

## 3. How to support children living with Fetal Alcohol Spectrum Disorder (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. FASD is more common in the community than previously thought.
- All practitioners, regardless of their role, are likely to encounter children and adults who are affected by FASD. It is important, therefore, that all practitioners understand the likely impact of FASD on children's lives, and how they can best support children and families living with FASD.
- FASD is an important issue in child development. It is associated with significant damage to children's cognitive development, and is often connected to difficulties in memory, attention, executive functioning, sensory regulation and language use.
- While the impact of alcohol on a child's brain development may not be reversible, there are some practices that can support a child affected by FASD. Accommodating potential difficulties can help to minimise the impact of FASD on the lives of children and families.
- Both universal accommodations and targeted strategies are important tools that practitioners, caregivers and teachers can use to create a supportive environment for a child living with FASD.



### What is this resource about?

This resource outlines the diverse neurocognitive challenges frequently faced by children living with FASD. It highlights some of the ways these differences may impact on children's learning, behavioural and social development, and outlines the general principles for supporting children.

### Who is this resource for?

This resource is for practitioners and other professionals working with parents of children with FASD, and workers who are supporting children with FASD. It is suited to child and family-facing practitioners, but may also be relevant for anyone working with parents who may be raising a child affected by FASD. The aim of this resource is to highlight the range of neurocognitive issues that children can face, and support practitioners to understand the possible impact of these difficulties on children's lives.

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## Developmental consequences of FASD

Children who have been exposed to alcohol in utero are at increased risk of developing one or more of a range of physical, emotional, or cognitive difficulties. The range of reported changes in the physical, genetic and morphological aspects of development is extensive, and a complete description of these difficulties is outside the scope of this resource (see Popova et al., 2016; Weyrauch et al., 2017 for more detail).

The Australian Guidelines for the Diagnosis of FASD (2016) specifically identify ten domains of cognitive development that can be affected by prenatal alcohol exposure. The guidelines require significant levels of impairment in at least three of these domains to warrant a diagnosis of FASD.

[Related: What is Fetal Alcohol Spectrum Disorder \(FASD\)?](#)

## Brain development in children affected by FASD

The impact of FASD is unique to each child and depends on factors such as dosage, timing and duration of alcohol exposure. However, there appear to be some difficulties which are reasonably common; in particular, cognitive issues that impact on social relationships and educational achievement. While not all children will experience all of these difficulties, being aware of these challenges is an important first step in supporting children affected by FASD.

## Potential neurocognitive impacts of FASD

The full range of cognitive difficulties experienced by children living with FASD is still being understood. While the extent and nature of difficulties that children might experience varies, some of the most common challenges are outlined below:

### *Impaired executive functioning (including behavioural regulation and metacognitive skills):*

One of the main ways that children's thinking is affected by FASD is through their developing executive functioning. Executive functioning refers to a group of related cognitive skills that, when working together well, ensure that the brain works smoothly and efficiently.

Executive functioning covers two broad areas – behavioural regulation and metacognition. Behaviour regulation refers to how well a child manages and controls behavioural impulses. Metacognition refers to a child's ability to monitor and apply their attention and thinking skills to a range of tasks. Metacognitive skills are closely associated with working memory – a skill that is often quite impaired amongst children living with FASD.



### *Behavioural and emotional regulation:*

A child with poor behavioural regulation may have trouble managing strong emotions and behavioural impulses. They may experience strong emotions that escalate quickly and are sometimes accompanied by impulsive behaviours. Children with behavioural regulation difficulties may also be slow to calm down following strong emotions. Without support, children that have difficulty regulating their behaviours and emotions may be at risk of developing mental health difficulties, including both 'internalising' difficulties (e.g. anxiety disorders and depression) and 'externalising' difficulties (e.g. attention deficit hyperactivity disorder [ADHD] and conduct disorder). Behaviour regulation difficulties are also common in developmental conditions such as Autism Spectrum Disorder. These difficulties can occur alongside FASD.

Difficulty in self-regulation can lead to social difficulties and affect peer relationships. A child living with FASD may be at risk of becoming socially isolated, and can benefit from support focused on social skills training and strategies for managing emotions and behaviours in social situations. It can also be helpful to support caregivers to identify and predict situations that might frustrate a child; and to monitor social situations.

### *Metacognition:*

Metacognition refers to a child's capacity to effortlessly control and direct their attention; to retrieve information from memory; to sustain attention; to direct attention towards a goal, and to switch their attention flexibly from task to task.

These metacognitive skills are central to a child's ability to plan and organise their activities and behaviour; to monitor and reflect on their actions, and to remain 'on task' in learning situations.

Metacognitive difficulties are also found in many mental health conditions (e.g. ADHD), although the exact nature of the difficulties experienced can be different. In children living with FASD, common metacognitive difficulties include impaired working memory and poor attentional control (particularly, the ability to switch attention from task to task). These difficulties may be most noticeable in a classroom environment, where these skills are most relied upon. Even the simple task of moving between scheduled classroom activities relies on intact metacognitive skills (for example, the ability to rapidly switch attention). These aspects of metacognition often appear to be affected by prenatal alcohol exposure.

### ***Impaired language skills:***

Children living with FASD often have significant language and communication difficulties. Language includes the ability to understand what others say (receptive language); to communicate to others (expressive language); and to use language socially (pragmatic language) (Carmichael Olson, King, & Jirikowic, 2008).

Children living with FASD frequently have both delayed language and language disorders. Language delay is typically associated with limited exposure to language rich environments, intellectual difficulties, chronic childhood ear infections, or other early adversities. A diagnosis of language delay might occur when a child's communication skills are behind what would be expected for their age.

Language disorders involve difficulties in putting words together to convey meaning, in a socially appropriate context. A language disorder diagnosis might occur when a child has difficulty in producing and expressing speech, or in adapting and using language in different contexts and for different purposes. Children living with FASD also appear to have unusual language profiles – for example, caregivers report that children can appear talkative and engaged while at the same time having little actual understanding of the conversations they are taking part in.

Without support, children living with language difficulties are at risk of developing academic and social difficulties over time. This is because language plays such an important role in the processing of academic information, in understanding and following group activities and goals, and in conforming to 'implicit' social conventions (like taking turns, talking about the same topic, talking about common goals and interests, etc.).



There are a few strategies that can be helpful in supporting children living with FASD and language difficulties. These include taking steps to:

- simplify the language that a child needs to understand
- slow down the rate of communication
- explicitly teach social communication skills (e.g. taking turns in conversation).

### ***Sensory regulation difficulties:***

Children living with FASD are likely to have difficulty with sensory regulation. This type of neurodiversity is not as widely recognised in the research literature, although caregivers say it is common.

Reports state that the sensory environment can be a major trigger for behavioural outbursts. When a child has sensory regulation difficulties, they often also have difficulty in maintaining the attention, concentration and arousal level necessary to effectively take part in learning. In susceptible children, the sensory environment can alter their level of arousal, making them excessively sleepy or hyperactive. Sensory processing occurs below the level of consciousness, like our digestion or heartbeat. It is not something that we are able to control. When sensory processing occurs efficiently, sensory inputs from multiple and competing sources are processed simultaneously, automatically, and without any conscious effort.

Children with sensory processing issues react differently to sensory stimulation in the environment. They could experience oversensitivity to light, touch or sound; or they could have difficulty in registering and responding to sensory experiences. This inefficiency is often associated with fluctuating levels of alertness and arousal, which affects a child's capacity to engage in new learning.

It can be helpful for caregivers to understand that each child living with FASD will have a unique sensory profile. Managing a child's sensory environment, and avoiding sensory triggers are important aspects of supporting a child with these concerns. Occupational therapists are skilled in developing management strategies to support these kinds of difficulty.



## What do these difficulties mean for children living with FASD?

The cognitive difficulties experienced by a child living with FASD will differ in nature and degree. These difficulties can make it harder for a child to successfully negotiate their learning and social environments, negatively impacting their development.

The impact of cognitive and sensory difficulties on each of these areas is outlined below:

### *Impact on new learning:*

Cognitive, sensory and language differences can significantly impact on children's capacity to engage with learning. In the learning environment, a child living with FASD can struggle with:

- managing frustrations in response to failure
- self-regulating to maintain optimal level of arousal and attention
- screening out visual, tactile and auditory distractions
- listening to and retaining classroom instructions
- keeping tasks in mind
- working out and completing steps of a task in sequence
- retaining what has been learned that day
- remembering information from one day to the next
- managing and directing attention as required
- transitioning seamlessly from task to task
- managing and regulating themselves in response to changes in expected routines or activities
- working together with their peers as part of a group activity
- learning from typical teaching techniques without additional support (e.g. short instructions, repeated instructions, visual supports)
- taking part in unstructured or 'free play' learning opportunities.

Cognitive difficulties can also affect social interactions and friendships. In social environments, a child living with FASD can struggle with:

- regulating strong emotions and being appropriately assertive
- remembering important social interactions and social information
- forward thinking to anticipate difficulties and problem solve solutions
- controlling behaviour and impulses in order to comply with social norms
- reflecting on social information by recalling past experiences
- reflecting on how a current experience relates to their past learning
- drawing on past social experiences to learn from mistakes and inform future decisions
- taking in and processing social information quickly
- responding quickly and acting on social information
- adjusting social behaviour in response to feedback from the social environment (e.g. peers)
- expressing themselves, their feelings and needs and understanding what others are communicating
- understanding and using social language conventions
- understanding humour, metaphors and sarcasm in social interactions.

By being aware of these differences, practitioners can make it easier for children living with FASD to experience positive and inclusive interactions within their broader social networks.

## How can I support the development of children living with FASD?

Children living with FASD are believed to do best in highly structured, simplified and predictable environments, in which expectations are clear. Most children will also require concrete, explicit teaching of social skills, communication skills and academic skills.

There are two broad approaches to supporting children living with FASD: universal and targeted accommodations.



**Universal accommodations:**

Universal accommodations are strategies that can be applied across all settings. They help children to succeed by creating an environment in which the child's cognitive load, or sensory or language input is reduced.

Universal accommodations also create a supportive scaffold for a child's development, by modifying the immediate environment to make it less overwhelming, and simplifying verbal interactions and instructions to make them more understandable. These universal approaches can act as a bridge, connecting the child with an otherwise fast-paced and potentially confusing world.

Universal approaches to helping children living with FASD include:

- modifying the environment to minimise sensory stimulation, removing known sensory triggers, and using visual reminders and visual aids to convey expectations
- modifying verbal interactions by shortening instructions, simplifying language, using lots of repetition, and supplementing instructions with visual cues and prompts; and
- supporting transitions of any kind. The redirection, focusing, and transitioning of attention can be supported by using stepped instructions; providing visual and verbal warnings about impending changes; providing clear task expectations, and modelling self-monitoring skills.



Examples of what universal accommodation strategies might look like in a classroom, home or social environment include:

Universal and inclusive accommodations to create FASD sensitive environments		
Aim and rationale	Ask caregiver/teacher to...	
<p><b>To provide a simple, structured, predictable and consistent environment.</b></p> <p>Children with neurocognitive challenges are more comfortable in highly-structured and predictable environments in which expectations are clear.</p>	<ul style="list-style-type: none"> <li>• provide predictable routines and structure</li> <li>• explain each step of the daily routine, using visual cues as prompts. This may need to be repeated daily</li> <li>• avoid changes in routine/explain clearly any change in routine</li> <li>• give clear and simple explanation of expectations; use visual reminders to support this understanding</li> <li>• use consistent caregivers where possible, provide photos and explanations of any change in carers or teachers</li> <li>• minimise the number of different settings a child must manage</li> <li>• avoid unstructured settings or large social groups, keep peer groups as consistent as possible</li> <li>• provide two choices of activities to help children to cope with unstructured situations (rather than asking them to generate ideas).</li> </ul>	
<p><b>To reduce the amount of sensory stimulation, and the impact of potential sensory triggers.</b></p> <p>Children living with FASD can have extreme difficulty with self-regulation in response to the sensory environment. Therefore, it is important to be aware of common sensory triggers.</p>	<ul style="list-style-type: none"> <li>• remove or reduce fluorescent lighting</li> <li>• provide a separate carousel for schoolwork/ study to reduce unnecessary visual distractions</li> <li>• help highlight key information and avoid 'figure-ground' confusion (not having important information on pages with 'busy' backgrounds or neon colours)</li> <li>• allow access to sensory regulation tools and strategies.</li> </ul>	
<p><b>To provide clear verbal instructions to support understanding and memory.</b></p> <p>Children living with FASD can have difficulty in attending to, processing, and memorising incoming verbal information. Speech and language processing can be slowed, and children can have difficulty with abstract and social language.</p>	<ul style="list-style-type: none"> <li>• group instructions into manageable 'bits' of information</li> <li>• think of the 'rule of 5' (no more than five words in a sentence)</li> <li>• use simple language – e.g. "Close books. Put books back on shelf."</li> <li>• give clear instructions, indicating what activity you require, and then what the steps are</li> <li>• teach and practice memory rehearsal strategies (e.g. teach child to repeat instructions to themselves)</li> <li>• repeat instructions and supplement verbal instructions with visual prompts</li> <li>• be prepared to repeat themselves more than once</li> <li>• allow additional time to 'take up' instructions</li> <li>• use consistent key words in communication</li> <li>• teach/discuss one concept at a time</li> <li>• supplement verbal learning with mind maps and other visual aids to assist categorisation of learning material</li> <li>• use concrete language, avoid metaphors or idioms that may not yet be understood</li> <li>• teach the use of a non-verbal signal to let them know the child has forgotten what to do or didn't understand</li> <li>• play both verbal memory and visual memory games</li> <li>• not assume what is learned today will be remembered tomorrow, repetition may be necessary.</li> </ul>	
<p><b>To support the direction, focus, and transitioning of attention by using stepped instructions, warnings of impending change, and clear task expectations.</b></p> <p>Children living with FASD can have difficulty in focusing, sustaining and managing attention to competing tasks.</p>	<ul style="list-style-type: none"> <li>• always use the child's name to gain their attention</li> <li>• use a variety of speech tones and pace to maintain attention</li> <li>• provide instructions and check for understanding prior to giving out equipment/ materials</li> <li>• break activities into smaller steps and give instructions for one step at a time</li> <li>• avoid providing additional instructions during an activity</li> <li>• consider using a regular auditory clue to remind children of where their focus should be and what they have been asked to do (e.g. chime or cue word).</li> <li>• monitor progress to ensure an activity is completed before beginning another one</li> <li>• provide warnings and prompts ahead of any change in activity or focus, supplemented with auditory and visual cues</li> <li>• provide reinforcement based on increasing time on task, not whether or not task is completed</li> <li>• preface stories with metacognitive questions that tell a child what the key points are – e.g. "During the story, see if you can see what Jonny does to help his sick dog."</li> <li>• use visual/kinaesthetic supports (e.g. abacus, dominos) to help embed numeracy concepts.</li> </ul>	

## Targeted strategies:

Children living with FASD can also benefit from adopting a targeted approach to new learning. Specific, tailored approaches to instruction and learning can be helpful for children experiencing memory and attention problems. Although the evidence base for these approaches is still being developed, caregivers report that specific and tailored teaching methods can work well for children living with FASD.

Tailored learning approaches involve:

- starting with the simplest form of the target skill and building from there
- breaking complex skills into component skills and skill sequences, and teaching each in order
- repetition and overlearning of each skill in order to embed skills.

When deciding where to begin in teaching new skills, it is important to keep in mind a child's developmental age, rather than their chronological age, as the two can be quite different. Specific and targeted teaching methods can build a child's sense of competence by explicitly teaching skills which might be delayed, and which may not be picked up otherwise.

Examples of how targeted strategies might be used are outlined in the table below:

Tailored teaching strategies for supporting children living with FASD		
Aim and rationale	Support caregiver/teacher to...	
<p><b>To build executive functioning skills (behavioural regulation and metacognition [memory and attention]).</b></p> <p>Children living with FASD can have difficulty with tasks that involve executive functioning. Structuring and sequencing tasks can reduce the cognitive load for a child and make it easier for them to succeed.</p>	<p>support new learning by adopting a structured approach as follows:</p> <ul style="list-style-type: none"> <li>• explain clearly what the child needs to do (e.g. 'Pack your bag for school').</li> <li>• teach/remind the child of each step in this process using simple language, addressing one step at a time. Supplement with visual cues until the steps have been learned. For example, 'Put your homework in your bag'; then 'Pack your lunch in your bag'; then 'Put in your water bottle'. Supplementing instructions with visual reminders of the sequence will help the child to build independent skills over time.</li> </ul>	<ul style="list-style-type: none"> <li>• teach self-monitoring skills (e.g. visual scheduling of tasks and timetables).</li> <li>• teach self-talk (e.g. 'What am I supposed to do next?' 'What is the next step?')</li> <li>• teach and practice basic memory techniques, such as rehearsal and 'chunking' long pieces of information into smaller bits.</li> </ul> <p><i>Repetition is important. Computerised programs that are designed to train memory, attention and academic skills use high levels of repetition that may be needed to improve the learning of children living with FASD.</i></p>
<p><b>To build and extend language skills.</b></p> <p>Children living with FASD may have delayed language and vocabulary, slowed language processing and poor understanding of the social use and social conventions of language.</p> <p>While other children pick up language conventions implicitly, children living with FASD will need to be explicitly taught vocabulary and social skills.</p>	<ul style="list-style-type: none"> <li>• teach basic vocabulary first at the child's developmental age</li> <li>• place emphasis on building emotional literacy, beginning with basic emotions and expanding vocabulary over time. Start with basic feeling words (e.g. happy, sad, angry, scared), using visual prompts to support learning. Extend vocabulary over time, from simple to more complex terms (e.g. 'scared' can be extended to 'frightened', 'anxious', 'fearful', 'terrified', etc.)</li> <li>• make sure you teach children the vocabulary and story-telling skills needed to talk about their interests, their family and their likes/dislikes. Children are not likely to be able to do this without explicit support</li> <li>• use mind mapping or similar visual strategy to teach how words are connected in meaning.</li> </ul>	<ul style="list-style-type: none"> <li>• teach children a socially acceptable way to signal that they do not understand</li> <li>• teach children the skills of joining in, greeting friends, being assertive and saying no politely, etc.</li> <li>• teach children the implicit rules of social language (e.g. how to take turns in conversation; how to ask about another's interests; how to change your language to suit the situation [formal vs. informal settings])</li> <li>• use visual aids to support language and vocabulary development whenever possible</li> <li>• be aware of difficulty in understanding or in forming words or speech sounds, which indicates the need for formal speech and language therapy.</li> </ul>
<p><b>To build capacity for sensory regulation.</b></p> <p>Children living with FASD are quite affected by their sensory environment. It is common for these children to experience drowsiness, hyperactivity and/or anxiety in direct response to their sensory world. Identifying and managing sensory sensitivities using sensory regulation strategies can support children to remain in an alert and calm state that helps learning.</p>	<ul style="list-style-type: none"> <li>• use a sensory profile to establish the child's sensory triggers and to identify what the child's sensory likes and dislikes are</li> <li>• identify ways that the sensory environment or sensory strategies can be used to soothe and regulate the child. Identify at least one 'transportable' strategy that a child can use across different settings</li> </ul>	<ul style="list-style-type: none"> <li>• incorporate sensory regulation strategies at regular intervals throughout the day, these might include movement, deep muscle and oral resistance</li> <li>• teach the child the skills to monitor their sensory 'temperature' – self-monitoring strategies to support them to identify if and how the sensory environment is affecting them.</li> </ul>

*\*Strategies adopted from: Adnams et al., 2007; Coles, 2007; Kable, 2007; Kerns, 2010; Loom, 2008; McLean & McDougall, 2014; McLean, 2018a, b; O'Connor et al., 2006, 2012; Padgett, 2006; Petrenko, 2015.*



## Summary

Children who are affected by prenatal alcohol exposure may experience one or more significant neurocognitive difficulties in one or more areas of development. At present, there does not appear to be any way to reverse the impact of prenatal alcohol exposure on the developing fetus (Australian Medical Association, 2016).

Currently, the best way to support children is to create a better 'fit' between a child's ability and their social and learning environment; thereby minimising the risk of educational disengagement, social and peer relationship difficulties, and behavioural and emotional concerns.

There are two main approaches to this:

1. applying universal strategies that modify the child's environment to create a better 'fit' for the child and make the environment and expectations more manageable
2. applying targeted approaches to learning, supporting the child to build the skills necessary to strengthen their executive functioning and counteract the neurological challenges they experience.

Practitioners can play a key role in supporting caregivers and teachers to adopt both universal and targeted approaches. The evidence base for social learning and pharmacological interventions for children living with FASD is still growing (McLean & McDougall, 2014; McLean, McDougall & Russell, 2014; Peadon, Rhys-Jones, Bower, Elliot, 2009; Premji et al., 2007). In the meantime, the approaches outlined in this resource can help to support children and may minimise the impact of FASD on children's development.

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**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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