

4. How to support caregivers and families living with FASD

Dr. Sara McLean, 2019

Key Messages

- Fetal Alcohol Spectrum Disorder (FASD) refers to a range of distinct but related developmental difficulties caused by exposure of the developing fetus to alcohol in utero.
- Stable caregiving has been identified as a significant protective factor for children living with FASD. An important way to maximise developmental outcomes is to support the child's caregiver and family.
- Caregivers and families living with FASD experience a range of unique stressors associated with obtaining diagnosis and with a child's ongoing behavioural and learning difficulties.
- All practitioners, irrespective of their role, are likely to encounter children and families that are living with FASD. It is important, therefore, that all practitioners understand the likely impact of FASD on families, and how they can best support children and families living with FASD.



What is this resource about?

This resource describes caregivers' experiences of supporting a child living with FASD – from obtaining a diagnosis, through to supporting families to adapt following diagnosis. It outlines some of the key issues that families describe as important to them, and that are helpful for practitioners to understand. For the purpose of this resource, the terms 'parent' and 'caregiver' encompass the biological and adoptive parents of a child as well as individuals who have chosen to take up a primary or shared responsibility in raising that child.

This resource is suited to practitioners and other professionals working with parents and families of children living with FASD. It aims to highlight the range of issues that families can face, and to support practitioners to understand the possible ways in which they can offer support.

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Parenting a child with neurodiversity

Parents of children with developmental differences experience more stress compared with parents of similar-aged children without developmental issues (Crettenden, 2008). These include increased risk of depression, psychological distress, strained family relationships, and poor physical health (including chronic fatigue and disrupted sleep) (Crettenden, 2008; Gilson et al., 2018; Skok, Harvey & Reddihough, 2009).

Raising a child with a disability also means dealing with a range of problems, including difficulty in obtaining specialised professional services; managing the costs involved with caring for a child with a disability; arranging and maintaining appropriate educational placements and services; dealing with challenging behaviour; finding opportunities for self-care; managing multiple roles, and dealing with the health care system (Brown & Roger, 2009; Gilson et al., 2018).



These caregivers also have considerable resilience and resourcefulness. Parents of a child living with a disability are likely to draw on a range of unique skills and attributes that they value and identify as important (Brown, 2007). These include personal characteristics such as being caring and attentive, respectful and energetic; having clearly defined roles and responsibilities; and knowing how to access practical, emotional and financial supports (Brown, 2007). Caregivers also value capacities such as self-reflection; being able to understand the child's perspective; being flexible and creative, and maintaining hope and optimism (Bennet, 2015).

Families living with FASD

Caregivers raising a child with FASD face additional complexities and support needs. A recent study of caregiving stress amongst both biological and non-biological parents of children living with FASD documented very high levels of caregiver stress, and low sense of personal control (Bobbitt et al., 2016). Only 30% of the caregivers surveyed reported feeling ok about how things were going, and almost 90% felt that they wanted more support. Adoptive parents reported more child-related stress, but biological parents were more likely to experience poor parental wellbeing, possibly due to feelings of self-blame. Overall, caregiver stress levels were around double that typically found in a community sample (Bobbitt et al., 2016).



Most research into caregivers' experiences of raising a child with FASD has been conducted on foster carers. This recognises the prevalence of FASD in the out-of-home care sector, and the potential impact of FASD on placement stability (Walker, 2011).

In the lead up to and immediate aftermath of receiving a diagnosis for their child, caregivers are likely to experience a range of mixed emotions, including anger, guilt, relief, and concern about what the diagnosis might mean for their child (Baksin et al., 2016).

During this time, it can be helpful to support parents in developing a new understanding of their child. This might include specific education about the diagnosis, and information about how FASD affects children's behaviour and appropriate parenting practices for a child living with FASD (Baskin et al., 2016; Petrenko et al., 2016). It can also be helpful to connect them with a knowledgeable community of parents that have also 'been through it' (Baskin et al., 2016).

Caregivers will need additional support to reframe and adjust their hopes and expectations for their child. Diagnosis often follows a prolonged period of time in which caregivers have been aware that something was not right, and sought solutions from a range of professionals (Sanders & Buck, 2010).

Caregivers can also enter the diagnostic process with expectations and hopes that may or may not be met (Baskin et al., 2016; Chamberlain et al., 2017). Caregivers often hope that their child can lead a productive life, and diagnosis can be experienced as something of a 'double-edged sword' of relief and sadness for the loss of future possibilities (Chamberlain, 2017; Sander & Buck, 2010).

It can be unclear to families what, if any, additional supports and services they will be able to access as a result of obtaining a diagnosis. Caregivers can feel guilt or relief, and non-biological caregivers can also experience feelings of anger towards the biological parent/s (Sanders and Buck, 2010).

Obtaining a diagnosis of FASD can also have advantages. In particular, it can help caregivers to reframe their interpretation of children's behaviour. Caregivers begin to feel more effective as parents, because they are now able to correctly attribute difficulties to the underlying neurodevelopmental issues, rather than a child's wilful disobedience or 'bad' parenting. Diagnosis can help caregivers to develop a clearer understanding about what the child's experience is, and about their child's strengths and abilities as well as their needs (Chamberlain et al., 2017). This knowledge also often leads to a shift in parenting techniques, in which they become more likely to use proactive strategies, such as managing environmental triggers, rather than relying on consequence-based strategies to manage behaviour (Petrenko et al., 2016).

Overall, the experience of obtaining a diagnosis within a supportive environment can be empowering for caregivers, and can counter past situations in which they have not felt heard by professionals (Chamberlain et al., 2017).

Living with FASD

Following diagnosis, caregivers will continue to deal with constant and ongoing challenges in relation to raising a child affected by prenatal alcohol exposure. These include managing the behavioural and emotional symptoms of FASD; but also those challenges associated with getting the kind of practical and emotional support children and families need.

The impact of FASD on family life

One of the main sources of strain for caregivers following diagnosis is its impact on the lives of their child and the rest of their family.

The daily challenges that arise from a child's neuro-cognitive difficulties are significant. Difficulties such as poor and inconsistent memory, lack of cause and effect thinking and planning, and poor impulse control are extremely stressful for carers (Gardner, 2000), as they mean children are unable to learn from their mistakes. In particular, memory difficulties make it harder for parents to discipline effectively, because affected children have very poor ability to learn from consequences.

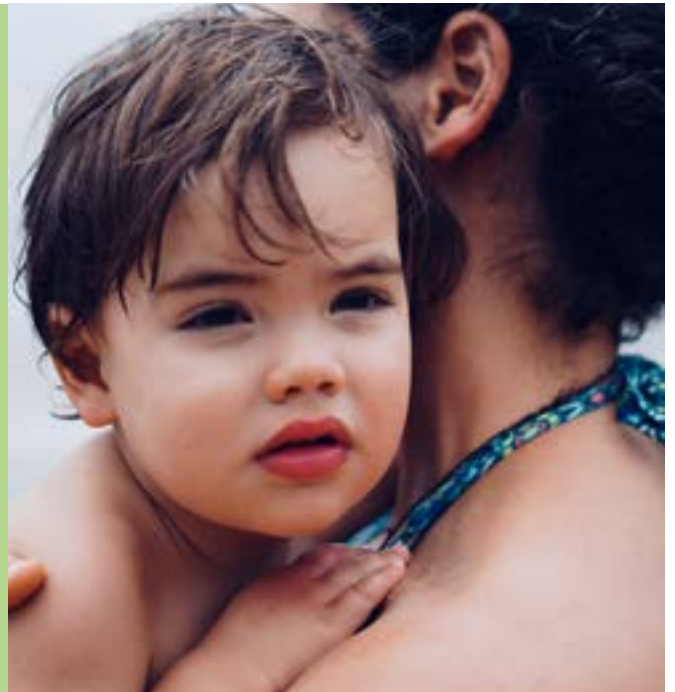
Other cognitive difficulties are also likely to place pressure on families. A child living with FASD lacks cognitive flexibility, often making it difficult for families to act spontaneously. The child is likely to find change in routines very difficult to handle, and enforced changes often result in high levels of anxiety or behavioural 'meltdowns' (Bennet, 2015).

Children living with FASD can lack a sense of permanence and persistence in rules, meaning what they learn today may not be remembered tomorrow (Sanders & Buck, 2010). They may also experience high levels of hyperactivity, aggression and destructiveness related to poor cognitive and behavioural impulse control. This can lead to social isolation and exclusion from school settings (Bennett, 2015; Gardner, 2000), placing further strain on their family.

Neurocognitive difficulties with impulse control in particular, mean caregivers are also often worried about their child's safety. Poor impulse control, lack of ability to understand the consequences of their actions, decreased sensitivity to pain, and poor comprehension and retention of information all increase the risk of children with FASD coming to unintended harm, injury or victimisation (Bennet, 2015; Gardner, 2000; Sanders & Buck, 2010).

Parents of children living with FASD report high levels of anxiety and stress related to their child's condition. The unpredictable nature of FASD and chronic uncertainty about the future, in particular, cause caregivers high levels of stress. Concerns around how the child might be able to finish schooling, achieve a healthy relationship with someone who understands them, and whether or not they will find and keep a job are common (Brown et al., 2017; Gardner, 2000; Sanders & Buck, 2010). Parents also worry that their child may be taken advantage of, or get involved with the wrong crowd, and what that might mean for the child's future.

At the same time as having to contain this anxiety, caregivers are often drawn into battles with their child, and can be subject to physical aggression, especially in the case of older children (Sanders & Buck, 2010). The need to simultaneously maintain normality and structure and manage their child's routines, and pre-empt potentially difficult situations is incredibly stressful for caregivers (e.g. Gardner, 2000).



Relationships with professionals

Practitioners have the ability to improve their interactions with children and families living with FASD, no matter what their support role is.

Parents have frequently found their interactions with practitioners frustrating, citing the 'invisible' nature of FASD as a major contributor. This invisibility can lead practitioners to dismiss or minimise the physiological basis for their child's behaviour (Caley et al., 2009; Chamberlain et al., 2017), and to attribute difficulties to poor parenting or family stressors, rather than the underlying neurological condition (Sanders & Buck, 2010). Parents also reported that practitioners were often unaware of FASD, and of how it impacts on children. As a result, they often felt blamed for their child's behaviour (Caley et al., 2009; Chamberlain et al., 2017).

When they sought help, parents were offered general parenting advice, rather than techniques specifically for parenting neuro-diverse children (Caley et al., 2009). On the other hand, caregivers also felt that professionals couldn't ever really understand FASD from just reading about it, unless they had 'hands-on' experience of the condition (Brown, Bednar & Sanderson, 2007; Sanders & Buck, 2010). Practitioners were often seen as being dismissive of caregivers' knowledge and reluctant to 'label' a child. This frequently left caregivers feeling abandoned to cope with multiple challenges without sufficient support (Salmon, 2008).

General practitioners (GPs) have the potential to play a key role in supporting caregivers. They are seen as important gatekeepers to accessing other specialised services, and their attitude and knowledge determine how supported caregivers feel (Coons et al., 2018). However, caregivers feel that GPs do not necessarily offer the kind of support that is needed. For example, GPs lacking a basic understanding of FASD could be reluctant to refer to specialist assessment and support. On the other hand, practitioners that understood that behavioural issues can be caused by neurobiology, rather than simply poor parenting, were more likely to comply with parents' requests for medication or specialist referral (Coons et al., 2018). Overall, caregivers want practitioners to acknowledge and respect their understandings and lived experiences, and be willing to trial different solutions suggested by the caregivers' own research and intuition.

Teachers also have an important role to play in supporting children and families living with FASD. However, teachers often appear to mistake the behaviour of a child with FASD as their having a 'difficult personality' or simply engaging in wilful antisocial behaviour.

It is also difficult for caregivers to explain FASD to teachers. Caregivers report that it is more effective to explain children's needs as 'brain damage' than to try to educate teachers about the range of issues associated with FASD (Coons et al., 2018).

Caregivers really value teachers that respect them as partners in their child's education, and accept that they have special insights into their child's needs (Cleversey et al, 2017). Caregivers want educators that are adaptable; interested in learning about triggers, classroom accommodations and the impact of brain-based difficulties, and willing to help set tangible and realistic goals for children (Cleversey et al., 2017).



What kind of support is helpful?

Caregivers require three broad types of support from professionals:

1. Practical and emotional support, including feeling heard and having their experiences acknowledged.
2. Social and community support.
3. Support with creating a well-functioning family life.

Practical and emotional support

Caregivers want to be heard and believed by professionals when they speak about their child's needs. They have often done a lot of research regarding FASD and are extremely knowledgeable about what might help (Chamberlain et al., 2017). As a result, they are looking for respectful relationships with professionals who are also knowledgeable about FASD (Bennet, 2015; Brown, Sigvaldason & Bednar, 2005), and who treat them as part of the collaborative team.

Caregivers can feel conflicted between being responsible for their child's future versus letting go of the need to control what the future might hold. They want support with the feelings of guilt, loss, and sense of blame that can arise as they learn to relinquish control and move forward (Michaud & Temple, 2013; Whitehurst, 2011).

Foster caregivers also want practical support, including access to the information and resources necessary to support their child. They want to be informed about the fact that their child was exposed to alcohol in utero; however, they were often unaware that their child could be affected (Brown, Bednar & Sigvaldason, 2007). They also need access to sufficient funding to address additional medical needs, special education support and resources for computers and other learning aids (Bennet, 2015; Brown, Sigvaldason & Bednar, 2005).

Social and community support

In terms of social support, caregivers want to connect with other experienced carers to get advice on parenting. They are also looking for support for their biological children (in the case of foster caregivers), and extended family and friends. Caregivers want to build a sense of community around their child, but often feel isolated because of their child's behaviour (Bennet, 2015; Brown, Sigvaldason & Bednar, 2005).

Caregivers also want support with fostering friendships and social connections for their children, dealing with their child's social isolation, and with building their child's social problem-solving skills and social independence (Bennet, 2015).

When caregivers were able to engage in advocacy and education activities about FASD, they were able to build meaningful social connections and bring a sense of purpose to their situation. This suggests that professionals should support these opportunities when possible (Cleversey et al., 2007; Coons et al., 2016; Coons et al., 2018), provided the caregiver does not perceive the activities as an obligation (Baskin et al., 2016).

Creating a well-functioning family life

Caregivers want professionals to support them to create a functional family life, in which FASD can be accommodated. They would like support to understand and come to terms with a disorder that is a lifetime commitment, and to help them to focus on their child's gifts and strengths (Sanders & Buck, 2010). They want practitioners to support them to 'redefine' parenting success, and to focus on their child's positive achievements (Sanders & Buck, 2010).

At the same time, they also want support with other aspects of family functioning, such as establishing daily routines, creating structure in the home, setting reasonable expectations and limits, helping their child to self-regulate, and giving clear instructions to their child (Brown, Sigvaldason & Bednar, 2005).

Summary

Fetal Alcohol Spectrum Disorder (FASD) is a life-long condition that is associated with significant family and caregiver stress. FASD is more common in the community than previously thought, meaning practitioners are likely to encounter children and families affected by FASD. Children living with FASD may be more likely to experience difficulties over time, including increased risk of family and caregiver strain, social isolation and lack of support.

Much of what is known about FASD and its impact on families comes from research on the experiences of foster parents raising children affected by FASD. The presence of a stable caregiver is one of the main protective factors for children living with FASD. Supporting a child's family and caregivers is likely to be an important aspect of enhancing outcomes for children living with FASD. Therefore, it is important that all practitioners understand the likely impact of FASD on families, and how they can best support children and families living with FASD.

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Acknowledgments

Dr. Sara McLean (BSc, Hons [Neuropsych]. M, Clin Psychology, PhD) is a registered psychologist who has been working in the area of child and adolescent mental health for over 20 years. She has a special interest in supporting the behavioural and mental health needs of children who have experienced early adversity, or who are living in out-of-home care.

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