol use with referrals for services and specialised support, an increase in diagnostic services [118], and the introduction of liquor restrictions [119].

There have been no known studies describing the extent of FASD, the experiences of, or interventions which manage and treat FASD for Aboriginal and Torres Strait Islander adults. Interventions for FASD assessment and diagnosis are described in the literature [29, 120]. Increasingly, these interventions are being designed and led by Aboriginal and Torres Strait Islander people [62, 76, 120, 121]. In March 2021, the Australian government reported on a Senate inquiry into approaches to preventing, diagnosing and

supporting FASD [7]. The Committee considered 16 terms of reference covering prevention, diagnosis and support for FASD and delivered 32 recommendations. In relation to Aboriginal and Torres Strait Islander people, the Committee noted that ‘Alcohol-related harm in First Nations communities is strongly linked to the impacts of colonisation, entrenched poverty and inter-generational trauma’. They 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. This is specifically reflected in Recommendation 32: ‘The committee recommends the Department of Health allocate specific funding aimed at supporting First Nations community-led projects to prevent and manage FASD’.

FASD research, programs and initiatives in states and territories

States and territories have undertaken or commissioned research and have a range of strategies related to the prevention and treatment of prenatal alcohol exposure and FASD [122]. State and territory approaches are highly variable and there was no framework for a consistent approach until the National FASD Strategic Action Plan 2018-28 (described below).

Services provided by states and territories include; maternal health assessments that include alcohol use and referral to appropriate services, brief intervention support for identified substance use in pregnancy, information and supports including Aboriginal and Torres Strait Islander delivered initiatives, and training and education for health workers.

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. Following the Lililwan (all the little ones) study, [40, 62, 123] the Marninwarntikura Women’s Resource Centre in Fitzroy Crossing set up the Marulu Unit to; provide multi-level advocacy and support for families, influence policy and service delivery (particularly health, education, justice and child protection services) and continue to raise awareness about FASD and its prevention [63, 121]. The Jandu Yani U (for all families) project was initiated to respond to high rates of behavioural problems in children living with FASD in the Fitzroy Valley by introducing the Indigenous Triple P (Positive Parenting Program) and training Aboriginal people to deliver the program. To follow up the long-term outcomes of children from the Lililwan project, the Bigiswun (adolescent) Kid project was initiated.

The Bigiswun Kid project will evaluate the health and wellbeing of young people from the Lililwan cohort at age 17-19 years and listen to their voices to identify their needs. A range of negative outcomes related to FASD have already been identified in the children diagnosed in the Lililwan project, as have positives and successes [9]. Bringing together key stakeholders, the aim of the Bigiswun Kid project is to draw together government and ACCHOs to develop

long term mental health and disability services for children, youth, their families, and communities. The Marulu team has employed and will train local Aboriginal youth support officers to assist young people and to connect them with local health and mental health services, TAFE, and employment opportunities. They will also run yarnning sessions to draw together the experiences, concerns and needs of young people and their families involved with the Bigiswun Kid project. The project will support young people diagnosed with FASD to elicit NDIS funding and will work toward a culturally and community relevant strategy for implementing the NDIS scheme for the region.

Some of the participants in the Lililwan study have children and will participate in the Jandu Yani U project [121], an Indigenous positive parenting initiative for carers of children with complex learning and development needs [124]. It is a strength-based prevention and early intervention project that promotes positive and nurturing relationships between carers and their children. It is a community identified, place-based and co-designed initiative which aims to build and empower parenting skills and family relationships. Moreover, the project is conducted using parent coaches, who are locally trained community workers and brings together families and service providers offering professional training about culturally appropriate, positive parenting support.

The Marulu project team is working in partnership with Marninwarntikura Women's Resource Centre in Fitzroy Crossing, Royal Far West and the University of Sydney (Child and Adolescent Health) on the Marurra-U (to embrace with love) project, to develop models of culturally and trauma-informed health care for FASD, across the Fitzroy Valley [125].

Queensland: the Yapatjarrathati Project

In Queensland, a protocol for the first culturally developed tiered FASD assessments for the Yapatjarrathati project has been described [120]. A co-designed project, the protocol described the process from knowledge creation to completion. The project involves a number of tiers to the process including using culturally relevant materials to explain the project and seek informed consent; a culturally sensitive interview, including establishing prenatal alcohol use and conducting relevant physical measurements (i.e. lip philtrum) of children; and the application of a brief neurodevelopmental assessment that also screens for vision and hearing problems [120]. The project has also been co-designed to conduct holistic assessment which considers all aspects of the children's and families' social, emotional, spiritual, and cultural wellbeing which is designed to provide entry points to the health system.

Northern Territory

The Northern Territory Anyinginyi Health Aboriginal Corporation have, since 2011, sustained FASD prevention and early intervention in communities, following a 12 month project which aimed to increase community knowledge about FASD [126]. The project implemented a range of health resources and information for the community and advocated for warning signs in local licensed premises to ensure women understood the dangers of prenatal alcohol consumption. The Anyinginyi

Health Aboriginal Corporation has provided education forums about FASD in the community and services and continues to provide education and prevention sessions on FASD with various community groups [127].

Northern Territory and New South Wales

A multi-site prevention program, located in Newcastle, NSW and Alice Springs in the NT has been founded on the Marulu Strategy [63]. Based on community identified need, principles of sustainability, and a commitment to building the capacity of the community, this research program develops and implements health promotion materials, undertakes workforce training, develops targeted prevention programs primarily to pregnant women addressing prenatal alcohol exposure in Newcastle and in Alice Springs and surrounding communities, as well as supporting FASD affected youth involved with the justice system [128].

Policies and strategies

The National Fetal Alcohol Spectrum Disorder (FASD) Strategic Action Plan 2018–2028 (the Plan) has been released and is a guide 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 [122].

The main objectives of the Plan are to reduce the prevalence and negative effects of FASD for Australian people, and to improve the quality of life for people living with FASD [122]. Designed to inform a range of stakeholders at a national and local level, the Plan outlines a number of priorities to meet these aims over the next decade. The Plan identifies four national priorities: prevention; screening and diagnosis; support and management; and priority groups and people at increased risk [122].

The Plan aligns with, and is designed to inform other key health priorities, strategies and frameworks including the National Drug Strategy 2017-2026 [129]; National Alcohol Strategy 2019-2028 [130]; National Aboriginal and Torres Strait Islander People's Drug Strategy 2014-2019 [131]; National Strategic Framework for Chronic Conditions [132]; and National Aboriginal and Torres Strait Islander Health Plan 2013-2023 [133].

Recognising that there is a significant body of work and advocacy which has been undertaken to raise awareness of FASD and the personal and social impacts of the disorder, the Plan will build on and supplement this existing knowledge and the resources developed, while identifying new areas for future action over the next decade. Further, the Plan acknowledges the need to provide local, flexible responses to FASD programs and policies, community circumstances, and will give priority to funding local needs [122].

The Plan is guided by seven principles. First is collaboration and partnerships using cooperative working relationships to minimise siloed service delivery. Second is ensuring access to equitable, affordable prevention programs and supports. Third is ensuring evidence informs best practice in the prevention and management of FASD. Fourth is that approaches are place-based and acknowledge the diversity in the Australian population, centrally placing

the needs of individuals, families, groups and communities to ensure continuity of service. The fifth principle commits to developing sustainability, supporting access to funding and efficiently managing resources and the sixth principle commits to accountability and transparency in the management of and responsible use of public resources. The seventh principle, shared responsibility, requires everybody to responsibly fulfil their role in preventing and managing FASD in Australia [122].

The Plan outlines prevention mechanisms, screening and diagnosis, and support and management, with a particular focus on populations at increased risk of having children with FASD including alcohol-dependent women, women with FASD or impairments which affect decision making, young women involved with the criminal justice system and Aboriginal and Torres Strait Islander communities where alcohol and alcohol-related harm are predominant, ensuring access to specialised culturally relevant services. Targeted screening of high risk groups in addition to those just listed, include children born to mothers with substance use disorders, babies that are small or microcephalic, children involved with child protection services and those fostered or adopted, children with mental health or conduct disorder, children diagnosed with an unexplained intellectual disability and siblings of individuals diagnosed with FASD. The Plan specifies raising the recognition of FASD as a disability, the elimination of stigma, the importance of education and training and co-ordinating FASD policies, drawing on evidence, research and evaluation [122].

Other objectives of the Plan are education and employment support, implementation of therapeutic justice interventions, provision of education and training for youth justice staff, providing appropriate case management, the appointment of specialist clinicians in the courts, and a greater focus on diversionary programs for Aboriginal and Torres Strait Islander communities that are community controlled and culturally secure and to evaluate the barriers and facilitators to service delivery, particularly in Aboriginal and Torres Strait Islander communities and criminal justice services [122].

The Plan is comprehensive, and importantly, has a specific focus for reducing the prevalence and harmful effects of FASD. It has been developed with extensive national community and stakeholder consultation and holds the particular needs of the Aboriginal and Torres Strait Islander community as central. The Plan has a broad evaluation framework, and it is critical that all aspects of the plan are evaluated to establish evidence-based practices that work and that can then be supported to be implemented in the appropriate circumstances with adequate funding.

Northern Territory 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 [134].

The NT action plan sets out to ensure that health and community services provide consistent and clear messages and are aware of the important role they play in preventing FASD. This includes ensuring young girls and women of child-bearing age, and their partners, can access and are provided with information about sexual health, have access to contraceptives and are supported during pregnancy.

The NT action plan resolves to strengthen models to both attract pregnant women to treatment for AOD problems, provide follow up and after-care services and provide assurance that referral to and treatment for AOD problems are accessible and available, and that these are wrap-around services that address the social and cultural determinants of health.

With a focus on early intervention and assessing children for neurodevelopmental disorders, the NT action plan will provide parenting support and advice, and will upskill workers in ACCHOs to coordinate community responses and awareness raising about FASD, and to develop a coordinated approach to communication and information-sharing between services involved with assessment of children at risk of FASD [134].

Future directions and concluding comments

FASD is a preventable, lifelong disability. Early assessment and diagnosis are key to mitigating the many negative impacts of FASD. FASD disproportionately affects Aboriginal and Torres Strait Islander people, however, there are limited prevalence statistics available in the mainstream Aboriginal and Torres Strait Islander population. Two main studies that have driven the national FASD agenda involve Aboriginal and Torres Strait Islander children in remote Western Australia [62], and children and youth in detention where Aboriginal and Torres Strait Islander children make up the highest percentage [29]. Studies such as these represent systemic population bias, and potentially feed public perception that FASD is yet another ‘problem’ of Aboriginal and Torres Strait Islander people. As such, work on increasing public awareness/knowledge and assessment in both non-Indigenous and Aboriginal and Torres Strait Islander communities is required to increase understanding that FASD can affect the whole community.

Comprehensive prevalence surveys, with active case identification, in representative samples of Aboriginal and Torres Strait Islander and non-Indigenous children would provide valuable, population-based information on which to base preventive, diagnostic and management services in Australia. This should be in addition to collection of information on cases of FASD diagnosed (largely in specialist clinics) and notified to the national FASD Australian Registry (FASDAR).

Interventions 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 need to opt for investing in Aboriginal and Torres Strait Islander community organisations to develop their own evidence-based, fit-for-community FASD prevention, intervention,

and management strategies. In some regional and remote communities, organisations do not have the necessary resources or skilled clinicians to undertake this. In such cases, community leaders and organisations should be consulted to ensure strategies that are developed are culturally appropriate and relevant to the communities. There should also be investment in the place-based development of screening tools for community members to identify children who may be in need of assessment.

There is limited information on prevention and intervention programs that have been evaluated and found to be effective. Future prevention, treatment and management of FASD in the Aboriginal and Torres Strait Islander people should be community decided, led, driven and evaluated.

Given the impact of FASD on memory and communication, and the importance of both these factors to the oral transmission of cultural knowledge, the authors recommend that work be undertaken with Aboriginal and Torres Strait Islander children and 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. There is a need to involve Aboriginal and Torres Strait Islander men in research to understand the role they can play in the prevention, treatment and management of FASD.

There is a need to recognise that FASD may be a major barrier to a successful education for children and youth and undertake research to accurately measure the impact of FASD on the educational outcomes for Aboriginal and Torres Strait Islander students and develop and evaluate strategies for supporting children, teachers and families.

Children and young people who are involved with the justice system and the child protection system are more likely to have undetected neurodevelopment impairments associated with FASD. Routine culturally and neurodevelopmentally responsive screening and diagnosis are required for children and young people on entry to 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 benefit from successful programs to be implemented more broadly and efficiently. Adequately funding, implementing and evaluating the National FASD Strategic Action Plan will be critical to establishing evidence-based practices that work to prevent FASD and the harm associated with pre-natal alcohol consumption for individuals, families and communities.

Appendix 1

Data sources and limitations

All information in the review is based on published or publicly available resources and these have been clearly referenced throughout the review.

Limitations of the available data have been referred to in the review and include the following:

- There are few population-based prevalence data with active case ascertainment, so there are not good generalisable estimates of how common FASD is in Australia (Aboriginal and Torres Strait Islander and non-Indigenous).
- Comprehensive recording of prenatal alcohol use is only now coming into usage in state perinatal datasets for all births (Aboriginal and Torres Strait Islander and non-Indigenous), so it has been difficult to assess prenatal alcohol use trends over time and in relation to preventive programs.
- There are still only a limited number of clinics for diagnosing FASD, often with long waiting lists and generally mainly for children.
- There are few evidence-based and evaluated prevention programs for FASD for either Aboriginal and Torres Strait Islander or non-Indigenous people.
- There are few evidence-based and evaluated management programs for FASD for either Aboriginal and Torres Strait Islander or non-Indigenous people.

Appendix 2

Online resources

AOD Knowledge Centre

The Australian Indigenous Health*InfoNet's* Alcohol and Other Drugs Knowledge Centre has a topic section devoted to FASD that provides a curated collection of online resources, publications and programs specifically for health workers and community members working to address FASD in urban and regional communities.

<https://aodknowledgecentre.ecu.edu.au/learn/health-impacts/fasd>

FASD Hub Australia

The FASD Hub provides a dedicated section for Aboriginal and Torres Strait Islander resources and information.

<https://www.fasdhub.org.au/help-me-choose/for-australian-indigenous-research-and-resources>

It also provides an extensive collection of information about FASD available for a wide range of health and other professionals, service providers, researchers and parents and carers. The FASD Hub also provides a repository of Australian research and policy, and a directory of FASD-informed services and health professionals.

<https://www.fasdhub.org.au>

Foundation for Alcohol Research and Education (FARE)

The Pregnant Pause campaign encourages all Australians to go alcohol free during their pregnancy, or the pregnancy of their partner, family member, friend or loved one.

<https://www.pregnantpause.com.au>

Australian Government Department of Health

The Women Want to Know project encourages health professionals to routinely discuss alcohol and pregnancy with women and to provide advice that is consistent with the Australian Guidelines to Reduce Health Risks from Drinking Alcohol.

<https://www.health.gov.au/initiatives-and-programs/women-want-to-know-initiative>

Western Australian Mental Health Commission

The Strong Spirit Strong Future campaign provides resources to increase awareness about the risks of alcohol consumption during pregnancy and to promote the role of family and community members to support pregnant women.

<https://strongspiritstrongmind.com.au/resources-campaigns/strong-spirit-strong-future>

Marninwarntikura Women's Resource Centre, Fitzroy Crossing, Western Australia

The Marulu Strategy, Making FASD History website, provides an outline of the strategy and a range of information and resources. Resources include education resources developed to assist schools to understand and address the needs of children and young people living with FASD and are designed to support school leaders, teachers, Aboriginal educators and the broader school community to recognise, understand and work effectively with students living with FASD in schools.

<https://www.marulustrategy.com.au>

Menzies School of Health Research/New South Wales Health

These resources provide information to women and health care providers about the risks of drinking alcohol during pregnancy.

Yarning about alcohol and your health

https://www.menzies.edu.au/icms_docs/161613_Yarning_about_alcohol.pdf

Yarning about alcohol and pregnancy

https://yourroom.health.nsw.gov.au/publicationdocuments/FASD_Womens%20Yarning_web.pdf

National Aboriginal Community Controlled Health Organisation

This practical resource has been developed to provide health professionals with an accessible, user friendly guide to best practice in preventive healthcare for Aboriginal and Torres Strait Islander patients.

National guide to preventive health assessment for Aboriginal and Torres Strait Islander people: Evidence base

<https://www.racgp.org.au/FSDEDEV/media/documents/Clinical%20Resources/Resources/Evidence-base-to-a-preventive-health-assessment-3rd-edition.pdf>

National Drug and Alcohol Research Centre, University of New South Wales

This resource provides information for primary health workers about supporting pregnant women who use alcohol or other drugs.

Supporting pregnant women who use alcohol or other drugs: a review of the evidence

<https://ndarc.med.unsw.edu.au/resource/supporting-pregnant-women-who-use-alcohol-or-other-drugs-review-evidence>

National Organisation for FASD (NOFASD)

An extensive collection of information about FASD for parents and carers as well as health professionals, service providers and researchers.

<https://www.nofasd.org.au>

Telethon Kids Institute, Western Australia

This site provides links to a variety of resources that have been produced to provide awareness and information about FASD across a range of sectors.

Alcohol, pregnancy and FASD

<https://alcoholpregnancy.telethonkids.org.au/resources>

FASD and justice videos: professional development

<https://alcoholpregnancy.telethonkids.org.au/our-research/fasd--justice/professional-development>

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