



## VIEWPOINT

## Responding to fetal alcohol spectrum disorder in Australia

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**Abstract:** Fetal alcohol spectrum disorder (FASD) is a significant public health issue in Australia that is poorly diagnosed, chronic and costly. FASD is a diffuse acquired brain injury secondary to prenatal alcohol exposure. The prevalence rate of FASD among the general population in Australia is currently unknown; however, an Australian study in a selected high-risk population reported some of the highest rates of FASD in the world. A common misconception among clinicians is that a child must have 'the face' of FASD to have the disorder. This is incorrect. The three sentinel facial features only occur in the minority of individuals with FASD. FASD should be considered as a 'whole body' disorder as increased susceptibility to chronic health problems suggests suboptimal *in utero* environments places the individual at risk of later disease. Clinicians are reluctant to consider FASD as a possible diagnosis because of the concern of inducing stigma; however, this concern is neither supported by the evidence nor patient stories. The Australian Guide to the Diagnosis of FASD is now available to assist health professionals in providing timely and accurate diagnoses, which can lead to improved outcomes via evidence-based intervention and is an important first step in future prevention.

Fetal alcohol spectrum disorder (FASD) is a significant public health issue in Australia that is poorly diagnosed, chronic and costly. A survey in 2011 revealed only 16% of Australian health professionals could identify the essential features of FASD.<sup>1</sup> Approximately, 50% of pregnancies are unplanned and, given that alcohol use is common among women of reproductive age, prenatal alcohol exposure (PAE) is a frequent unintended consequence.<sup>2</sup> Approximately, 60% of Australian women reported consuming alcohol in at least one trimester of pregnancy.<sup>2</sup> There is currently no known safe lower limit of alcohol consumption during pregnancy.<sup>3</sup> It is difficult to make accurate estimates regarding the threshold of harm for women and their children as this varies due to a range of factors, including maternal health characteristics (e.g. nutrition and body size) and maternal and fetal metabolic and genetic differences.<sup>4</sup> In Australia, up until 2009, the National Health and Medical Research Council guidelines recommended abstinence but suggested if women chose to drink they should not consume more than two standard drinks on any one occasion and not more than seven standard drinks per week. However, there are increased risks of neurodevelopmental problems and preterm birth following PAE of 30–40 g per occasion and as little as 70 g/week, which is equivalent to approximately 2–2.5 standard drinks once or twice per week.<sup>4</sup> Thus, at most there is only a very small margin before there is increased risk to the fetus.<sup>4</sup> Hence, the current National Health and Medical Research Council recommendation is that no alcohol is the safest option for women who are planning pregnancy or who are pregnant.<sup>5</sup>

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### Definition and Evolution of the FASD Nomenclature

FASD is a diffuse acquired brain injury secondary to PAE. Numerous reports demonstrate a historical awareness of maternal alcohol use causing adverse child outcomes. The College of Physicians drafted a letter to the UK Parliament in 1725 that voiced their concerns that maternal gin consumption was 'too often the cause of weak, feeble and distempered children'.<sup>6</sup> The earliest journal article appeared in 1899, which noted higher still-birth rates in 'alcoholic prisoners'.<sup>7</sup> Dr Lemoine in France published a study in 1968 regarding the connection between PAE and dysmorphism.<sup>8</sup>

The nomenclature around FASD has changed significantly over time and, world-wide, diagnostic criteria continue to evolve, contributing to confusion (Table 1). The term fetal alcohol syndrome (FAS) was coined in 1973 by Drs Smith and Jones at the University of Washington in Seattle.<sup>9</sup> The term FAS initially denoted the presence of the three sentinel facial features (short palpebral fissures, thin upper lip and smooth philtrum), growth deficiency and severe neurodevelopmental deficits.<sup>9</sup> Then in 1996<sup>15</sup> and revised again in 2005,<sup>10</sup> the US Institute of Medicine defined five possible outcomes of PAE: FAS with and without confirmed alcohol exposure; partial FAS (pFAS; confirmed PAE, some of the facial features and either growth deficiency or neurodevelopmental impairments); alcohol-related birth defects (confirmed PAE and congenital physical abnormalities) and alcohol-related neurodevelopmental disorder (confirmed PAE, none of the physical features, but still severe neurodevelopmental impairments). Introduced in 1997, and revised again in 2004,<sup>11</sup> the 4-Digit Diagnostic Code provided standardised measurement scales to increase the accuracy and objectivity of diagnosis. The Canadian diagnostic guidelines published in 2005,<sup>12</sup> combined the institute of medicine nomenclature and the 4-Digit Code methodology. The Canadian guidelines have since been updated<sup>13</sup> and now specify FASD as a diagnostic term, with three

**Table 1** Summary and evolution of fetal alcohol spectrum disorder (FASD) terminology

Acronym	Name	Facial features	Neurodevelopmental presentation	Other
FAS	Fetal alcohol syndrome <sup>9–12</sup>	All three facial features (short palpebral fissures, thin upper lip and smooth philtrum) are present	Severe impairment in at least three neurodevelopmental domains	Growth delay
FASD with three facial features	Fetal alcohol spectrum disorder with the three sentinel facial features <sup>13,14</sup>	All three facial features (short palpebral fissures, thin upper lip and smooth philtrum) are present	Severe impairment in at least three neurodevelopmental domains	
pFAS	Partial fetal alcohol syndrome <sup>10–12</sup>	Most but not all three facial features	Severe impairment in at least three neurodevelopmental domains	+ – Growth delay
ARND	Alcohol-related neurodevelopmental disorder <sup>10,12</sup>	Less than three facial features present	Severe impairment in at least three neurodevelopmental domains	
SE-AE	Static encephalopathy (alcohol exposed) <sup>11</sup>		Severe impairment in at least three neurodevelopmental domains	
FASD without three facial features	Fetal alcohol spectrum disorder without the three sentinel facial features <sup>13,14</sup>		Severe impairment in at least three neurodevelopmental domains	
ARBD	Alcohol-related birth defects <sup>10</sup>			Presence of congenital abnormalities associated with prenatal alcohol exposure
ND-AE	Neurobehavioural disorder (alcohol exposed) <sup>11</sup>	Less than three facial features present	Mild to moderate brain dysfunction	
At risk of FASD	At risk of fetal alcohol spectrum disorder – For children <6 years <sup>13,14</sup>	Facial features present or absent	Criteria not met for severe impairment – Requires follow-up and reassessment after 6 years	

outcomes provided following assessment: FASD with sentinel facial features; FASD without sentinel facial features; and at risk of neurodevelopmental disorder and FASD, associated with PAE. It is this new terminology that has been adopted in the Australian Guide to the Diagnosis of FASD.<sup>14</sup>

## Prevalence

A very recent prevalence study in the general US population provided a conservative estimate of 11.3–50 per 1000 children.<sup>16</sup> The prevalence rate of FASD amongst the general population in Australia is currently unknown. An Australian study in a selected high-risk population reported some of the highest rates of FASD in the world (i.e. any diagnosis on the FASD spectrum 194.4 per 1000<sup>17</sup>; FAS and pFAS 120.4 per 1000 children).<sup>18</sup> The prevalence of FASD for vulnerable children in out-of-home care and in the youth justice system is considerably higher than the general population. An international systematic review and meta-analysis found the overall pooled prevalence of FASD to be 109–238 per 1000 among children and youth in out-of-home care.<sup>19</sup> A recent

Australian study reported a FASD prevalence of 36% in a youth justice setting,<sup>20</sup> which was even higher than a Canadian study, which reported that 23.3% of youth in the criminal justice system had an alcohol-related diagnosis.<sup>21</sup>

## Patient Presentation and Clinical Assessment

A common misconception amongst clinicians is that a child must have ‘the face’ of FASD to have the disorder. This is incorrect. The three facial features in Table 1 are characteristic of PAE, but only occur in the minority of individuals with FASD. For example, in a major US study of 1400 individuals, only 4% had the three sentinel facial features and were diagnosed with FAS.<sup>22</sup> All children however present with neurodevelopmental deficits, which can vary substantially between individuals and across the developmental trajectory. Deficits have been identified in general intelligence, attention, learning, memory, visuospatial reasoning, executive functioning, motor functioning, self-regulation, language and communication, social ability, academic achievement

and adaptive functioning.<sup>23</sup> The consequences of these difficulties can present in multiple ways in various contexts. Given the heterogeneous clinical features of FASD, care is warranted when selecting tests and measures for the assessment of cognition and behaviour. It is fundamentally important that the most appropriate measures to ensure a comprehensive accurate multi-disciplinary profile of the child are used.<sup>24</sup> This includes measures that provide the clearest understanding of how the child's brain works (process success) and perhaps more importantly how it does not work (process failure).<sup>25</sup> Under-assessing has significant diagnostic and treatment implications, particularly in the context of tightening health and disability service funding arrangements where there is a need to demonstrate improvement into the future as a consequence of investment.<sup>23</sup>

Therefore, whilst facial dysmorphology is included within an FASD assessment, the focus is on providing a comprehensive functional assessment of each child. A formal diagnosis of FASD requires a confirmed history of prenatal exposure and severe impairment (more than two standard deviations below the mean) in at least three of the 10 brain domains (Table 2).<sup>14</sup> A thorough paediatric medical assessment is also essential and consideration is given to any other pre- and post-natal factors that may have contributed to a child's presentation, as with any other developmental assessment. The assessment framework in the Australian Guide to the Diagnosis of FASD should be considered as a benchmark for the assessment of all children with complex neurodevelopmental presentations.

PAE can also result in fetal growth restriction and congenital deficits including heart, renal and gastrointestinal abnormalities.<sup>26,27</sup> FASD may be the explanation for some children presenting with poor growth during childhood. In some countries impaired growth remains a diagnostic criteria for FASD, although this has been removed from the Canadian and Australian Guide

to Diagnosis.<sup>28</sup> FASD should be considered as a 'whole body' disorder. Susceptibility to chronic health problems in this population aligns with the developmental origins of health and disease hypothesis, which suggests that exposure to suboptimal environments during *in utero* development places an individual at risk of later disease.<sup>29</sup> Evidence from preclinical animal models suggests PAE can result in hypertension, renal dysfunction,<sup>30</sup> insulin resistance,<sup>31</sup> impaired immune function,<sup>32</sup> increased risk of infections<sup>33</sup> and even some cancers.<sup>34,35</sup> Emerging clinical evidence suggests children with PAE/FASD are more likely to be overweight/obese<sup>36</sup> and have abnormal eating behaviours,<sup>37</sup> and have higher carotid-femoral pulse wave velocity, indicating stiffer vessels.<sup>38</sup> Paediatricians of all specialties have a significant and important role in accurate and timely FASD diagnosis leading to careful surveillance and early intervention to ameliorate the onset of future disease and premature mortality.

### Clinical Experience of FASD Assessment and Diagnosis

FASD assessment services within a public child development service<sup>39</sup> or the private sector are feasible with appropriate training. However, there continues to be an underlying reluctance by many clinicians to consider or recommend further FASD assessment. A survey of Australian paediatricians in 2004 identified that 76.5% had suspected but not diagnosed FAS and 12% had been convinced of a diagnosis of FAS in a patient but had not recorded it.<sup>40</sup> The most predominant concerns precluding recording an FASD diagnosis relate to the stigma. Bell *et al.*<sup>41</sup> theorised that this stigma falls into three areas: (i) *personal responsibility and blame towards the biological mothers*, including perceptions around blameworthiness, negative judgements if a women discloses prenatal alcohol consumption, media reports discussing criminalisation of

**Table 2** Fetal alcohol spectrum disorder (FASD) diagnosis according to the Australian Guide

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

women who admit to drug and alcohol use during pregnancy and the significant burden of shame; (ii) *felt and enacted stigma experienced by children and their families*, including discrimination against children with FASD, labelling behaviours as 'naughty' or 'deliberate', feelings of being misunderstood and blamed for their learning difficulties and having their capabilities underestimated; and (iii) *anticipated life trajectories for individuals with FASD*, that is the potential of a person with FASD to thrive is peppered by the belief about a future life of crime or drug/alcohol misuse. This negative public attitude also impacts on the self-esteem of these individuals. In addition to the stigma of FASD, a number of other concerns commonly voiced by health professionals include: Is FASD an actual diagnosis in itself? What is the diagnostic accuracy of an FASD assessment? Is it better to focus on the functional issues of a child rather than a diagnosis? and what's the point' it doesn't really change anything? While these concerns should be acknowledged, they also need to be explored, understood and challenged.

In contrast to clinicians' opinions, caregivers report that the assessment provided them with validation and understanding, and that the process of FASD diagnosis was empowering.<sup>42</sup> Research has demonstrated that the earlier a child gets an accurate FASD diagnosis, the better their long-term outcomes.<sup>43</sup> Australian caregivers' frustration often comes from a lack of knowledge and understanding from health professionals: 'We had a lot of GPs and I think they were just thinking that I'm a neurotic mother',<sup>42</sup> and a lack of knowledge and support from the education system and systematic discrimination through the lack of recognition of FASD as a disability 'There should be no blame on how or why they've got it ... But let's acknowledge that it is a real disability' (103).<sup>42</sup> Caregivers also report difficulties accessing supports for their children post-diagnosis.<sup>42</sup> Not considering FASD as a potential co-morbid diagnosis in children with PAE, regardless of other developmental risk factors that may be present, runs the risk of omitting a key element that assists with understanding the child. Caregivers often state that a FASD diagnosis is the missing piece of the puzzle, as their children were not responding to previous 'usual treatments' (see Table 3).

The guilt that biological parents experience around FASD is real and must be managed with sensitivity and compassion when providing a diagnosis. 'Nothing will take away the guilt ... You [health professionals] have to bring the question [of FASD] up, if only someone had brought it up earlier, I was going to so many doctors repeating my story over and over. How can we move forward and get the help we need?' – Biological mother, Carer workshop, May 2018. This can be improved by linking families into support groups (<https://www.fasdhub.org.au/>), providing support during the assessment process and guiding the mother towards an explanation regarding their child's presentation and facilitating an understanding of the overall situation, for example an unplanned pregnancy with inadvertent exposure ceased on discovery, pregnancy in the context of addiction, as well as unravelling their own complex histories or misinformation from friends, family members and health professionals. Clinicians also need to have awareness of their own thoughts and feelings of bias and judgement and how that may impact the diagnostic process. Paediatricians are uniquely trained to manage complexity skilfully and to advocate for individuals, families and systems so as to effectively 'get FASD out of the closet'.

**Table 3** Selection of quotes from Queensland Fetal Alcohol Spectrum Disorder (FASD) Support Group, following a Facebook-posted question – What they would like to tell their paediatrician? (May, 2018)

- 'A parent knows when there is something wrong with our children so listen'
- 'We come to professionals hoping you know more than us'
- 'Don't be afraid to ask the mum if alcohol could have been consumed in the pregnancy. But don't do it accusingly and don't judge the mother by making her feel guilty or blaming and shaming her'
- 'You don't have to be an alcoholic to have a child with FASD. I didn't know I was pregnant till 6/8 weeks and didn't touch alcohol at all (after). My son was still born with FASD. It explains his whole childhood now I know'
- 'It shouldn't take years to get a diagnosis when we could have been helping our kids and not wasting time. An early diagnosis can change things for us to start putting plans into place earlier'
- 'A diagnosis means more than just another label'
- 'Just because the kids look fine, you can't see inside their brain, this doesn't mean they don't have FASD'
- 'That long-term follow-up (including physical health) is imperative. Don't just send us away after a diagnosis'
- 'Don't give up on our kids putting them in the too hard basket'
- 'Consequences don't exist [for a child with FASD], our kids are not naughty and destructive on purpose, this is a permanent brain injury we can't fix'
- 'It [FASD] is totally exhausting for a child and parent, medication is not a quick and easy fix'
- 'We have good days, bad days, tired days and overwhelming days'
- 'This is one hell of a lonely journey'

## Training for Australian Health Professionals

FASD awareness among clinicians needs to include general practitioners, specialists, nurses, midwives and allied health professionals. Given that FASD is rarely addressed within university curriculums, it is imperative that Australian health professionals access additional training. FASD e-Learning modules are available through the Telethon Kids Institute – <https://alcoholpregnancy.telethonkids.org.au/alcohol-pregnancy-and-breastfeeding/diagnosing-fasd/e-learning-modules/>. In-person FASD training is available at some of the Australian FASD specialist services. Information about all the relevant FASD services and additional resources for health professionals is now available through the National FASD Hub – <https://www.fasdhub.org.au/>.

## Future Considerations

Much remains to be established in the approach to diagnosing FASD. Genetic predictors for fetal susceptibility, implications of other *in utero* exposures (e.g. nicotine and drug use), the possibility of inheriting some cognitive and behavioural deficits, and the impact of parental mental health may all prove to be significant contributors to the achievement and process deficits identified at assessment. They will likely also prove to be valuable predictors to the overall diagnostic algorithm.<sup>23</sup> In the interim, the focus

should remain on extending knowledge of the cognitive and behavioural features that most closely associate with FASD over other developmental disorders and acquired conditions. Doing so will ultimately lead to more cost-effective and differentially accurate assessments that are easily applied across health settings by diverse health practitioners.

Increased attention is required regarding the access to appropriate interventions and supports following an FASD diagnosis. Internationally, there are numerous evidence-based effective interventions (e.g. behaviour, social skills, academic and self-regulation focused programs) to which Australian children and families do not currently have access.<sup>44</sup> Even more rudimentary is providing families the range of supports available to children with other disabilities (e.g. assistance with daily life at home, respite and daily living skills training). Currently, the National Disability Insurance Scheme recognises FAS but not FASD as a neurodevelopmental disability. Similarly, the education system in Australia does not currently recognise FASD as a disability, and therefore children with FASD do not have access to educational supports. Policies need to adapt so that children with FASD are not discriminated against through the lack of recognition of FASD as a condition that necessitates access to funding and support.

Above all, the future of FASD in Australia needs to be focused on prevention. Prevention will only be possible through acknowledgment of the condition and through health professionals providing open and accurate information. The Commonwealth Action Plan to reduce the impact of FASD recommends a whole of government and population approach to FASD with emphasis on targeted approaches to prevention and management for populations at greatest risk.<sup>45</sup> Canadian experts have described a four-part framework to categorise the range of initiatives required that range from public awareness and health promotion through to support for individual women and their support networks.<sup>46</sup> FASD prevention projects based on this model are underway in WA, NT and NSW. Preliminary data from WA are promising, with rates of drinking in a high-risk community decreasing from over half to less than one fifth of women.<sup>47</sup> Focusing on prevention when planning a pregnancy is particularly important, because preclinical research is finding negative outcomes for offspring even if the alcohol exposure occurred around conception and prior to implantation.<sup>31</sup> Alcohol consumption in men may also affect the health of their children through epigenetic mechanisms.<sup>48</sup> This highlights the need to discuss alcohol usage with women and men when planning a pregnancy and promote effective contraception use by men and women of reproductive age.

## Conclusions

FASD is a common neurodevelopmental condition that is under-recognised and under-diagnosed in Australia. There are now Australian guidelines available to assist health professionals in providing timely and accurate diagnoses, which can lead to improved outcomes via evidence-based intervention and is an important first step in future prevention. Paediatricians can assist Australian families in diagnosis, intervention and support and must be aware of the chronic physical health impacts of FASD. Significant research and public attention is needed to facilitate effective prevention of FASD. Training and professional development is required for all current and future health professionals to

enable an expanded scope of practice to include the effective prevention, assessment, diagnosis and treatment of FASD.

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