

GUIDE TO SUPPORTING A CHILD WITH FETAL ALCOHOL SPECTRUM DISORDER

How prenatal alcohol exposure affects your child's
behaviour

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‘The best way to describe it is... He can go wherever he likes, as long as he takes another brain with him...’

(Foster parent of a young man living with Fetal Alcohol Spectrum Disorder)

Disclaimer

This resource is part of a series of resources for foster parents who are raising children living with developmental difference caused by early life adversity. The guides are intended to provide general educational information only, and are not intended as a substitute for professional assessment and intervention.

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Fetal Alcohol Spectrum Disorder- what is it?

We now know that when a woman drinks alcohol during pregnancy she risks affecting her unborn child in a range of ways. The range of lifelong disorders that can be caused by drinking during pregnancy is captured by the label Fetal Alcohol Spectrum Disorder (FASD).

FASD is often described as a 'hidden' disability, because children who are affected by this disorder may not look any different from other children; but can nonetheless be struggling with significant 'hidden' learning issues. We used to think that children who were affected by alcohol use before birth showed certain facial features and other physical abnormalities that were easy to detect. We now know that even profoundly affected children do not always show these facial changes and may not really look any different from other children. This is an important point, as many professionals still hold the belief that children must have clear facial features to be affected.

This resource sheet is for foster parents to help identify and support children that might be affected by alcohol exposure before birth. We used to think that brain damage caused by prenatal alcohol exposure before birth was relatively uncommon (up to 2 per 1,000 amongst most western populations). We now know that it is more common than that. A recent American study found that between 4 and 7 in every 100 children may have some form of brain damage caused by their mother's alcohol consumption before birth.

Unfortunately, the picture seems to be even worse for children who are placed in foster care. It is actually quite common for children affected by FASD to be raised by someone other than their biological parents (We know that around 60 % of children who receive treatment for FASD are being raised outside their family home). We also think that FASD is pretty common in foster care. On



average, almost 17% of children across all types of out of home care are believed to have some form of FASD (including both foster and residential care). That means that almost 17 out of every 100 children in out of home care could be affected by a brain disorder that carries with it life-long difficulties with thinking and behaviour. This is why it is important for foster parents to understand what it might be like for the child who is living with FASD.

So how much of a problem is FASD? We know that FASD is a life-long disorder, but the impact of the problem on children's lives depends on how well supported they are. Knowing exactly how your child may be affected by prenatal alcohol exposure is difficult, because it depends on a range of factors that we don't yet fully understand.

The extent of a child's brain damage seems pre-determined by the amount and timing of alcohol consumption during pregnancy. At this point we think that there isn't a lot that can be done to reverse this damage, but our knowledge in this area is growing. The results of this kind of brain damage vary from child to child, but there are some common patterns of difficulties that children experience, which will be described in this resource. The good news is that the effect of this disability on children's lives can be minimised by having a consistent, nurturing caregiver who can support the child to make friends and experience some success at school and later on in the work environment.

One of the main frustrations for foster parents who raise children living with FASD is the fact that they may never get a proper diagnosis. Many countries lack the specialist diagnostic clinics and teams that are needed to make a clear diagnosis and offer integrated support. This means that many children, particularly those in foster care, never get the correct diagnosis. Foster parents tell us that their children can receive a range of different diagnoses and treatments before the professionals involved finally determine the correct diagnosis. Without the correct diagnosis, it is not unusual for otherwise capable foster parents to doubt their competence (and their sanity). Receiving a diagnosis of FASD can be a huge relief, as it offers an explanation for otherwise 'inexplicable' behaviour. Without access to diagnostic facilities, the best that foster parents can do is to try to obtain accurate information from their child's caseworker about the biological mother's alcohol use during pregnancy.





How can I recognise if my child is living with FASD?

Many foster parents report that they care for children who have a unique set of challenges. Children living with FASD may present very real challenges to foster parents due to their challenging behaviour and difficulty in learning from their actions. Teachers and even other foster parents may not understand why these children can be so difficult to support. Foster parents tell us that when they are fortunate enough to have been given information about the child's history, they are finally able to make sense of their child's behaviour. Unfortunately, many foster parents never receive information about the history of their child either because it is not available or because it is considered confidential. This resource is aimed at foster parents who may not have access to their child's health information. It outlines some of the symptoms of FASD and suggestions for managing the behaviour association with this condition. Here are some of the indicators that the child you are caring for may be living with FASD. How many of the following apply to your child? My child...

- ✓ Has had a number of foster placements.
- ✓ Has biological parents that have alcohol and substance use issues.
- ✓ Has difficulty with friendships (lots of superficial friends or is easily led by others).
- ✓ Has been given lots of different labels or diagnoses over time, but none quite 'fit'.
- ✓ Has had lots of unsuccessful attempts at medication, intervention or counselling.
- ✓ Has behaviour that is impulsive; seems to repeat the same mistakes.
- ✓ Has trouble coping in unstructured situations.
- ✓ Has had a diagnosis of intellectual delay.



The way that children living with FASD interact with the people in their world is affected by the way that their thinking and processing of information has been changed by exposure to alcohol before birth. We have discussed elsewhere the importance of cognitive flexibility for learning new ways of behaving and for adapting to the many changes in life (see resource on executive functioning). For children living with FASD, difficulties in cognitive flexibility can be much more extreme. There are also often other significant 'brain- based' problems like memory and language problems that affect their behaviour. For this reason, parents and carers of children living with FASD talk about needing to become the 'external brain' for the child- to take on the role of ordering, structuring, organising and interpreting the world for children so that they can manage.



What kind of difficulties do children with FASD experience?

Children living with FASD can experience a range of difficulties in thinking, learning and remembering. They may have lower overall IQ but this is not always the case. Almost invariably their difficulties in these areas will mean that they will need a very different parenting approach to other children. While many of the symptoms experienced by children with FASD overlap with other traumatised children, the difficulties faced by this group of children can be more extreme and more difficult to manage.

While it is important to emphasise that each child will vary in the extent to which they are affected, there are nonetheless some difficulties that seem very common amongst children affected by FASD.

For example, the majority of children will show impaired executive functioning. This will mean they show poor planning and organisation, inflexible thinking and difficulty with inhibiting



behaviour. They can have impaired learning with significant impairment in their memory. This will mean they will have problems remembering recently learned information, may make the same mistakes repeatedly, and have, difficulty in remembering long verbal instructions. These children can also have marked spatial problems; for example in telling left from right, or aligning numbers in columns.

Children living with FASD also have difficulty with self-regulation. They can experience fluctuating mood and behaviour; showing frequent intense behavioural outbursts and poor impulse control (e.g., difficulty with waiting in line, or complying with rules).

Finally, children living with FASD can experience lots of difficulty in other important areas of daily functioning, such as social communication, and daily living skills. For example, they can have trouble understanding a normal rate of speech. They may have difficulty in social interactions and social boundaries (e.g., being overly friendly or intrusive to strangers). They may also experience delays in other daily living skills such as feeding, toileting or managing daily schedules.

Common features of FASD

Common difficulties experienced by children living with FASD include:

Serious MEMORY problems, affecting all daily tasks: For example:

- Your child will have trouble learning and remembering new information.
- Your child will seem to forget things that have been learnt previously (due to trouble retrieving memories that have been formed).
- Your child will frequently forget what you have just told them.
- Your child will remember how to do something in one setting but be unable to recall how to do the same task in another setting.
- Your child may appear to tell lies- this is likely to be caused by a memory gap that leads the child to make up facts to plug this gap (confabulation). This is not intentional lying on the part of the child.

‘With him there was just never any, there was no natural internal clock, and there was no forcing an internal clock. It’s still the same today. He will stay up... and I’ve just learned to not even let it bother me’





Significant problems in TALKING AND/OR UNDERSTANDING (language). For example:

- Your child can seem talkative, but seems to ‘miss’ important parts of a conversation (due to speed of conversation or due to non- concrete language).
- Your child cannot understand non-concrete language – e.g., phrases with double meanings (e.g., I’m tied up at the office); or metaphors or sarcasm.
- Your child can have difficulty in taking turns in conversations.
- Your child may be unable to carry out your instructions, despite being able to repeat them due to difficulty in quickly processing and remembering language.
- Your child may not understand instructions unless these are given slowly, with lots of repetition; may miss key pieces of information.
- Your child thinks at a slower pace (can only understand instructions given slowly, may need lots of repetition, may miss key pieces of information).

Significant problems with FLEXIBLE THINKING and planning ahead. For example:

- Your child has trouble in taking what is learned from one situation and applying it to another situation.
- Your child is always repeating the same mistakes.



- Your child seems unable to link actions to consequences.
- Your child has trouble with generalising a rule from one setting to another. (For example, she will comply with a rule at home but doesn't seem to understand that the rule also applies to a friend's home).
- Your child has trouble paying attention
- Your child has lots of difficulty in moving from one task or activity to another.
- Your child often acts before thinking (difficulty in foreseeing danger, easily led, impulsive).
- Your child processes information more slowly, needs more uptake time than other children.

'He really really likes to have ice... chewing ice... like a popsicle... if we can just have him sit down and have a popsicle, it really helps to just kind of bring him down... and just things like that will settle him down enough that either he's talked through the situation or he'll forget it'.

(Foster parent of child living with FASD)

Significant difficulty in THINKING IN ABSTRACT terms. For example:

- Your child finds it hard to plan ahead or set goals.
- Your child has difficulty in reflecting on actions.
- Your child has trouble is seeing similarities and differences between situations.
- Your child has trouble thinking about and talking about abstract ideas (time, money, setting goals for the future).

Significant changes in bodily rhythms and sensations, For example:

- Your child has profoundly unusual sleep wake cycle. For example, he sleeps in short bursts, and is often awake throughout the night.
- Your child has profound sensory sensitivity- she will react in extreme ways to relatively minor sensory stimulation (for example, touch, water drops, noise from vacuum cleaner).
- Your child has difficulty in recognising bodily signals for hunger or thirst; needs reminders to eat or drink.



‘It’s hard to remember when you’re in the midst of all this going on that the reason that they’re acting this way is because of the damage that’s been done... it’s not because they’re maliciously wanting to knock your brains out’

(Foster parent of child living with FASD)

What can foster parents do to support children’s development?

As you can see, the range of possible impacts is wide; and research into how to support children affected by FASD is growing. At the moment, we think that the best way to support these children is to structure the environment to allow them to experience success and to stick to a set of guiding principles in all your interactions with your child. These principles include simplifying things for the child, making the environment as structured as possible and providing a high level of monitoring and supervision.

Caregivers experienced with FASD call this “**The three S’s**”:

- **Structure:** Make the environment as structured and predictable as possible. Adapt the environment to suit children’s impaired ability to deal with change.
- **Simplify:** Simplify what you are asking of the child. Adapt the task or break it into smaller, simpler tasks to suit children’s impaired ability to deal with complexity.
- **Supervise:** Make sure you provide adequate supervision. Affected children need more monitoring to ensure their safety and that of others. Affected children should not have the same independence as same age children- take into account their inability to control impulsive behaviour and poor ability to predict consequences.

In essence, your job is to make sure your child’s environment is made as simple, predictable and structured as possible; and to make sure you provide supervision at all times. Changing some aspects of the physical environment can make it easier for children to manage (for example putting up barriers or visual reminders). Simplifying and adjusting our expectations of children can also make it more likely that they can experience success (think in terms of your child’s developmental age, rather than their actual age). Supervision and monitoring of children can help to keep them on task and



minimise potential danger that might otherwise come from their poor ability to predict consequences.

Experienced foster parents report that traditional discipline techniques don't work because the children cannot easily link their behaviour with a consequence. Unlike traumatised or neglected children, this difficulty in linking actions with consequences doesn't improve over time. Adapting your environment, your expectations and your approach to parenting will help optimise your child's development over time. In many ways, it can be helpful to think that you are a kind of portable 'external brain' for the child, and your job is to provide the necessary 'scaffolding' to enable the child to interact successfully with the world.

Tips for providing STRUCTURE:

Many foster parents of children living with FASD think of structure as the 'glue' that helps the world to make sense to the child living with FASD. As foster parents, the aim is for you to change their physical or social environment to make it as structured, predictable, and free from distractions as possible. This continues to be important, even with older children, as affected children do not develop the self-monitoring and self-control abilities that other children do over time. It can be useful to think in terms of the 'developmental danger level' – In other words; what is the developmental age that your child is functioning at, and what does this mean for how aware they might be about potential dangers in the environment and the consequences that might follow from their actions. Would you expect a child that is functioning at a developmental level of four years of age to be able to cross the road safely? Would you expect them to be able to predict danger without adult support? Provide children with as much structure as is appropriate for their developmental level and understanding of danger.

Some examples of how to provide developmentally appropriate structure include:

- ✓ Place a barrier between the child and danger (install gates in doorways and on stairs).
- ✓ Create a barrier between the child and distraction (e.g., headphones or a study corral to surround the child and eliminate distraction in a classroom environment).
- ✓ Ensure the sensory environment is as consistent as possible (and minimise or avoid sensory triggers).
- ✓ Provide structure to social interactions & reduce social complexity (try to limit the number of children your child needs to interact with; play games with clear rules and structure).
- ✓ Have consistent expectations from one setting to another (children can't adapt easily to meet changing expectations from situation to situation). State the rules of each setting clearly.



- ✓ Make the environment as consistent as possible; avoid sudden change.
- ✓ Ensure all key adults use the same key words to talk to your child.
- ✓ Practice teaching skills and concepts in more than one setting. Due to difficulties in transferring learning from one setting to another, children may not see similarities between school and home settings; therefore rules and expectations need to be re-taught for each setting.
- ✓ Provide a daily routine that is clear and predictable.
- ✓ Allow adequate time to complete daily routines.
- ✓ Use visual prompts, visual schedules, provide task lists or steps, using alarms and timers as prompts to remind about important health and safety information (e.g., when to eat, reminder to drink, check that doors are locked).

Tips for SIMPLIFYING:

In addition to providing as much structure as possible, it is important to reduce the complexity of the environment for children. You can simplify your child's world in several ways by simplifying how you talk to your child, by lowering your expectations to the child's developmental level, and by using visual prompts to provide your child with additional support. Simplifying their environment will also help manage sensory arousal levels so that they don't become too overwhelmed to learn. Making things as simple as possible reduces the mental work children have to do and maximises their opportunity to succeed.

Some examples of how to simplify include:

- ✓ Minimising background noise and bright colours as these can trigger children's behavioural outbursts.
- ✓ Ensuring you de-clutter regularly; it is difficult for your child to process too much sensory information at a time
- ✓ Ensure you talk to the child in plain, concrete language.
- ✓ Talk at a slowed pace, using shorter sentences.
- ✓ Break complex jobs into small steps – and teach each one.
- ✓ Use concrete language – don't use double meanings (e.g., 'catch the bus').
- ✓ Use language that is lower than the child's actual age.
- ✓ Give two choices in decision making (avoid abstract goal setting).



- ✓ Set out the steps to tasks, using visual aids and prompts as appropriate.
- ✓ Avoid giving vague instructions; ensure you give clear, short, simple instructions.

Tips for providing SUPERVISION:

There are many ways that you can manage your child's environment to maximise their success. Be on the look-out for potential triggers in your child's environment. Triggers are any factors that make it more likely that your child will misbehave or have an explosive outburst. Aspects of the sensory environment commonly trigger a child's behaviour- there may be too much noise, the light may be too bright- sensory stimulation that most children can manage can cause a child with FASD to meltdown. Transitioning from one activity to another is also extremely likely to be difficult for the child affected by FASD - they will need explicit warnings and supervision and support in order to successfully negotiate changes in activities or in moving from place to place. Try to pre-empt potential difficulties ahead of time and provide additional supervision during this time. The most important thing to remember is that many of the behaviours your child displays aren't normal behaviour problems- they are signs of neurological difficulties that reflect permanent damage to the brain and are NOT within the child's control at all. When we realise that children cannot control themselves in many situations, we realise that the onus is on us as adults to provide the necessary monitoring and supervision.

Some examples about supervision include:

- ✓ Work out a way to provide warning to your child of impending change and transition.
Transitions should be cued both visually and verbally (e.g., egg timer, paper chain, 5 minute warning tone).
- ✓ Teach using repetition (and more repetition!) to embed learning. Use repetition or 'overlearning' to overcome memory difficulties. Expect to repeat yourself-often!
- ✓ Provide learning through more than one sensory modality.
- ✓ Break complex tasks down into single steps. Then teach and monitor each step. Keep rehearsing with your child- what step do we do next?
- ✓ Simplify language, use repetition and rely on visual prompts to supplement your instructions.
- ✓ Issue one direction at a time; tell the child what you want them to do in concrete terms. Do not use non-literal language, such as sarcasm, irony and metaphor.
- ✓ Expect to repeat instructions. Do not assume a skill that is demonstrated is retained. Learning may not be retained from one day to the next.



- ✓ Expect to explicitly teach life skills, problem solving and friendship skills – these will not be picked up automatically.
- ✓ Use visual cues (picture social stories) to teach household routines and social conventions (e.g., saying hello to friends at the start of the school day).
- ✓ Monitor your child’s activities and provide prompts to stay on track.
- ✓ Do not expect your child to be able to discriminate safe and unsafe behaviour.

A final word... It’s not that she won’t, it’s that she *can’t*

It is important to remember that one of the hallmark characteristics of FASD is that the child’s learning in one setting will not necessarily be retained, or applied, to another setting (on in some cases, will not be retained the next day!). It is critical to your child that whenever possible, you communicate well with other relevant adults in your child’s life, such as teachers, to help ensure consistency in approach across all key settings. Share your understanding with other significant adults in the child’s life, using consistent language and expectations.

One of the most important aspects of supporting a child living with FASD is reminding yourself to **reframe** the behaviours you are seeing. What might be defiance or non-compliance in another children can simply be a **lack of ability** in children with this kind of brain damage.

Ask the question ‘**Is it that the child won’tor is it that the child can’t?**’ (Malbin, 2002).

Experienced parents report that this is the most crucial question to keep in mind when responding to your child’s behaviour. The following table shows the difference that this reframing can make...

What are the behaviours you might see...? What might you think?	What might actually be going wrong for the child?
‘He won’t listen, he can’t be taught’	The speed that his brain processes your words is slowed because of damage to the brain. He has trouble remembering instructions for long enough to carry them out due to damaged short term memory.
‘He must be doing this on	He does not understand what you are asking him to do or stop doing. He



purpose’	has trouble linking cause and effect, meaning that he keeps on repeating the same mistake again and again.
‘She’s so inflexible, she has to have her way’	Trouble with flexible thinking caused by brain damage means that she can have trouble and be slow to switch from one activity to another. This makes it seem like she is being disobedient when interrupted mid task. She has trouble in stopping an old activity when asked to do something new without warning.
‘I know he can do it, she behaves at school- why not at home?’	He has trouble in planning ahead so he can’t organise himself unless he clearly knows what is expected of him. Trouble with flexible thinking means that he finds it difficult to think apply the rules from one situation to another setting.
‘She doesn’t take any responsibility for her behaviour...’	She has trouble in linking her actions to the consequences (linking cause and effect). Memory problems mean that she may not recall what she actually did that was wrong and why.
‘She can’t handle change’	Problems in flexible thinking mean that the child has trouble in working out the rules in new situations unless someone can explain them. Problems in flexible thinking mean that she is likely to keep doing the same thing in the same way, even when the expectations or rules have changed.
‘She can never be bothered ...’	Problems in executive functioning mean she has trouble in planning out and starting actions. Sensitivity to stimulation in the environment can be making her drowsy.
‘He’s hyperactive, can’t sit still ‘	Sensory overload, overstimulation and dysregulation of sensory system.
‘She has no sense of humour, takes everything literally’	She has problems understanding double meanings in language, for example in jokes. Everything is understood in terms of its concrete meaning. She cannot think in the abstract.



Want to know more and connect with other foster parents?

There are a wealth of tips and suggestions available, based on the principles outlined in this resource. This disorder has traditionally been under-recognised by professionals, but foster parents have long recognised the need to share tips and strategies. For further detailed information about strategies that might be useful for your child you are encouraged to review the downloadable resources developed by parents of children with this disorder. For example, see:

RFFADA Essential Tips for managing FASD <http://www.rffada.org/resources/17-strategies-and-interventions>

There are also some associations and bodies that can provide information and advice regarding diagnosis and support:

National Organisation for Fetal Alcohol Spectrum Disorders Australia (NOFASD Australia) is an independent not-for-profit charitable organisation and the national peak organisation representing the interests of individuals and families living with Fetal Alcohol Spectrum Disorders (FASD). NOFASD aims to prevent alcohol exposed pregnancies in Australia and to improve the quality of life for those living with FASD. The website provides a range of resources and links to national and international resources and support groups. www.nofasd.org.au

The Russell Family Fetal Alcohol disorders Association is a national not-for-profit health promotion charity dedicated to ensuring that individuals affected prenatally by alcohol have access to diagnostic services, support and multidisciplinary management planning in Australia and that carers and parents are supported with a “no blame no shame” approach. The website provides links to a range of research, projects, information and support resources related to FASD. <http://www.rffada.org/?view=featured>

McLean, S., & McDougall, S (2014). Fetal alcohol spectrum disorders: Current issues in awareness, prevention and intervention CFCA Paper No. 29 Published by the Australian Institute of Family Studies, December 2014. <https://www3.aifs.gov.au/cfca/publications/fetal-alcohol-spectrum-disorders-current-issues-awareness>

McLean, S., McDougall, S., and Russell, V. (2014). Supporting children living with fetal alcohol spectrum disorders: Practice principles. Practitioner Resource. Published by the Australian Institute of



Family Studies, December 2014. <https://www3.aifs.gov.au/cfca/publications/supporting-children-living-fetal-alcohol-spectrum-disor>

Note: FASD cannot be established in the absence of confirmed history of prenatal alcohol exposure and specialised diagnostic procedures. Challenging behaviour and learning difficulties may be caused by many factors, especially in complex and vulnerable populations. This paper is intended to outline some principles of engaging with young people who are suspected to have FASD, but includes principles that may also be helpful to other populations where neurocognitive compromise may be present

To find out more about Developmental Difference and your child,
visit;

www.fosteringdifference.com.au

