

5. Systems and service supports for children and families living with Fetal Alcohol Spectrum Disorder (FASD)

Dr. Sara McLean, 2019

Key messages

- The term Fetal Alcohol Spectrum Disorder (FASD) covers a range of developmental disorders associated with a variety of physical, mental health, and behavioural difficulties. FASD is caused by exposure of the developing fetus to alcohol in utero.
- Children living with FASD often require support from multiple service providers, including health services, mental health services, child protection, intensive family support, and alternative and mainstream education services.
- Many aspects of conventional services, such as referral pathways, information provision, and support provision may be less suited to children living with FASD. Access to these services assumes well-developed memory, language or organisation skills that may be lacking in children affected by FASD.
- Collaborative service provision that relies on a shared understanding of children's needs is possibly the best way of engaging with and supporting children and families living with FASD.



What is this resource about?

This resource outlines some of the broader issues related to the provision of appropriate, timely and relevant services and supports for children and families living with FASD. For more information about FASD, its impact on the child and their family, and the relationship between FASD and mental health concerns, see our suite of **FASD resources**.

Children's health and development occurs within multiple contexts, including their own individual characteristics, their family, school, local neighbourhood, and community environments (for more, see **'The Whole Child'**). For children living with FASD, however, it can be more difficult for them to access this support. Cognitive and language issues can make it hard for them to access mainstream services due to the way services are currently configured. Even when services are accessed, service providers may not be aware of FASD and, as a result, children may not receive the tailored support that they need.

This resource highlights some of the complexities of service provision for this group of children, focusing on child protection, family support and child mental health services.

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Why is it important to align services with the needs of children with FASD?

It is widely recognised that a good 'ecological fit' between a child and their family, school, and community life can have a significant and positive impact on the child's development and mental health (Eriksson, Ghazinour & Hammarström, 2018; Mian, Wainright, Briggs-Gown & Carter, 2011). Children raised in non-supportive environments and exposed to poorly suited services and systems find it difficult to realise their developmental potential and optimal wellbeing.

While this is true for all children, it is particularly the case for those children living with FASD. When there is a mismatch between what a child needs to thrive and the kind of services and supports they are able to access, it can result in poorer social and vocational outcomes in adult life (Streissguth et al., 1998; Streissguth et al., 2004).



Some key issues make it difficult for children living with FASD to access appropriate and tailored support. These issues revolve around:

- services that are set up in a way that makes them difficult to access (services that are not 'fit for purpose'); and
- services that offer 'routine' interventions, rather than support that is tailored to the needs of children living with FASD (interventions and supports that are not 'fit for purpose').

Making an effort to better align services with what children and families need – making them more 'fit for purpose' – may contribute to optimal wellbeing development for children affected by FASD.

Services that are not 'fit for purpose'

Many of the ways in which a service is designed, such as its referral process, rules for admission, and the kind of support it provides may unintentionally make it less accessible to families and children living with FASD. Barriers to access for children and families living with FASD may include:

- assumptions about children's language and cognitive skill levels
- reliance on language-dependent counselling approaches
- narrowly prescribed referral criteria
- constraints imposed on the duration of treatments; and
- therapeutic approaches unsuited to their needs (see McLean, McDougall & Russel, 2014 for more detail).



The table below summarises some of the procedures and practices normally employed by services that may pose unintended barriers to children living with FASD. The ‘child’s functioning’ column shows how these practices align with some of the key difficulties experienced by children and families.

Limitations in child’s functioning	Service features
<p>Poor verbal comprehension, language and literacy skills</p>	<ul style="list-style-type: none"> • Services that use language-rich, language-reliant, narrative approaches to counselling and support provision. • Counselling approaches that use complex language, metaphors, and verbal ‘contracts’. • Counselling approaches that discuss abstract goals (time, money, commitment). • Services that rely on the use of referral forms and other paperwork containing large amounts of written material in the absence of visual aids to understanding. • Services that rely on children and families to keep track of time, days and weeks; to monitor and track upcoming appointments using diaries or other means. • Services that don’t use the child’s language, don’t explain technical language and/or don’t use language consistently. • Counselling approaches that ask the child/young person to engage in self-reflection or self-monitoring.
<p>Difficulty with executive functioning (memory, planning, monitoring and self-reflection)</p>	<ul style="list-style-type: none"> • Services that discontinue service or remove families from the waiting list after missed (non-attended) appointments. • Services that consider it the client’s responsibility to keep track of appointments and passage of time. • Services that set a limit on the number of appointment times a child can be allocated. • Services that are provided on a time-limited basis (less suited to addressing long-standing support needs). • Counselling approaches that ask the child to anticipate the outcomes of their actions or ask them to recall/reflect on historical events as part of a narrative. • Approaches and services that rely on the child to develop self-control, rather than focus on managing their environment and providing adequate supervision. • Services that exclude or restrict access for the child due to a critical incident or abnormal behaviour. • Counselling approaches that rely on the child monitoring their own progress and reporting/reflecting on progress towards their goals.
<p>Difficulty with executive functioning (memory, coordination, organisation and planning)</p>	<ul style="list-style-type: none"> • Services that set irregular appointment times that are harder to keep track of. • Siloing of service provision, requiring the child to access multiple services and professionals. • Placing the onus on children and families to coordinate multiple services and appointments. • Frequent changes in service providers or services. • Lack of access to a professional who can have an ongoing relationship with, coordinate services around, and advocate for the child. • Lack of one consistent person to follow the child through their journey; who has a strong knowledge of the child’s history and the context of their journey and relationship with services. • Lack of adequate handover when the child is required to change service providers, contributing to a lack of consistency in approach.

Supports that are not ‘fit for purpose’

Two service types that commonly encounter children living with FASD are child protective services and child mental health services. These services have great potential to help children living with FASD, if their workers are able to identify FASD and provide appropriate support to children and families.

Child protection services can span from early intervention and family support programs, through to statutory services for children who have been removed from their families of origin. They encompass parental issues, parenting issues, and issues related to child safety, wellbeing and mental health, and need to be able to offer support that is suited to the needs of families living with FASD.



Child mental health services tend to offer a more specialised and narrow range of services. It is also important for these services to be able to recognise and provide support for children living with FASD.

Child protection services

There is a pressing need to upskill the child protection workforce in relation to FASD (Walker, 2011). Research estimates that FASD is at least 10 times more common in the out-of-home-care population than in the general population (Popova et al., 2019; Walker, 2011), which suggests that workers who are involved with children at any stage in the child protection system will come into contact with children affected by FASD.

There are a number of ways in which child protection workers can improve outcomes for children and families living with FASD:

Early detection and intervention: The child protection workforce has a critical role to play in the early identification of affected children. Alcohol and substance use is common amongst parents who come to the attention of the child protection system (Jeffreys, Hirte, Rogers & Wilson, 2009). Family stress, problematic alcohol consumption by a father, and the presence of family and domestic violence are all risk factors for alcohol consumption during pregnancy (McLean & McDougall, 2014). It is important for child protection and family support workers to be aware of the factors that increase risk of alcohol use during pregnancy, and to enquire about alcohol use using a structured screening tool as part of routine assessment and practice.

Recording the child's experience: There is also a unique opportunity for workers to thoroughly investigate and document a history of maternal alcohol and substance use as part of their early investigations. Lack of recorded information about alcohol use during pregnancy is one of the main barriers to children in the out-of-home care system receiving an accurate diagnosis of FASD. Clear documentation of maternal alcohol use in a child's record can facilitate accurate diagnosis at a later date.

Offering more effective supports to parents: It is also important that child protection and family support workers are able to recognise the negative impact that a child's cognitive challenges will have on parents, and on the effectiveness of standard parenting approaches.

Children with cognitive challenges need approaches that emphasise managing and simplifying the environment, rather than enforcing consequences (Petrenko, 2015). Conventional parenting approaches based on social learning principles may be ineffective with children living with FASD. Social learning approaches assume that a child is capable of ‘cause and effect’ learning; has good working memory,

reflective capacity and self-regulation skills; and behaviour that is intentional and within their control. It is important for workers to 'let go' of these kinds of approaches, focusing instead on ones which pre-empt and minimise environmental and internal triggers (Petrenko, 2015).

Routine and predictability are also important for children affected by FASD. Families living with FASD may experience multiple stressors which make it difficult to provide this structure. For example, ongoing drug and alcohol issues can impact on parents' abilities to provide consistency and routines, no matter how motivated they are to care for their child. Families may need additional support to create an environment that supports their child to develop problem-solving, coping and different behavioural skills.

The challenge of parenting a child with ingrained behavioural and learning issues can increase the risk of child protection involvement. Once a child living with FASD is removed from their family, they may spend longer periods in care and may be less likely to be reunified with their family (Popova et al., 2014). Child protection workers can reduce this risk by supporting families with tailored parenting approaches.

Child protection workers have an important role to play in identifying and responding to FASD in vulnerable families. Services that are trained in identifying and supporting families living with FASD can have a significant impact on children's developmental trajectory. This suggests that child protection workers should be trained in positive behavioural approaches (rather than conventional social learning approaches), and that they should not assume that conventional parenting advice will be effective in families living with FASD.

Instead, workers should focus on supporting parents to modify their environment in order to reduce their child's frustration, build missing skills, and strengthen alternative behaviours (Petrenko, 2015). Within the overarching context of positive behavioural approaches, there should be particular emphasis placed on the need for repetition, structure, and on helping parents persist in the face of difficult behaviour. It is particularly important that when FASD is suspected, support is provided in an ongoing way, and not discontinued prematurely.

Child mental health services

There is great potential for FASD knowledgeable workers to enhance children's outcomes within the child mental health system. However, most mental health professionals are not confident in recognising and responding to FASD (Mukherjee et al., 2015). In addition, FASD does not fit well with existing criteria for mental health services, increasing the chances of children living with FASD falling through the gaps in services.

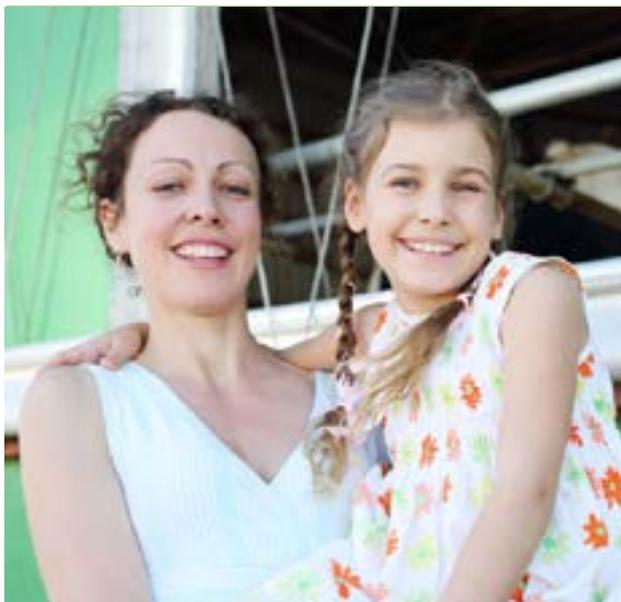
FASD may present in a range of ways. It may be overshadowed by more common mental health symptoms, making it harder to recognise than many other conditions. It may or may not be accompanied by intellectual disability, offending behaviours, and learning or behavioural issues. The nature of the primary presenting issue, rather than the primary cause, may determine whether a child is eligible for mental health support, or whether they fall under the remit of other services, such as youth justice or disability services.



[Related: Understanding the impacts of Fetal Alcohol Spectrum Disorder \(FASD\) on child mental health](#)

Child mental health practitioners can improve outcomes for children living with FASD by:

Modifying assessment protocols to include the contributions of FASD



Many mental health professionals will need training in recognising the red flags and risk factors associated with FASD (Brown et al., 2017). Key skills for mental health workers include understanding the need for early diagnosis and intervention; the appropriate use of screening tools and measures; the application of Australian diagnostic guidelines, and understanding the secondary difficulties associated with FASD (Brown et al., 2017). Fortunately, there are now several diagnostic clinics that can work alongside mental health professionals to develop their diagnostic capacity in the area of FASD (see **FASD Hub** for details of the diagnostic clinics in Australia and how professionals can access support in developing diagnostic capacity in FASD).

Practitioners may need to adapt their practices to include the possible contribution of FASD in children's mental health presentation. Mental health assessments that rely entirely on intelligence tests may not adequately

capture the adaptive functioning deficits experienced by many people living with FASD (Brown et al., 2017). Assessments and interviews that rely on yes/no responses can mask the extent of language and comprehension difficulties that children living with FASD experience. Similarly, memory difficulties such as confabulation (imagined memories), memory loss, and suggestibility (tendency to agree) can significantly impact the accuracy of a mental health assessment (Brown et al., 2017).

Assessment of FASD often requires a “nuanced differential diagnosis” (Brown et al., 2017, p. 2.) that is beyond the traditional training and skill set of mental health professionals. Additional specialised support can help practitioners to build their capacity to recognise and assess FASD.

Adapting therapeutic approaches to better accommodate FASD

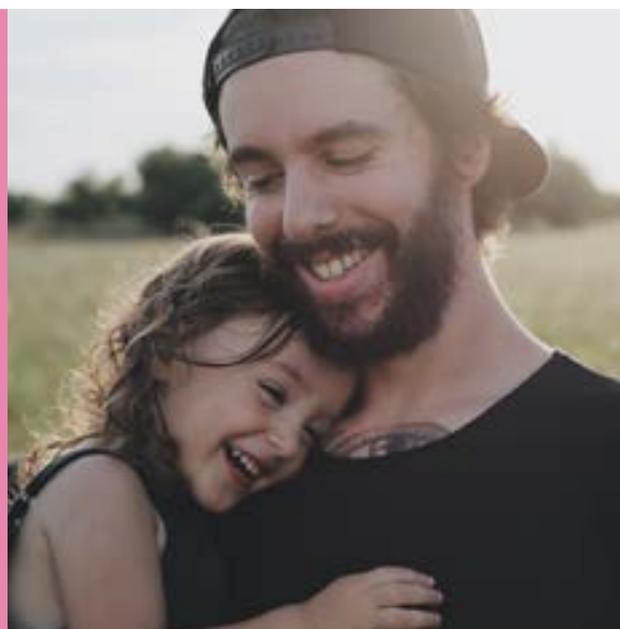
Mental health services may not always recognise children affected by FASD. These children may present with attention deficit hyperactivity disorder (ADHD), oppositional defiance disorder (ODD) or conduct disorder; leading practitioners to offer support based on social learning principles and aligned with these conditions.

While the presentation of FASD may seem similar to these common childhood disorders, children with FASD have additional difficulties that require modified interventions. The cognitive and language issues present in FASD mean that children are less able to benefit from the kind of reflective counselling approaches that can be used with other children (Bagley, 2019).

Caregivers need support to create a simplified, structured environment, combined with step-by-step coaching targeted to a child's unique strengths and difficulties. Effective support is likely to include strategies to build a child's organisation and planning and life skills, along with strategies to address sleep disorders and behavioural and emotional regulation (Brown et al., 2017; McLean & McDougall 2014).

Practitioners should avoid the use of insight-based, narrative therapeutic and group therapy approaches, which may be difficult for this population (Brown et al., 2017).

Child mental health workers have an important role to play in identifying and responding to FASD in vulnerable children and families. Services that are trained in identifying and supporting children living



with FASD and are knowledgeable about the connection between FASD and other mental health symptoms, can have a significant impact on children's developmental trajectory. This suggests that workers should be trained in screening and assessing for FASD, and in providing interventions that create structured, managed environments; explicit skill development, and support with behavioural and emotional regulation. It is also important that support is ongoing, can be understood by a child with language and memory issues, and is not discontinued prematurely.

Developing responsive services for children and families living with FASD

The poor fit between children's needs and mainstream service models can mean that key services (e.g. child protective programs and child mental health services) can be less accessible and meaningful for families living with FASD. This can lead to higher drop-out rates, or fewer families accessing these services to begin with.

Families living with FASD are often labelled as 'hard to engage'. While this may be true for some families, current service design can also make it difficult for children living with FASD to engage. It is important for services to understand the possible reasons for non-attendance or lack of engagement as part of their ongoing quality assurance processes.

This paper has touched on some of the reasons why services can be inaccessible and unsatisfactory for families living with FASD. These centre around aspects of service design such as referral and intake procedures, constraints on service duration, lack of staff recognition and awareness regarding FASD, and limitations in the type of support that is offered to families.

Service provision for children and families living with FASD may be enhanced by offering more responsive approaches that are not constrained by existing service parameters and conventional models of intervention. Approaches based on collaborative casework models have been used effectively to support families living with FASD (McLean & McDougall, 2014). In collaborative models, a key worker coordinates input from legal guardians and professionals working in health care, assisted living, financial management, and mental health. This model can more effectively coordinate the services needed to support an individual living with FASD across the lifespan (Brown et al., 2017). A collaborative approach may ultimately prove more effective for families than a number of visits to siloed services that do not fully address the complex developmental needs of affected children. Similarly, services may benefit from connecting with a professional or a clinic that has specialist knowledge about FASD. This can be done in a range of ways, from informal communities of practice, to formalised 'train the trainer' approaches, upskilling and ongoing support for the workforce.

Ultimately, developing more effective services to address the needs of children living with FASD will require collaboration between policymakers, researchers, practitioners, and those with lived experience and their families (Anderson et al., 2017; Stewart 2015). In the meantime, there is considerable scope for services to adapt their approach in order to better accommodate the needs of children and families living with FASD, who may otherwise go without the supportive relationships and services they need.



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Acknowledgments

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