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# Fetal Alcohol Spectrum Disorder (FASD): An update on policy and practice in Australia

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Child Family Community Australia | information exchange



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## Summary

Fetal Alcohol Spectrum Disorder (FASD) is a term used to describe the wide variety of lifelong developmental effects associated with prenatal alcohol exposure. This paper outlines developments for the prevention of FASD and the diagnosis and support of children and young people living with FASD in Australia. It describes some of the key policy and practice initiatives since 2016, including the [National FASD Strategic Action Plan 2018–2028](#), and considers further opportunities for responding to the needs of children and families affected by FASD. This paper is intended to provide an overview of the key issues for child and family practitioners who may encounter children and families living with FASD. This paper is a companion paper to *Fetal alcohol spectrum disorders: Current issues in awareness, prevention and intervention* (McLean & McDougall, 2014), which outlines research on the prevention of FASD and provides implications for practitioners.

### Key messages

- The diagnostic protocol for FASD in Australia is a significant step forward in developing a shared understanding of FASD and in supporting early detection and intervention.
- The ability to diagnose children with FASD may be improved through:
  - encouraging practitioners to identify and refer for FASD assessment
  - increasing the workforce capacity to offer diagnostic services
  - encouraging the accurate documentation of alcohol use during pregnancy.
- The [National FASD Strategic Action Plan 2018–2028](#) was developed to create a clear pathway for priorities, focus areas and opportunities to improve the prevention, diagnosis and management of FASD in Australia.
- [FASD Hub Australia](#) was created with the aim of providing a hub of transparent and reliable health information about FASD for professionals and caregivers.
- FASD is associated with a range of neurodevelopmental impairments. More work is needed to understand how the neurocognitive impairments of FASD differ from other childhood conditions associated with neurodiversity.
- FASD is also commonly associated with mental health challenges and there is a need to develop and trial therapeutic approaches to address mental health concerns in children with cognitive impairment.
- Like other childhood disorders, FASD can be understood in the context of cognitive, developmental, ecological and holistic frameworks that may result in more meaningful support for children and families living with FASD.

## Introduction

Fetal Alcohol Spectrum Disorder (FASD) is a diagnostic term that is used to describe the diverse and lifelong developmental effects that exposure to alcohol during pregnancy has on the developing fetus (Cook et al., 2015). Early descriptions of the effects of prenatal alcohol exposure, during the 1970s through to the 1990s, placed emphasis on the sentinel facial features<sup>1</sup> and intellectual disability associated with prenatal alcohol exposure (Benz, Rasmussen, & Andrew, 2009; Jones & Smith, 1979; Jones, Smith, Ulleland, & Streissguth, 1973). These accounts focused on the link between sentinel facial features and intellectual disability. It is now understood that some forms of neuro-cognitive difficulty can exist in the presence and absence of any visible facial features (Popova et al., 2016). For this reason, FASD is now commonly referred to as an 'invisible' disorder – it can exist in the absence of overt physical features (Mather, 2015).

Recent conceptualisation of FASD is moving away from a medical narrative towards a more holistic, person-centred understanding, including the effects of FASD over the life course (Dowse, Dillon-Savage, Dew, & Strnadova, 2020). The Canadian Fetal Alcohol Research Network describes FASD:

*Fetal Alcohol Spectrum Disorder (FASD) is a diagnostic term used to describe impacts on the brain and body of individuals prenatally exposed to alcohol. FASD is a lifelong disability. Individuals with FASD will experience some degree of challenges in their daily living, and need support with motor skills, physical health, learning, memory, attention, communication, emotional regulation, and social skills to reach their full potential. Each individual with FASD is unique and has areas of both strengths and challenges. (Harding, Flannigan, & McFarlane, 2019, p. 3.)*

Prenatal alcohol exposure affects a wide range of genetic and neurodevelopmental functions influencing every aspect of the developing embryo and fetus' physical and neurological development. This can alter the developmental trajectory and life course of an affected fetus. As such, prenatal alcohol exposure has the potential to disrupt the development of multiple body systems and structures. FASD is now understood as a 'whole-body' disorder (Anderson, Mela, & Stewart, 2017, p. 69) that can result in changes to the body's nervous, immune, respiratory, digestive and endocrine systems, not just at birth but across an individual's lifetime (Akison, Moritz, & Reid, 2019; Akison, Reid, Wyllie, & Moritz, 2019; Anderson et al., 2017; Hayes, Reid, Akison, & Moritz, 2021; Reid, Akison, Hoy, & Moritz, 2019; Reid, Hayes, Akison, Young, & Moritz, 2020; Reid, Moritz, & Akison, 2019).

In light of this, it is important for child and family practitioners and services to understand the effects of prenatal alcohol exposure, and to develop the skills to recognise and support children who may be affected. Practitioners supporting a child living with FASD will need to use therapeutic approaches that are better suited to the cognitive, memory and language needs children with FASD can experience (see McLean, 2019a, 2019b).

This paper describes the key policy and practice initiatives implemented in Australia since 2016, and the effect these initiatives have had on workforce capacity in relation to FASD. Many practitioners working with children and families, although highly skilled, may not be familiar with more specialised approaches and principles for working with children living with neurodiversity, including FASD. This paper provides practitioners with information on the principles of effective practice when working with children with FASD, how to assist families seeking diagnosis, and how to find credible sources of information about FASD.

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<sup>1</sup> Sentinel facial features refer to facial malformations, mostly affecting the eyes and midface, that can appear with fetal exposure to alcohol during the first trimester (Bower & Elliott, 2016).

## Prevalence of FASD in Australia

Internationally, prevalence studies indicate that FASD occurs in between 1.1% and 5.0% of children in Western countries (May et al., 2009; Lange et al., 2017; Roozen et al., 2016; Thanh, Jonsson, Salmon, & Sebastianski, 2014). However, currently, there is no accurate data that measures the prevalence of FASD in the general population in Australia. Australian researchers and practitioners have highlighted the need for accurate data to capture the extent of FASD in Australia to help with prevention efforts and when planning services (Burns, Breen, Bower, O'Leary, & Elliott, 2013; Reid, 2018). A more nuanced understanding of the cohorts of children who may be in greater need of support services would help increase understanding of the dynamics and drivers of alcohol consumption during pregnancy, and populations that may be at increased risk, as well as support the development of tailored initiatives over time (Department of Health, 2018).

Concerns are often raised about the prevalence of FASD in some Indigenous communities. Interpreting prevalence data on Aboriginal populations is particularly complex. Overall, the rate of risky alcohol consumption among Aboriginal people is declining (Australian Institute of Health and Welfare [AIHW], 2020a). At the same time, rates of alcohol consumption are also highest in rural and remote areas, where there is a relatively greater proportion of Aboriginal than non-Aboriginal people (Australian Institute of Aboriginal and Torres Strait Islander Studies [AIATSIS], 2015; AIHW, 2017). The data on the number of Aboriginal Australians living with FASD is limited.

One Australian study on a remote Indigenous community found the highest estimated rates of FASD reported in the literature to date (12%–19.4%) (Fitzpatrick et al., 2015; Fitzpatrick et al., 2017). While this study used active case ascertainment (which is the most accurate means of determining prevalence), the sample was based on one remote community, with just over 100 cases (Fitzpatrick et al., 2015). Prevalence rates will vary widely in Aboriginal communities, particularly given that different communities have different relationships to alcohol.

There is also no Australian prevalence data for children living in out-of-home care (OOHC) (Reid, 2018). An international systematic review and meta-analysis on the rates of FASD among children living in OOHC found an overall pooled prevalence<sup>2</sup> of 16.9% (ranging between 10.9% and 23.8%; Lange, Shield, Rehm, & Popova, 2013).

Young people with FASD are overrepresented in youth justice settings (Bower, Watkins, Mutch, & Marriott, 2018; Fast, Conry, & Loock, 1999). An Australian study found a prevalence rate of 36% in a Western Australian youth justice setting (Bower et al., 2018), which is the highest rate established in a youth justice setting and higher than any international research (Fast et al., 1999). It is acknowledged that high proportions of Indigenous young people in youth detention in Western Australia will confound this result; Indigenous young people make up 7% of those aged 10–17 in the general population in Western Australia but 61% of those under supervision (AIHW, 2020b). More Australian research is needed to establish FASD estimates in this cohort, to underpin FASD-informed diversionary options and support services in Australian youth justice settings (see e.g. Blagg & Tullich, 2018; Blagg et al., 2020).

The CFCA paper *Fetal alcohol spectrum disorders: Current issues in awareness, prevention and intervention* (McLean & McDougall, 2014) outlines research on the prevention of FASD and provides implications for practitioners.

## Recent FASD policy and service developments

Several key projects and workforce development initiatives have been undertaken since 2016. While a complete review of these activities is beyond the scope of this paper, some of the major initiatives relevant to child and family practitioners are outlined below. This section provides interested practitioners with information about these developments. Practitioners may pursue further training and development if desired.

These initiatives have increased workforce capacity to recognise and respond to FASD in Australia. In addition, they have supported a growth in diagnostic capacity through the formation of diagnostic clinics and through increasing the accessibility of FASD training and knowledge to all Australian child and family practitioners.

<sup>2</sup> The term 'pooled prevalence' is used to refer to the 'pooled' number of cases across studies, instead of an average rate, to more accurately reflect the number of cases in a sample.

## National FASD Strategic Action Plan 2018–2028

The [National FASD Strategic Action Plan 2018–2028](#) (the Plan) was developed to create a clear pathway for priorities, focus areas and opportunities to improve the prevention, diagnosis and management of FASD in Australia (Department of Health, 2018). The Plan is part of a suite of broader initiatives set up by the Australian Government and complements existing national health strategies and frameworks.

The Plan outlines several strategic activities that will reduce the incidence and impact of FASD in Australia. It identifies four key priority areas for research and policy development:

1. **Prevention** – recommends activities to reduce access and exposure of pregnant women to alcohol; and activities to raise awareness of the harmful effects of alcohol consumption during pregnancy
2. **Screening and diagnosis** – outlines the populations for which targeted screening activities may be useful; and recommends that the child and maternal health workforce is supported to upskill in relation to the screening and diagnosis of FASD
3. **Support and management** – outlines the importance of developing and implementing models of support that are suited to both metro services and those in remote and culturally diverse communities; and the need to enhance support for parents and caregivers and in education and employment settings
4. **Priority groups and populations at increased risk** – includes the development of approaches that are suited to pregnant women, youth justice and Indigenous communities; and the implementation of non-custodial therapeutic jurisprudence in youth justice settings.

In addition, the Plan identifies the following potential enablers of change:

- enhancing the capacity of the child and family health services, education and justice workforces to recognise FASD
- taking steps to eliminate the stigma surrounding FASD
- ensuring education and training for the workforce
- coordinating policy responses across sectors.

The National FASD Strategic Action Plan 2018–2028 represents a significant step forward in the development of a coherent plan to address FASD in Australia. It reflects the consensus view of key stakeholders and researchers and serves to focus and align efforts in this field. Future iterations of the Plan may include a specific focus on the needs of children in care settings, given the overrepresentation of FASD in this group of children (Lange et al., 2013; Reid, 2018). Research to determine the priorities and views of non-Aboriginal and Aboriginal stakeholders could also help shape a more nuanced understanding of community need and inform future iterations of the Plan (Finlay-Jones et al., 2020).

## Australian Guide to the Diagnosis of FASD

The [Australian Guide to the Diagnosis of FASD](#) (Australian FASD Guide) is part of a suite of resources funded by the Australian Government designed to support clinicians in the diagnosis, referral and management of FASD. The guide was developed in 2016, following a systematic literature review, a synthesis of existing international guidelines and consultation with a range of clinical experts. It is based on the initial criteria for FASD identified in international research. The guide has provided consistency with the terminology and diagnostic approach (Astley, 2004; Bower & Elliott, 2016; Cook et al., 2015), including practical information about the diagnostic criteria and how to apply them in practice (Bower & Elliott, 2016).<sup>3</sup>

The Australian FASD Guide conceptualises FASD as an overarching diagnosis that subsumes two diagnostic subcategories:

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

Table 1 provides a summary of the Australian FASD Guide.

<sup>3</sup> The Child Health Research Centre, as part of FASD Research Australia, has been funded by the Australian Government Department of Health to review and update this guide. The review and update will consider all internationally available guidelines and current research evidence, and will integrate this with Australian clinician, consumer, cultural and other experts' input and recommendations (for further details, see [www.clinicalguidelines.gov.au/register/australian-fetal-alcohol-spectrum-disorder-fasd-assessment-and-diagnostic-guideline](http://www.clinicalguidelines.gov.au/register/australian-fetal-alcohol-spectrum-disorder-fasd-assessment-and-diagnostic-guideline)).

**Table 1:** Australian diagnostic criteria and categories for FASD

Diagnostic criteria	Diagnostic categories	
Prenatal alcohol exposure	Confirmed or unknown	Confirmed
Neurodevelopmental domains	Number of domains affected	
<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 (including impulse control and hyperactivity)</li> <li>• Affect regulation</li> <li>• Adaptive behaviour, social skills or social behaviour</li> </ul>	Severe impairment in at least 3 neurodevelopmental domains	Severe impairment in at least 3 neurodevelopmental domains
Sentinel facial features	Number present	
<ul style="list-style-type: none"> <li>• Short palpebral fissure<sup>a</sup></li> <li>• Smooth philtrum<sup>b</sup></li> <li>• Thin upper lip</li> </ul>	Presence of 3 sentinel facial features	Presence of 0, 1 or 2 sentinel facial features

Notes: <sup>a</sup> Palpebral fissure refers to the space between the inner and outer margins of the eyelids. <sup>b</sup> Philtrum is the midline groove in the upper lip that runs from the top of the lip to the nose.

Source: Bower & Elliott, 2016, p. 5

## FASD Hub Australia

In 2017, the Australian Government Department of Health provided funding to develop and create the [FASD Hub Australia](#),<sup>4</sup> with the aim of providing a hub of transparent and reliable health information about FASD for professionals and caregivers. This online hub provides Australian clinicians and health and other professionals, policy makers and caregivers with a single source of information, tools and resources that are based on the best available evidence. It includes a directory of service providers; information about training opportunities and support options; research programs and papers; and a range of free practice resources tailored to different audiences.

## Australian FASD diagnostic clinics

Internationally, multidisciplinary diagnostic teams represent the best practice approach in FASD diagnosis and support (Anderson et al., 2017; Coons-Harding, Flannigan, Burns, Rajani, & Symes, 2019). This is because multidisciplinary assessments and clinics are considered the best way to capture and support the complex and multidimensional presentation of FASD. Multidisciplinary lenses are thought to reduce the risk of misdiagnosis (FARE, n.d).

Considerable activity has been undertaken in Australia to build workforce capacity in the early detection and diagnosis of FASD. This includes the establishment of several multidisciplinary national diagnostic clinics (both government-funded hospital-based clinics and private provider clinics). These clinics exist in many of the capital cities and the [FASD Hub Australia](#) website provides a listing of these clinics by location. However, there is also a need to increase the capacity of practitioners to diagnose and support children across a range of settings to meet the demand for services in Australia, including in rural and remote settings (Shanley et al., 2019). Significant funding has been provided by the Commonwealth Department of Health to build diagnostic capacity across multiple settings.

Two other recent initiatives are the:

1. [FASD Australian Registry](#). This registry aims to collect detailed information about Australian children under 15 years living with FASD to improve the diagnosis, treatment and prevention of FASD.
2. [National FASD Program](#). This program is delivered by the Foundation for Alcohol Research and Education (FARE). It aims to increase Australians' awareness of the risks associated with alcohol consumption during pregnancy and while breastfeeding and promote behaviour change.

<sup>4</sup> The website was created by a consortium of organisations with an interest in promoting evidence-based practice and policy; including researchers from the University of Sydney, Telethon Kids Institute, FASD Research Australia Centre for Research Excellence, Menzies School of Health Research, practitioners from the Australian and New Zealand FASD Clinical Network, and advocates and stakeholders from the National Organisation for Fetal Alcohol Spectrum Disorder (NoFASD) Australia.

## Improving services to children and families

The recent efforts of government, consortiums and FASD researchers outlined above have increased the awareness of FASD among practitioners working with children and families. There is now an opportunity to build on this to ensure appropriate service responses informed by practice-relevant evidence are developed (particularly for vulnerable children, such as those in out-of-home care or in some Indigenous populations; Pei, Denys, Hughes, & Rasmussen, 2011; Reid, 2018; Reid et al., 2015; Weyrauch, Schwartz, Hart, Klug, & Burd, 2017). Three key strategies to improve Australian services and practices for children and families living with FASD are described here:

1. Building workforce diagnostic capacity for FASD
2. Developing workforce therapeutic capacity for children with comorbidities
3. Evidence-informed interventions that address systemic influences.

### 1. Building workforce diagnostic capacity for FASD

#### Record keeping and practices that support diagnosis

The Women Want to Know initiative was launched by FARE in 2014 in response to research indicating that many pregnant women were not receiving much information, or were hearing conflicting information, about alcohol consumption (Department of Health, 2021; FARE, 2014). The initiative highlights the significance of engaging women in conversations about alcohol consumption as a valuable preventative practice for frontline medical professionals. It provides practical resources for medical professionals to enquire about and document maternal alcohol use during pregnancy (FARE, 2016).

For children living in OOHC settings, it can be difficult to obtain an accurate diagnosis of FASD if they are no longer connected with birth families (Bakhireva et al., 2018). Developing the capacity of child, family and community welfare professionals to ask about alcohol consumption and to identify FASD where it is present, and to record alcohol consumption during pregnancy, could assist with this – particularly for child protection workers.

#### Innovation in diagnostic process

Research has highlighted the need for more practitioners to be able to identify Australian children living with FASD (Reid, 2018). While multidisciplinary team assessments are the recommended approach to FASD diagnosis, specialist multidisciplinary clinics are not available in all areas of Australia and have extensive waiting lists. There is recognition that FASD diagnosis needs to be accommodated in routine assessment practices of child development units and other allied health practitioners across all locations to meet demand.

There are additional considerations when serving Australian rural and remote settings that may require some innovation in approaches to diagnosis (Dossetor et al., 2019). When innovating, the advantages offered must be balanced against the effectiveness and accuracy of diagnosis (including comparative assessment and stakeholder feedback). These innovations could be through smaller diagnostic collaborations or the use of virtual diagnostic programs or other technologies (such as promising facial recognition and eye tracking technologies; see Popova, Dozet, & Burd, 2020).

FASD diagnosis can now also be made by practitioners from various disciplines who hold specialist FASD knowledge.<sup>5</sup> Smaller diagnostic collaborations may be more suited to regional and remote settings, where access to multidisciplinary clinics is often not possible. The use of virtual diagnostic programs or other technologies could also increase the capacity of practitioners to diagnose Australians in rural and remote settings or whenever face-to-face service provision is not possible (see Commonwealth of Australia, 2021, p. 80; Whittingham & Coons-Harding, 2021).

<sup>5</sup> Professionals who would like to undertake diagnostic training can contact NOFASD Australia on 1800 860 613 or through the [FASD Hub](#).

## Further development of methods for assessing neurocognitive issues

Children living with FASD can have significant neurodevelopmental delays. These children can show impairments across any or all of the neurodevelopmental domains that form part of the current Australian FASD Diagnostic Guide (Bower & Elliott, 2016). Research attempting to differentiate the neurocognitive profile of FASD from other childhood conditions (e.g. trauma, ADHD and ASD) using neuropsychological measures has been largely unsuccessful (Kingdon, Cardoso, & McGrath, 2016; Mattson, Bernes, & Doyle, 2019). A 2019 review concluded that there is no clear neuropsychological profile for FASD and current methods for assessing neurocognitive domains remain insufficient to identify children without sentinel facial features (Mattson et al., 2019).

More evidence is needed on how to differentiate FASD from other disorders characterised by behavioural or attention difficulties (such as ADHD or ASD) (Fryer, McGee, Matt, Riley, & Mattson, 2007; O'Connor & Paley, 2009; Pei et al., 2011; Popova et al., 2016; Weyrauch et al., 2017). More research is also needed to better understand how FASD diagnosis is enhanced or diminished by assessing neurocognitive skills as part of the 10 neurodevelopmental domains in the current guidelines.<sup>6</sup> As part of a project funded by the Commonwealth Government, the neurodevelopmental criteria in the Australian FASD Guide are undergoing review through consultation with researchers, stakeholders and practitioners to improve the assessment and diagnosis processes.

One of the complexities of developing diagnostic criteria is the overlap in clinical presentation between children with FASD and children with a range of other early-life experiences that can also result in neurocognitive delays. In particular, guidelines for assessing the impact of pre- and postnatal adversities on a child's neurodevelopmental presentation are needed, especially for children living in OOHC (Ali, Kerns, Mulligan, Olson, & Astley, 2018; Mattson et al., 2019; Nyongesa et al., 2019; Olson, Jacobson, & Van Oot, 2013). Unfortunately, many practitioners are not easily able to obtain this information if it has not been included as part of a child's health record.

## Expanding criteria to include other possible clinical features

Increasing evidence suggests that the inclusion of other clinical issues in the diagnostic guidelines could assist in the diagnosis of FASD. In particular, there are several clinical issues that are often reported by caregivers and are supported by an emerging research base. These include:

- significant sleep disturbance (Chen, Olson, Picciano, Starr, & Owens, 2012; Hayes, Moritz, & Reid, 2020; Inkelis & Thomas, 2018; Murghal, Hill, Joyce, & Dimitriou, 2021; Tiffany, Hanlon-Dearman, & Fjeldsted, 2011; Wilson et al., 2016)
- difficulties in reading, saccadic eye movement,<sup>7</sup> visual tracking<sup>8</sup> and visual integration<sup>9</sup> (Green et al., 2009; Maurage, Bollen, Masson, & D'Hont, 2020; Paolozza, Titman, Brien, Munoz, & Reynolds, 2013)
- significant difficulty with sensory processing and sensory integration<sup>10</sup> (Jirikowic, Olson, & Kartin, 2008; Jirikowic et al., 2020; Tiffany et al., 2011)
- the presence of significant health issues, including cardiac, renal, metabolic, reproductive and immunological difficulties, and obesity (Akison, Moritz et al., 2019; Akison, Reid et al., 2019; Hayes et al., 2021; Reid et al., 2020; Reid, Akison et al., 2019; Reid, Moritz et al., 2019).

## 2. Developing workforce therapeutic capacity for children with comorbidities

The National FASD Strategic Action Plan 2018–2028 (Department of Health, 2018) identifies the provision of effective support to children and families as a key priority area. There is an emerging evidence base on the effectiveness of interventions tailored to the attentional, learning or behavioural aspects of FASD (e.g. see McLean & McDougall, 2014 and Reid et al., 2015). However, comparatively little evidence exists on how to support children living with FASD and other common mental health challenges.

<sup>6</sup> The neurocognitive components of the 10 neurodevelopmental domains refer to the assessment of Cognition, Language, Memory, Attention and Executive Functioning (see Bower & Elliott, 2016 for more information about how these are assessed).

<sup>7</sup> Saccadic eye movements are small rapid eye movements that occur when the eyes change from one point of fixation to another; for example, during reading.

<sup>8</sup> Visual tracking is a visual processing skill that occurs when the eyes focus on an object as it moves across the field of vision.

<sup>9</sup> Visual integration involves the coordinated and seamless functioning of several visual skills.

<sup>10</sup> Sensory processing refers to a child's registration and interpretation of sensory input in the environment (including the body). Sensory integration involves the seamless processing and organising of sensory input from multiple sensory modalities.

- Children living with FASD present with higher rates of mental health comorbidities compared to the general population. For example, one study found that of children living with a FASD diagnosis: 50% had a diagnosis of ADHD (10 times the expected population rate); 23% had an intellectual disability (23 times the expected population rate); and other mental health disorders also occurred at rates that exceeded those expected in the community (Flannigan et al., 2020; Weyrauch et al., 2017; see also McLean 2019c). Although the reason for this is not fully understood, it is likely to reflect the complex interplay of underlying cognitive deficits (e.g. poor impulse control and poor cognitive flexibility).
- There is an overlap between FASD symptomatology and other mental health conditions.
- There is a 'poor fit' for children with FASD in the available health and mental health services (McLean, 2019c).
- There is a lack of understanding of FASD in available health and mental health services (Olson et al., 2013).

The effect of these mental health challenges in the context of FASD can be significant; therefore, practitioners should be aware of mental health comorbidity in children who have FASD. Retrospective accounts of suicidality among adults living with FASD indicate that around 3% of children (then aged 6–11 years), 12% of young people (then aged 12–20 years), and 23% of adults (then aged 21–51 years) had attempted suicide (Huggins, Grant, & Streissguth, 2008; O'Connor, Portnoff, Lebsack-Coleman, & Dipple, 2019). These rates are approximately five times higher than the general population (Huggins et al., 2008; O'Connor et al., 2019) and believed to be the leading cause of death in this population (Thanh & Jonsson, 2016).

Given this, there is a need to build the confidence and capability of the workforce to better meet the needs of the cohort of children with known or suspected mental health and neurodevelopmental impairments (see e.g. Department of Developmental Disability Neuropsychiatry, 2014). Without an awareness of the potential contribution underlying neurocognitive issues, the effectiveness of traditional therapeutic interventions may be minimised. Conversely, a model of practice that focuses on the neurocognitive aspects of FASD alone may unintentionally minimise significant comorbid mental health concerns, particularly if these are externalised (McLean, 2019c; Trollor, 2014; Whittle, Fisher, Reppermund, Lenroot, & Trollor, 2018). While some aspects of mental health conditions, such as affect regulation, are currently considered as part of the neurodevelopmental impacts of FASD, there is a need to better understand this overlap.

Better understanding on how to support child and family practitioners to recognise and work with FASD and its common comorbidities would be beneficial. In the absence of well-developed guidelines on how to support children living with FASD and other mental health conditions, it is worth exploring the effectiveness of interventions developed for other populations (e.g. adapted interventions for children with intellectual disability and children with autism) and their potential applicability to child and family practitioners working with FASD (Hronis, Roberts, & Kneebone, 2017).

### 3. Evidence-informed interventions that address systemic influences

There is a need to invest in developing and trialling interventions based on theoretically sound, evidence-informed and holistic approaches with Australian families living with FASD (including foster and kinship carer families) (McLean, 2019b; National Indigenous Drug and Alcohol Committee [NIDAC], 2012). Petrenko (2015) highlighted the absence of theoretical drivers for many interventions directed at children living with FASD and has created an overarching conceptual framework that could guide future applied intervention research. The framework is based on a synthesis and integration of well-supported child development and ecological theories (see Petrenko, 2015 for more detail). It emphasises:

- the significance of the family and broader ecological context in which a child with neurodiversity is raised. This includes the range of risk and protective factors that influence a child's developmental trajectory and how the condition manifests throughout a child's development (Olson, Oti, Gelo, & Beck, 2009).
- the role of neuroplasticity and the possible benefits of providing an enriched early learning environment for children with neurocognitive impairment. There is the potential for targeted and scaffolded learning experiences to extend a child's learning and development (Kodituwakku, 2010; Kodituwakku & Kodituwakku, 2011; Petrenko, 2015).
- the significance of interventions that target underlying deficits in attention and self-regulation; and the role of these issues in driving many of the difficulties and skill deficits experienced by children living with FASD (Kodituwakku, 2010; Kodituwakku & Kodituwakku, 2011; Petrenko, 2015).

Taking into consideration this broad framework, and when viewed as part of a holistic and coordinated approach, the following supports are key components:

- *Psychoeducation and support of caregivers*  
Addresses the cognitive nature of the disorder and appropriate locus of control; teaches positive behaviour approaches rather than contingent behaviour management approaches; models how to apply environmental accommodations, scaffolding and supports; teaches how to create structured learning environments that reduce cognitive burden; teaches how to deliver effective instruction; builds parental self-efficacy and manages parental stress. Supports caregivers whose quality of life may be impacted by raising a child with FASD (Biddle, O'Callaghan, Finlay-Jones, & Reid, 2020; Reid & Moritz, 2019).
- *Environmental accommodations*  
Teaches how to simplify and structure a child's environment, in recognition of the underlying cognitive difficulties a child is likely to experience; acknowledges that children living with FASD do best in predictable and structured settings; focuses on modifying environments where a child is developing (including school and social environments) and adjusts expectations accordingly (Skorka, McBryde, Copley, Meredith, & Reid, 2020).
- *Pharmacotherapy*  
Stimulant medications may be warranted when FASD is associated with impairment in attentional control and hyperactivity; and neuroleptics may be indicated when FASD is associated with social behaviour deficits (Ritfield, Kable, Holton, & Coles, 2021).
- *Child-focused interventions*  
Targeted interventions shaped by a child's unique neurocognitive profile that leverage a child's strengths; explicit friendship and social skills training; and interventions delivered *in conjunction* with parent training in order to increase the generalisability of learning (Skorka et al., 2020).
- *Ongoing supportive/integrated case management*  
Provides an ongoing relationship with the family; supports the development of a shared language and shared understanding of need among a child's network; advocacy and coordination of supports; assistance with skills of daily living; and assistance with accessing financial and practical supports. This includes the integration of case management and coordination of different services across all domains of children's development (physical, mental and family support) (Reid et al., 2020; Skorka et al., 2020).  
(Adapted from Petrenko, 2015; see also Hagan et al., 2016; Mansfield et al., 2018; McLean, 2019a; McLean & McDougall, 2014; Petrenko, Tahir, Mahoney, & Chin, 2013; Reid et al., 2015.)

Programs of support that can leverage these principles may be more effective in improving outcomes for children and other family members who are living with FASD (Adebiyi, Mukumbang, & Beytell, 2019). Adopting a holistic and ecological lens has the potential to help generalise skills and minimise secondary conditions that arise from the lack of coordinated support.

## Practice questions

### Building workforce diagnostic capacity for FASD

- What possible benefits to children might there be when practitioners ask about prenatal alcohol exposure, and when practitioners document maternal drinking history?
- Where might practitioners go to learn more about FASD services, diagnosis, training and professional development?

### Developing workforce therapeutic capacity for children with comorbidities

- How might your practice need to be adapted to better meet the needs of children with neurocognitive impairments and possible mental health needs?
- In what ways might highly reflective and verbally mediated therapies be adapted to better suit the needs of children living with FASD?

### Evidence-informed interventions that address systemic influences

- What components of collaborative, systemic and evidence-informed approaches are part of your current practice or service model?
- What are some of the ways that environmental accommodations, supportive case management and caregiver education and support can be integrated into your current practice approach?

## Conclusion

Significant developments in Australia since 2016 have improved understanding of how to diagnose and respond to FASD. The publication of the Australian FASD Diagnostic Guide, the establishment of FASD diagnostic clinics and expanded provision of FASD-informed services within routine health services, and the establishment of the FASD Hub have contributed to ensuring that children and families living with FASD receive evidence-informed support from knowledgeable professionals.

In order to further improve outcomes for affected children and families, a number of issues need further exploration, so that the evidence base on effective service delivery for FASD can continue to grow, and more meaningful and longer-lasting change is created for children and families living with FASD.

A key issue is increasing the capacity for children to access diagnostic services and the capability of practitioners to identify FASD and/or to refer for diagnosis where indicated. Practitioners are now able to access information about diagnostic services and professional development from the FASD Hub in addition to No FASD Australia.

Another key issue is the need to introduce workforce and practice development initiatives that can build capacity to work with children who have a neurocognitive compromise and need therapeutic mental health support.

Finally, the development of service approaches that are based on theories of child development; are ecological and holistic in nature; and that recognise the need to adapt parenting, counselling and service models are needed to better support Australian children and families living with FASD.

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