



Fetal Alcohol Spectrum Disorder: an Australian toolkit for parents, caregivers and families



Fetal Alcohol Spectrum Disorder: an Australian toolkit for parents, caregivers and families, November 2020, NOFASD Australia. Available online at: nofasd.org.au

This resource was first published as the *NOFASD Australia Toolkit for parents, carers and families*. Second edition revised and expanded by Prue Walker, FASD consultant, and funded by the National Disability Insurance Scheme (NDIS).

NOFASD Australia would like to acknowledge and thank Sue Miers, the Founder of NOFASD, who first dreamed of a FASD Toolkit for families. As a practical person she turned her dream into a reality and wrote the first version of this Toolkit. We have been revising, adapting and increasing this work, always with the aim of supporting Australian families living with possible, or diagnosed, FASD.

NOFASD is grateful to Healthy Child Manitoba for permission to include content from *Every Day is an Adventure: What Parents and Caregivers Need to Know About Fetal Alcohol Spectrum Disorder (FASD)* (March 2017.) https://www.gov.mb.ca/fs/fasd/pubs/fasd_caregivers.pdf

Special thanks to the parents and carers who shared their experiences to help others. Thanks to Jessica Birch for her comments and design.



www.nofasd.org.au
1800 860 613



This project is funded by the National Disability Insurance Scheme (NDIS) in collaboration with NOFASD Australia.

I think my child may have FASD....

You may be reading this toolkit because you are worried about your child; or a child you know, may have Fetal Alcohol Spectrum Disorder (FASD). There is no blame or shame associated with a diagnosis of FASD. Families need support and guidance to support their children and look after themselves, too.

This guide includes:

- Information for birth parents
- Information for carers and families
- A FASD checklist
- How to get a diagnosis

My child has been diagnosed with FASD, now what?

You may have received this toolkit after your child has received a FASD diagnosis. It's common to feel overwhelmed, worried, anxious and sad after finding out your child has FASD, even if you were expecting it.

This guide will help you make sense of:

- What does the diagnosis of FASD mean for my child?
- What do I tell people?
- What does my child need to succeed, to fulfil their potential, and how can I support them?
- Where can I go now for help, funding and support?

I think I may have FASD...

You are not alone! Many young people and adults with FASD in Australia have never been diagnosed. You might feel overwhelmed reading about the types of problems and difficulties children and young people with FASD may experience. But NOFASD also focus on strengths and abilities – and learning more about your own brain may be the first step in understanding and accepting yourself, and working out what kind of supports you need for your future.

If you are feeling overwhelmed, you may prefer to contact NOFASD for support before reading further. We provide confidential telephone and email support to individuals living with FASD and their parents, carers, family members and service providers.

Call our National Helpline on 1800 860 613

Contents

Language Matters: No Blame, No Shame	6	Sensory Processing and Everyday Activities	27
Promoting dignity and respect	6	What is sensory processing?	27
Messages of hope	6	FASD and sensory processing issues	27
Using this guide	7	Practical Strategies for Daily Life	29
What is FASD?	8	Self-regulation	29
How much alcohol causes FASD?	8	Bedtime	29
What about dads?	8	Mornings	29
Why is diagnosis important?	8	Mealtimes	30
Effects of Prenatal Alcohol Exposure (PAE)	9	Clothing	30
The first two weeks	9	Shopping	30
Weeks 3-8	9	Homework	30
Week 9 – 14	9	Bathing and hygiene	31
Second and third trimesters	9	Restaurants	31
10 Domains of Brain Function	10	In the community	31
Understanding FASD	12	Car rides	32
A Neuro-behavioural approach	12	General calming	32
FASD Across the Lifespan	13	Praise	32
Infants	13	Transitions	32
Preschool aged children	13	Learning	33
Primary school aged children	13	Impulsivity	34
Young people	13	Managing physical activity	34
Adults	13	Teaching and rehearsing with your child	34
FASD across the lifespan	14	Your child's environment	35
FASD across the lifespan	15	FASD and sleep	36
FASD across the lifespan	16	Sleep strategies	36
Unique Challenges – What's Different About FASD?	17	Language and communication	37
Parenting: What Doesn't Work and Why	18	Ownership	37
Maturity and Development	19	Storytelling/filling in the blanks	38
FASD Success Stories	21	Getting along with others	38
Strategies for Parents of Children and Young People with FASD	22	Communication	39
Eight Magic Keys	22	Within the Community	40
Building on strengths	22	Sex Education and FASD	40
Strengths vs talents	23	Supporting a Young Person with FASD	42
How do you build on strengths?	23	Understanding and minimising secondary effects	42
Avoiding failures	24	Education and schools	42
Structure, routine and consistency	24	Sexuality and relationships	43
Expectations and rules	25	Supporting the transition to adulthood	43
Visual schedules	25	Finding Support	45
Managing family life	26	Family, friends and the community	45
		Support from other parents and carers of children with FASD	45
		Self-care	46
		Grief and loss	46
		FASD Diagnosis and Assessment	47
		Australian diagnostic criteria	47
		Facial features	47

Growth and sensory issues	47	How do I talk with my child about FASD?	62
Getting a diagnosis	48	Find positive role models	63
After a diagnosis	48	Talking to children about their sibling who has FASD	63
Diagnosis FAQs	49		
Making sense of a diagnosis	49		
Getting Professional Support	50	Adults with FASD	64
A multidisciplinary approach	50	FASD Diagnosis for Adults	64
Paediatric/GP care	50	Supporting adults with FASD	64
Allied Health services	50	FASD and employment	64
Psychological and behavioural supports	51	Parenting with FASD	65
Trauma-informed care	51	If you are an adult with FASD	65
Counselling and therapy	52	Your rights	65
Advocating for your Child or Young Person	53	Parent and Carer Support	66
Working with child protection and foster care services	54	Financial support	66
Advocating for your child at school	54	Support groups	66
Home schooling	55		
Education department disability policies	55	Resources	67
National Disability Insurance Scheme (NDIS)	56	Stories of living with FASD	67
Planning tips	56	Information about alcohol in pregnancy	68
Support for NDIS planning	57	Parenting resources	68
When Things Get Tough...	58	Books	69
Managing extreme behaviour	58	Education resources	69
Crisis intervention	58	Education department contacts	70
After a crisis	59	Young people with FASD	70
Getting in trouble with the law	60	Adults living with FASD	70
Mental health concerns	60	NOFASD Australia	72
		FASD websites – Australia	72
Talking with Children and Young People About FASD	62	A Glossary of Diagnostic Terms	73

Language Matters: No Blame, No Shame

The language we use when talking about FASD is important. You might hear or see FASD described as a 'brain injury' – but how does this feel for a child or a young person with a FASD diagnosis? You might also read about the 'damage' alcohol causes during pregnancy – but children and young people don't need to think of themselves as damaged, and mothers who used alcohol during pregnancy can feel ashamed. By choosing respectful language and promoting people's dignity, we can create more positive ways of talking about FASD - with no blame or shame.

Sometimes young people or adults with FASD find it helpful to talk about having a disability or describing FASD as a brain injury. FASD being recognised as a disability is important, particularly in accessing supports, and when explaining FASD to people who don't understand. If your children or young people don't want to think of FASD as a disability, it may be more helpful to use the words "condition" or focus on their areas of challenge.

Promoting dignity and respect

As a parent or carer of a child or young person with FASD it is also important to remember to always talk about your child living with FASD with dignity and respect. In her blog entitled [What About Dignity and Respect?](#) Ellen Stumbo writes:

Looking back at my own blog entries from years past, I can't help but notice the language I used and the over-sharing of personal details about my children. It turns out that even as a parent, I need to look at my own disability attitudes. If I don't give my children dignity and respect, how can I expect others to do that too? If I want my kids to be treated with dignity and respect, I have to start by being an example. An example in the way I write, in the way I speak, in the way I advocate.

As a parent or carer of a child with FASD, you need to make decisions about what information you share, where and who with, to honour your child's story. If your child is not with their birth parents, as their carer you have an additional responsibility to tell them about their life story and to choose what to share with others, particularly as it relates to your child's birth family. You can always share more information later, but can't take something back once you have shared it, especially on social media. If friends, family or acquaintances ask too many questions, especially in front of your child, you might want to have a comment ready:

"Katie has FASD which means her brain works a bit differently to other people. We are focussing on learning about what she needs so she can do her best".

It is also important that children with FASD are able to talk about their condition and tell others when they choose to. If children hear their family talk about FASD in hushed voices, they may feel that FASD is something to be ashamed of. Being open about their disability can help children and young people explain their needs to others. As parents and carers, it's important to get the balance between openness vs oversharing.

Messages of hope

If you have searched for information about FASD online, it's likely that you have seen some upsetting statistics or read some stories with a negative focus. You might be feeling like FASD is too hard to deal with and wonder what the future holds. Remember:

- Statistics only tell one part of the story – they can't predict what your child can achieve with your help.
- Everyone with FASD is different! Stories you may read about FASD in the news might focus on negative stories and not reflect the full spectrum of the disorder.
- No-one knows what your child or young person can achieve, with the right supports. Identifying FASD can be the first step to a brighter future.



Sunrise Silhouette by Jacob (16) who has FASD. Every day is a new day with hope.

Using this guide

This guide is designed to be read in print format. If you are reading this guide and want more information, you can visit the NOFASD website and follow the links to the resources mentioned.

If you are reading this guide in electronic form, you can click on the links which may be text links, e.g.:

[Information for individuals and Caregivers after a FASD Diagnosis.](#)

What is FASD?

Fetal Alcohol Spectrum Disorder (FASD) is a lifelong disability that affects the brain and body of people who were exposed to alcohol in the womb. Each person with FASD has both strengths and challenges and will need special supports to help them succeed with many different parts of their daily lives.

How much alcohol causes FASD?

Alcohol can cause harm to the unborn child at any time during pregnancy and the level of harm is dependent on the amount, frequency and timing of alcohol use. Other factors also influence the outcome such as individual genetic factors in both the mother and the child, maternal age, the physical and mental health of the mother, other substance use and external factors such as exposure to stress, violence or other negative experiences.

Leading health authorities and researchers across the world advise that there is no safe time and no safe amount of alcohol that can be consumed if you are pregnant, planning a pregnancy, could become pregnant or are breastfeeding.

While we don't know how much alcohol may cause harm in any one pregnancy, we know that in some cases, even low levels of alcohol can cause changes to the developing infant's brain. This means that there is no safe level of alcohol use in pregnancy.

The Australian Guidelines to Reduce Health Risks from Drinking Alcohol state very clearly that maternal alcohol consumption can harm the developing fetus or breastfeeding baby and for women who are pregnant or planning a pregnancy, not drinking is the safest option.

What about dads?

There have been a [number of studies](#) that show that men's use of alcohol, tobacco and other drugs may affect their children's health and development. We are still learning about these possible effects, but [recent research found](#) that a father's drinking before pregnancy affected their baby's heart, and advised men that they should stop drinking 6 months before conceiving a child.

Why is diagnosis important?

The effects of prenatal alcohol exposure are life-long. Individuals with FASD will experience some degree of challenges in their daily living, and need support with motor skills, physical health, learning, memory, attention, communication, emotional regulation, and social skills to reach their full potential.

FASD is often referred to as an 'invisible disability' as it often goes undetected. The Australian health and medical community is gradually becoming more aware of FASD, but there are still professionals who are not aware of how common FASD is in the community, or who have not had training in diagnosis. We hope that the [Australian Guide to the Diagnosis of FASD](#) will change this.

Research has found that early diagnosis of FASD is a *protective factor* – it can prevent other problems developing later in life. A formal, medical diagnosis of FASD will help anyone who is working with your child to better understand that their learning and behavioural issues are a symptom of FASD, and this is important when making plans to support your child with the challenges they face.

When children or adults have no visible signs of alcohol exposure, their problems may be wrongly blamed on poor parenting or on other disorders. If your child has experienced trauma, abuse, neglect, or is not growing up with their parents, their developmental delays or behavioural issues may be attributed to their early life experiences. FASD is a complex disability which is unlike many other developmental conditions, and interventions that work are often specific to this disability. International studies tell us that early diagnosis and interventions for FASD are linked with better long-term outcomes for the child and the family who support them.

It's also important for birth families to have the information that prenatal alcohol exposure may have affected their child. Parents need this information so that future pregnancies can be alcohol-free.

Effects of Prenatal Alcohol Exposure (PAE)

Exposure to alcohol during pregnancy affects a developing fetus in different ways, depending on when the exposure occurs, and how much alcohol is consumed. Alcohol is a teratogen, or toxin, and crosses the placenta, so the baby's blood alcohol level is the same as the mothers. The baby's liver is not developed enough to metabolise the alcohol. PAE can have a greater effect if combined with smoking, poor diet or genetic factors.

The first two weeks

In the first two weeks of pregnancy, PAE may cause problems in the embryo being implanted in the uterus, but it is too early in the pregnancy to affect development.

Weeks 3-8

Week 3 is a critical week in pregnancy as this is when the birth defects begin to affect the embryo. The stem cells responsible for the development of the central nervous system and the face are most vulnerable around week 3 and PAE causes these cells to die prematurely, resulting in abnormal brain development and the facial changes associated with FASD.

The heart is also developing and PAE in weeks 3-4 can cause structural defects. The eye is also developing at this time and PAE can cause microphthalmia (small eyes) and affect the optic nerve. Other organs can be affected by PAE between weeks 3-8.

In weeks 6-7 the corpus callosum, a band of nerve fibres which is responsible for communication between the two hemispheres of the brain is developing. PAE harms the stem cells responsible for the development of this structure causing abnormalities or in some cases, absence ("agenesis") of the corpus callosum.

Week 9 - 14

After the first 8 weeks of pregnancy PAE has less effect on organ development, but continues to affect the development of the central nervous system. PAE interrupts the normal development of neural pathways. Normal growth of cells is reduced due to PAE which can cause fetal growth restriction.

Second and third trimesters

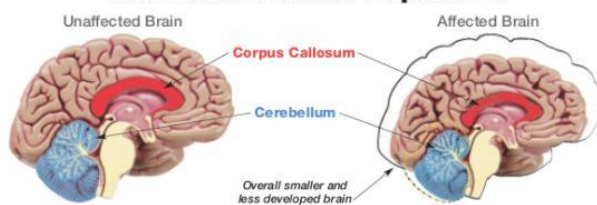
From week 24 the brain undergoes a growth spurt during which time the cerebellum is developing. This structure coordinates sensory information from the brain, sensory systems and spinal cord and regulates motor movements. The cerebellum is responsible for voluntary movements including posture, balance, coordinator and speech. It also plays a role in attention and executive function. PAE reduces the size and interrupts the development of the cerebellum.

The basal ganglia forms part of the central nervous system. PAE can interrupt the development of the basal ganglia and lead to motor coordination and executive function deficits. Children with basal ganglia deficits experience motor control problems, deficits in memory and verbal learning, and hyperactivity and impulsivity. They may have an increase in perseverative behaviour. These impacts translate to a wide range of motor control, cognitive and behavioural issues.

PAE also affects the neurotransmitter systems including dopamine and serotonin which play an important role in brain development and can cause anxiety and mood disorders.

Some of the impact to the brain can be seen on an MRI, but most cannot. We need to look at the person's functioning in different areas to see the impact.

Brain Structures Most Sensitive to Prenatal Alcohol Exposure



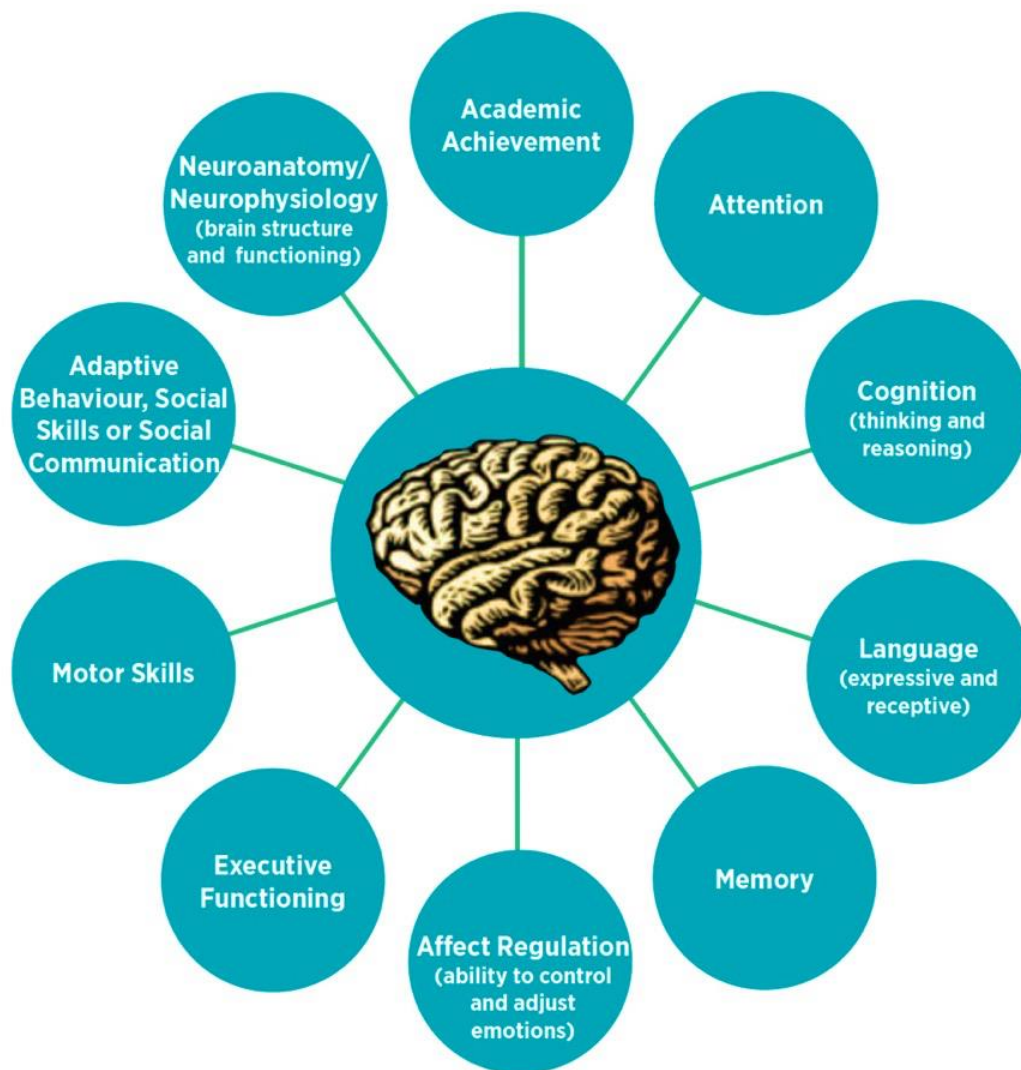
Brain Structure	Function	Prenatal alcohol exposure may result in problems with:
Corpus Callosum	Communicates motor, sensory and cognitive information between the two hemispheres of the brain	Storing and retrieving information, problem solving, attention and verbal memory
Cerebellum	Processes input from other areas of the brain to coordinate motor and cognitive skills	Controlling movements, maintaining balance and fine motor skills

National Organization on Fetal Alcohol Syndrome (NOFAS)
1.800.66NOFAS or visit www.nofas.org



10 Domains of Brain Function

There are ten areas of brain function or “domains” which may be affected by prenatal alcohol exposure. Diagnosing FASD involves assessing a person’s functioning in each area, by testing their abilities and comparing them to the general population. A severe impairment in three areas of brain function can lead to a diagnosis of FASD under Australian Guidelines.



Impairments in these domains of brain function can include:

Planning and Decision Making (Executive Function)

- May have trouble with planning, sequencing, problem solving and organising
- May be impulsive
- Challenges with transitions and change
- Often repeats mistakes and has difficulty understanding consequences
- Difficulty with concepts and abstract ideas

Attention

- Easily distracted and impulsive
- Difficulty paying attention and sitting still
- Has trouble stopping one thing to do another

Cognition (thinking and reasoning)

- Difficulty reasoning, planning, and solving problems
- Difficulty understanding complex ideas.
- A wide range of IQ scores

Communication

- May speak well, but not fully understand the meaning
- Difficulty following conversations
- Delayed language milestones for age
- Difficulty understanding lengthy instructions
- May be able to repeat instructions or rules, but may not follow through

Memory

- Difficulty with long and short-term memory – forgetful
- Often forgets steps in daily activities

- May appear to lie, but is actually 'filling in the blanks'
- Trouble with memorising and may seem forgetful
- Difficulty with accessing, selecting and organising information when needed

Living and Social Skills (Adaptive Behaviour)

- Difficulty with personal boundaries and reading social cues
- May be socially vulnerable and taken advantage of
- Difficulty seeing things from another's perspective
- Socially and emotionally immature and may behave younger than actual age
- May have difficulty with some of the tasks of daily living

Motor Skills

- Difficulty with balance, strength, endurance, coordination, and muscle tone
- Difficulty with handwriting and fine motor skills.

Affect Regulation (ability to control and adjust emotions)

- Anxiety, depression or mood disorders
- Difficulty regulating emotions

Academic Skills

- May have difficulty in school: reading, maths, comprehension (understanding) and abstract concepts
- Achievement at school may not reflect academic ability.

Sensory issues

- Difficulties processing sensory input
- May be over or under sensitive to light, noise, touch, movement, smell or taste.

Understanding FASD

A Neuro-behavioural approach

The individual characteristics of FASD will vary from child to child however, there are some common patterns in the way different symptoms of prenatal alcohol exposure may present over a person's lifetime.

Many of the behavioural difficulties associated with FASD are also affected by the child's environment and our expectations of them. Diane Malbin's "Trying Differently Rather Than Harder"¹ outlines a Neuro-Behavioural approach to FASD that has been adopted by many parents and carers. This approach encourages us to recognise:

- **Primary characteristics** - caused by the direct impact of alcohol on brain development. These changes are permanent – the child will continue to learn and develop new skills, but the effects of alcohol exposure are lifelong.
- **Secondary characteristics** - the problems or behaviours that occur when the primary characteristics are not well understood or supported in the child's environment.

When we think about FASD, we need to think about the child's primary characteristics and what these mean in their day-to-day life, i.e. their "environment". We need to recognise that some of the secondary behaviours we see in children with FASD are a result of a poor "environmental fit".

For example, a child who has a slow auditory pace, and has difficulty hearing and understanding verbal

instructions, is going to struggle in a noisy classroom where a teacher is reading out lengthy instructions.

In this situation, the primary symptom of FASD is the child's difficulty in processing verbal instructions (receptive language) and might also be affected by their attention difficulties or working memory. In response, the child might talk over the teacher, distract others, not pay attention, get up and leave their desk, or maybe become frustrated, leading to an emotional outburst or meltdown. The teacher is likely to notice these secondary behaviours, but may not notice the primary symptom.

Supporting children with FASD requires us to notice when the child's environment is not supporting their primary symptoms and think about whether it is contributing to secondary behaviours. If we shift our focus away from trying to change the child's behaviour and focus instead on adapting the environment - which might include changes to seating, noise cancelling headphones, teacher giving shorter instructions or writing down instructions, or a classroom aide – we can reduce the impact of the primary symptom and then we are likely to see a reduction in secondary behaviours.

Many therapeutic supports for children involve trying to change behaviours – e.g. learn self-regulation, learn turn-taking or sharing, learn to remember instructions. Explicit teaching of these skills can be very important for children with FASD but there also needs to be some acceptance that behaviours are a result of brain differences, and that we need to adapt the child's environment instead of expecting the child to change.

¹ Available on Amazon or other booksellers, or at www.fascets.org.

FASD Across the Lifespan

FASD is more than a checklist of symptoms – we see different presentations of FASD in each individual, according to:

- Which domains are affected, and to what degree;
- The age and developmental stage of the individual;
- The support provided in their environment/s which help reduce secondary effects.

Individuals with FASD can defy expectations and need to be treated as individuals. Factors like early diagnosis and intervention, a supportive family, and environmental accommodations all reduce the secondary effects. At the same time, there are some common patterns in the way FASD presents that can help us understand this complex disorder. The table on the following pages identifies some of the ways FASD can present in children, young people and adults, according to which brain domains are impacted.

Infants

In infants, the brain functions impacted by alcohol exposure are less developed, so we tend to notice more of the physical indicators of FASD. Some babies may not show any immediate signs of prenatal alcohol exposure. Others may have physical indicators from an early age. Infants with prenatal alcohol exposure may present with:

- Prematurity
- Presence of facial features
- Small head circumference
- Being floppy, with poor muscle tone
- Weak sucking reflex, slow feeder
- Over-sensitive startle reflex, difficulty calming down
- Small size, may have Intrauterine Growth Restriction (IUGR)
- Other health issues such as heart defects, which require early medical intervention.
- May have withdrawal symptoms if exposed to other drugs prenatally.
 - Irritability, crying a lot, difficult to settle
 - Taking a long time to feed
 - Over-sensitive to sound or light
 - Difficulty sleeping, or establishing a sleep pattern

Over time, babies may show:

- Developmental delays, e.g. slow to roll, crawl, sit up, poor coordination
- Speech delays, slow to babble
- Difficulties with eye contact or bonding

Preschool aged children

Developmental delays due to FASD, such as speech or motor skills delays are most commonly identified in pre-school aged children. Behavioural problems are also common and it is important to identify whether these are primary characteristics – a result of the child's brain function – or secondary effects which can be reduced by changes in the environment.

Primary school aged children

At primary school, these challenges may continue. However, the expectations of behaviour and social skills increases as the child gets older, and tasks get more complex, while children are also expected to develop more self-reliance and self-control. This can lead to the gap widening between children with FASD and their peers.

Young people

The primary characteristics may become less visible as a child gets older, as the focus shifts from meeting developmental milestones to academic and social skills, developing independence, and expectations shift toward young people taking more responsibility for managing themselves at home and at school.

Adults

Adults with FASD are likely to experience challenges in many areas of life. They may experience substance use, mental health issues or struggles with daily living, but not understand why. Secondary effects are more evident than the primary, underlying symptoms.

FASD across the lifespan

<i>DOMAIN</i>	<i>Preschool aged children</i>	<i>Primary school</i>	<i>Young people</i>	<i>Adults</i>
<i>Sensory</i>	<ul style="list-style-type: none"> • May be over-sensitive to light, noise, stimulation, busy environments. May overreact with anger or running away when they hear loud noises • May be under aware of sensory input – may not be aware of hunger, thirst, temperature or pain • May avoid or seek out sensations - e.g. sand, dirt, playdoh, dislike labels on clothing • Dislike hair brushing, teeth cleaning 	<ul style="list-style-type: none"> • Difficulty with regulation in busy environments, e.g. classroom • May be inappropriately intrusive, not understanding personal space • May want to smell or touch items in the environment • As for pre-schoolers 	<ul style="list-style-type: none"> • Difficulties managing school environment • May find it harder to concentrate in noisy and bright environments e.g. classroom • May be tactile or respond strongly to smell • Difficulty with multiple conversations or talking with the TV on 	<ul style="list-style-type: none"> • Difficulty coping with challenging environments such as group discussions, being on a team • Easily overtired; may need to work in short bursts • May have difficulty socialising or working in noisy environments • May be affected by bright lights, perfumes, or other sensory input
<i>Emotional regulation</i>	<ul style="list-style-type: none"> • Difficulty regulating emotions, leading to tantrums, meltdowns, withdrawal, tearfulness, angry outbursts • Anxiety, separation anxiety 	<ul style="list-style-type: none"> • Difficulty coping with frustration, conflict • May be angry, aggressive 	<ul style="list-style-type: none"> • Emotional dysregulation may include aggression, self-harming • Mental health conditions – anxiety, depression, mood disorders may emerge 	<ul style="list-style-type: none"> • May have mental health diagnosis, self-harming or suicidal thoughts • May have difficulty controlling aggression or offending behaviour • Difficulty coping with pressured situations
<i>Communication Receptive/ expressive language</i>	<ul style="list-style-type: none"> • Speech delays, slow to develop language, fewer words and less complex language • Difficulty following simple verbal instructions 	<ul style="list-style-type: none"> • Difficulty following or remembering 2-3 step verbal instructions • May say they understand, but lack real comprehension • May be able to repeat instructions, but not put into practice 	<ul style="list-style-type: none"> • Receptive or expressive difficulties continue. • May have superficially good verbal communication skills, but conversation may be lacking depth • May appear to understand instructions, but not be able to follow through 	<ul style="list-style-type: none"> • May say they understand and agree, but fail to follow through e.g. “talk the talk”, but not “walk the walk” • Misunderstanding communication or expectations
<i>Social Skills</i>	<ul style="list-style-type: none"> • Social skills – slower to develop social skills such as sharing, turn taking, slower to develop cooperative play skills 	<ul style="list-style-type: none"> • Wants to make friends, but has difficulty understanding social rules and expectations • Difficulty with sharing, turn taking, following rules • May prefer to play with younger children or spend time with an adult • Difficulty reading body language or facial expressions 	<ul style="list-style-type: none"> • Difficulty making and keeping friends • Few friends and superficial friendships • Behaviour may seem immature to peers • May make social ‘faux pax’ • May not show social skills e.g. remorse or take responsibility for actions, affecting peer relationships • Vulnerability to exploitation or being taken advantage of by others 	<ul style="list-style-type: none"> • Poor social skills, limited support networks and few genuine friendships, may be isolated or struggle with social contact

FASD across the lifespan				
DOMAIN	Preschool aged children	Primary school	Young people	Adults
<i>Adaptive function/skills of daily life</i>	<ul style="list-style-type: none"> Delays in toilet training, learning to dress or self-care skills 	<ul style="list-style-type: none"> May need supervision for self-care - e.g. dressing, showering May have toileting difficulties 	<ul style="list-style-type: none"> May continue to struggle with independence in self-care or household tasks May need more supervision when cooking, etc., than expected for age 	<ul style="list-style-type: none"> Struggle with tasks of adult life including managing a household, cooking, cleaning and self-care. May struggle with skills of parenting and have difficulty parenting children safely
<i>Attention</i>	<ul style="list-style-type: none"> Poor concentration – short attention span Difficulty focussing for periods of time, moving from one thing to another, lacking focus, Difficulty sitting still 	<ul style="list-style-type: none"> May have ADHD Difficulties focussing in the classroom Difficulties in filtering out noise, easily distracted Forgets instructions 	<ul style="list-style-type: none"> May have ADHD Loses belongings at school, forgets timetable. Difficulty multi-tasking May get fixated on an interest or topic and have difficulty shifting attention 	<ul style="list-style-type: none"> May have ADHD – may be undiagnosed Difficulty focussing on tasks, forgets information, doesn't follow through.
<i>Cognition/ Thinking and Reasoning</i>	<ul style="list-style-type: none"> Challenges in learning routines, rules, expectations or following simple instructions. Difficulty adjusting to changes to routine. May have intellectual disability or normal IQ 	<ul style="list-style-type: none"> Difficulty with abstract concepts – e.g. telling time, ownership (which can result in stealing) May be very literal and argumentative Difficulty seeing others' point of view Challenges in learning routines, rules, expectations or following multi-step instructions 	<ul style="list-style-type: none"> Learning difficulties impact on school performance 	<ul style="list-style-type: none"> Likely to have developed coping strategies which mask underlying impairments Learning difficulties make it harder to learn new skills such as in workplace or parenting skills
<i>Memory</i>	<ul style="list-style-type: none"> Difficulty remembering information and routines May learn and then forget facts – e.g. colours, shapes 	<ul style="list-style-type: none"> Difficulty remembering routines or rules, even when they happen every day. May have difficulty remembering what is learned, or may seem to learn but then forget what has been learned May make up stories to fill memory gaps – not intentionally lying - "confabulation" 	<ul style="list-style-type: none"> May have difficulty telling an accurate account of events May lose belongings, forget timetable, forget to bring or complete homework 	<ul style="list-style-type: none"> Difficulty remembering appointments or agreements May not remember what was spoken about earlier Forgets to take medication, eat regularly or follow through plans; needs prompting

FASD across the lifespan

DOMAIN	Preschool aged children	Primary school	Young people	Adults
<i>Executive Function - planning and decision making</i>	<ul style="list-style-type: none"> • Impulsivity • Risk taking – running, climbing 	<ul style="list-style-type: none"> • Impulsivity • May get 'stuck' on something - e.g. "perseveration". Can't be distracted or shifted • Disorganised, can't plan to start or complete tasks • Loses belongings • Inattentiveness and impulsivity becomes more problematic as the expectations on child to self-regulate increase 	<ul style="list-style-type: none"> • Impulsivity leading to risk taking • Difficulty planning and organising self, managing a locker or belongings • Difficulty coping with new situations, managing time or money, and being independent - e.g. using public transport. The gap between their peers widens as expectations increase • Lack of inhibition may lead to socially inappropriate and/or sexually inappropriate behaviours 	<ul style="list-style-type: none"> • Difficulty with skills of adult life, such as managing money, negotiating bills or payments, banking, loans, housing or Centrelink • Challenges in the workplace if tasks or routines change • Difficulties with planning, problem solving and emotional regulation may impact on getting or keeping a job • More difficult to change behaviours, leave abusive relationships, engage in alcohol or drug treatment, work with child protection or comply with court conditions
<i>Academic skills</i>	<ul style="list-style-type: none"> • Slower to learn and write letters and numbers 	<ul style="list-style-type: none"> • Mild delays become more noticeable over time • May struggle more with maths than reading or writing. Recognises words, but may not comprehend sentences when reading • Difficulty with abstract concepts – e.g. time, money 	<ul style="list-style-type: none"> • Difficulty with abstract concepts • Reading skills e.g. reading aloud more advanced than comprehension • Gap between child and their peers increasing as academic expectations increase • Falling further behind peers, as world becomes increasingly abstract and concept-based • Greater difficulty mastering new academic skills 	<ul style="list-style-type: none"> • Difficulty with literacy and numeracy in adult life • Difficulty meeting deadlines or handing in work • May write very slowly • Learns from example/doing more than from verbal instruction
<i>Secondary Effects</i>	<ul style="list-style-type: none"> • Meltdowns, tantrums, defiance and angry outbursts • Frustration and anger; hitting and hurting others 	<ul style="list-style-type: none"> • Engaging with a negative peer group • Withdrawing, loneliness, isolation or exclusion • Defiance, running away, disengaging • Aggression, towards children or teachers • Suspension, school exclusion and school refusal 	<ul style="list-style-type: none"> • Behavioural disruption • Being unmotivated or disengaging • School avoidance, refusal, exclusion or suspension • Being wrongly labelled lazy, stubborn, not trying, intentionally or wilfully misbehaving • Involvement in criminal behaviour • Self-harming or suicidality • Inappropriate sexual behaviours • Being exploited by others 	<ul style="list-style-type: none"> • May be in abusive relationships or be sexually or financial exploited • Criminal involvement • May exhibit abusive behaviours towards others, showing impulsivity rather than planning • Difficulty finding or keeping a job • Drug and alcohol problems • Mental health problems

Unique Challenges - What's Different About FASD?



FASD has some similarities with other developmental conditions such as intellectual disabilities or Autism Spectrum Disorders, but also many differences. Some of the common issues that arise for people with FASD that are different for people with other disabilities include:

- Some infants develop like typical babies, and it may not be until early childhood that any concerns are noticed.
- Symptoms might be noticed when a child starts childcare or kinder, and they are usually seen as behaviour problems (defiance, not following rules, aggression) rather than primary problems (attention, language, emotional regulation).
- Many people with FASD have IQs in the normal range, but have other learning impairments, particularly in relation to planning, decision making and understanding consequences. Because they don't have an intellectual disability, the people around them expect them to function normally.
- Having a normal IQ means people are seen by the world around them as being more "competent" than they are – which can lead to stress, failure or being in risky situations. A person with an intellectual disability might be recognised as needing help (e.g. being able to manage money) but a person with FASD might be expected to do it alone – and when they make mistakes, they bear the consequences.
- Parents and carers often report that their child will seem to learn something but that the next day, it is gone. Diagnostic tests often don't capture these long-term memory issues. Teaching and re-teaching is required, but can be hard for educators and others to understand – they may think the child is not trying.
- When we see children as more capable than they are, behaviours at school like being disruptive or not completing schoolwork can be seen as intentional, rather than involuntary – due to the child not coping with the schoolwork or the classroom setting. If the issue is addressed by telling the child to try harder or improve their behaviour, problems might get worse because the child can't regulate their own behaviour.
- Most people with FASD have difficulty with at least some of the tasks of daily living. They might forget things like simple routines even if they do them every day. This means that life is often stressful. If the disability isn't recognised, it leads to a lot of frustration.

- Children with FASD often struggle with emotional regulation. While all young children are learning to regulate their emotions, involving a lot of tears, frustration and meltdowns, children with FASD might experience meltdowns that are more frequent and last longer than other children. Typical parenting strategies (like time-out) are usually not effective.
- Children with FASD may get “stuck” on something and not be able to let it go. This can be very challenging as typical strategies - distraction, explaining, rewards or consequences - either don't work or work only for a short time. Sometimes these behaviours are just a part of life that families have to live with.
- Children and young people with sensory processing difficulties have trouble managing information from their senses. Their brains either do not understand or the incoming information is mixed up. This is because sensory processing in the brain has been affected by alcohol exposure. Some people with FASD feel bombarded by sensory information and they tend to shut down or tune out. Others may need more input, and they are busy and actively seeking sensations.
- Children with sensory processing difficulties might need to touch or taste the object. Their reactions to everyday sensations can be either too strong or not

strong enough. Many children and young people also struggle to keep their sensory systems balanced. It is difficult for them to adjust and adapt to different environmental expectations (e.g. gearing up to play basketball, calming down after a party or adjusting to reading a book or getting ready for bed).

- Young people with FASD may get fixated on something (e.g. something they want to buy) and might argue about things and use faulty logic, but not be able to compromise or see another point of view. It might seem like they are selfish or inconsiderate. There may be frequent conflicts in the home, and this can lead to difficulties with sibling relationships. It is important that the young person's behaviours are understood as their developmental stage – the young person may be 15 but have the social maturity of an 8 or 9-year-old. Some of the behaviours can be managed with support, but sometimes families just have to cope with these behaviours the best they can.

Caring for an individual with FASD can be challenging. It is important to realise that their world is different from ours. The brain is complex and FASD is a permanent condition. Many people with FASD struggle with learning and relating to the world around them and the majority will need a circle of external support for their lifetime.

Parenting: What Doesn't Work and Why

*“Because our kids are more likely to have a normal IQ and less likely to have insight into their own needs - when I tried to access services they believed it was my parenting that was the problem and suggested I get some training. The last thing we need is mainstream parenting training.” **

Well-known parenting methods are usually based on learning theory and include strategies such as:

- time-outs
- grounding
- using consequences
- discipline involving added work/chores
- contracts and/or positive reward systems (e.g. sticker charts)
- verbal consequences (e.g. lectures, threats, shaming).

Parents often turn to these strategies because they are so popular. We are all familiar with the use of consequences and cause-and-effect reasoning to manage behaviour.

Unfortunately, these parenting methods do not recognise the brain differences of people living with FASD. They fail to consider that some brains have difficulty storing and retrieving information, forming associations, generalising, thinking abstractly and predicting. Strategies, such as time-outs and the use of consequences, require brain power that may not apply to people with FASD. For example, people with FASD struggle with cause-and-effect, so they have trouble connecting an action to a result. They may make the

* Carer of an adult with FAS, Breen et al (2012)

same mistake over and over. They may be unable to process and understand information or remember what happened the last time.

When using strategies to deal with behaviour, it is very important for parents to note:

- Typical strategies and learning-based parenting are not wrong, but they may not match how your child with FASD understands the world.

- Look for patterns of behaviour, anticipate problems and change the situation. This will help prevent the need for punishment and consequences.
- Pay attention to your child's most effective learning style and build on their strengths associated with this style.

"We found ourselves struggling with typical parenting approaches. Every time we used approaches such as time-outs, or taking something from our child it became the battle that never ended. We were told to try using no consequences. That was really hard but it did make things better. We now wait until they are calm, talk about what happened, how they were feeling, and plan for the future. We keep the conversation going."

Maturity and Development

As parents, we have expectations for our children based on their age (e.g. "Susie should be able to clean her room without help because she is 10"). This thinking assumes that your child is developmentally "on track." Research shows that children and young people with FASD are usually developmentally younger than their age peers in a number of areas. However, keep in mind that every child is unique. The diagram below illustrates how people with FASD may be performing at different developmental ages in different areas of their development.

When you look at these profiles, it may be easier to see how a person with FASD can become frustrated and discouraged when, over time, the expectations placed on them exceed their ability. This can lead to difficulties such as outbursts, anger, low mood or other secondary effects.

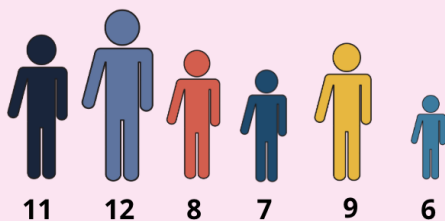
Diane Malbin suggests that we adjust our expectations and "think younger" when we support people with FASD. An example of this would be to consider a five-year-old with FASD. Normally, five-year-olds are ready to start school, can play co-operatively with friends and follow instructions. Your five-year-old with FASD may be more like a two-year-old, in that they are not ready to start school, can't sit still and always want their own way. If you are able to appreciate that your five-year-old is developmentally closer to two, then you can line up your parenting style for a two-year-old. "Thinking younger" reduces the frustration both children and parents feel when parental expectations are not being met. This does not mean that your child will not grow and develop. They will develop, but perhaps at a slower pace and not always in line with their age peers.

Adjusting your expectations and support does not mean ignoring your child's behaviour – but it does mean our expectations that they are accountable for their behaviour should fit their developmental age.

It is common for children and young people with FASD to have "on" days and "off" days. Even though all of us have those days, it is more frequent and noticeable for those with FASD. Because of neurological damage from alcohol exposure, the brain seems to misfire more often than normal. When a child is able to follow instructions one day, and is unable to follow the same instructions the next day, it may be misinterpreted as wilful behaviour. It would be helpful to think of these inconsistencies as what some parents call "FASD days" - times when the child's brain is misfiring because of their disability. It is important to be as flexible as possible in your parenting as these "FASD days" are beyond your control and more importantly, are beyond your child's control.

DEVELOPMENTAL AGE AND FASD

TOMMY - 11



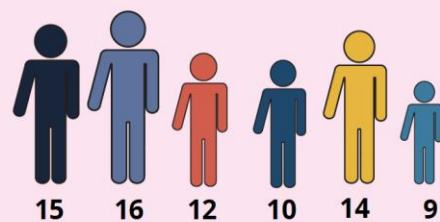
Tommy is 11.

His IQ is normal for his age

He has the expressive language of a 12 year old,
the receptive language of an 8 year old,
the social skills of a 7 year old,
and the motor skills of a 9 year old,
the attention of a 6 year old.

Tommy has ADHD and a fine motor disorder
but his gross motor skills are good.

ALEX - 18



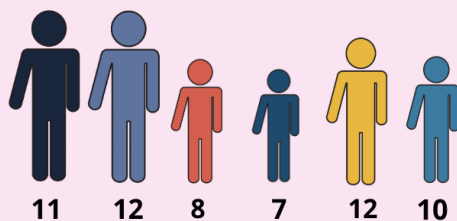
Alex is 18

His IQ is average for a 15 year old

He has the expressive language of a 16 year old,
the receptive language of a 12 year old,
the social skills of a 10 year old,
and the motor skills of a 14 year old,
the attention of a 9 year old.

Alex has ADHD and anxiety/depression. He has problems
with his joints, a heart murmur and poor eyesight.

MOLLY - 14



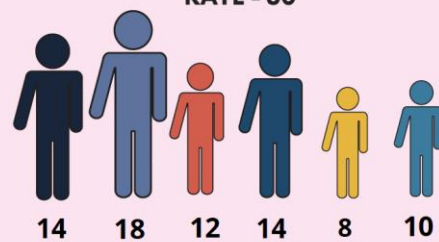
Molly is 14

Her IQ is average for an 11 yr old.

She has the expressive language of a 12 year old,
the receptive language of an 8 year old,
the social skills of a 7 year old,
and the motor skills of 12 year old,
the attention of a 10 year old.

Molly has good gross motor but difficulty
with handwriting. She also has anxiety.

KATE - 30



Kate is 30.

Her IQ is average for an adult.

She has the expressive language skills of an adult,
the receptive language of a 12 year old,
the social skills of a 14 year old,
and the motor skills of a 12 year old,
the attention of a 10 year old.

Kate also has difficulties with adaptive function and social
communication. She has social anxiety and PTSD.

FASD Success Stories

There are many children, young people and adults with FASD who have shared their experiences of living with FASD. Hearing people with FASD talking about their strengths and successes is really important for you and your child – because so much information about FASD focuses on the negatives, you will need to find the positive stories and share these with your child and family.



"I Struggle, but I also Succeed" is the title of a YouTube presentation by **Myles Himmelreich**, FASD Consultant and motivational speaker. Myles talks about FASD as Faith, Ability, Strength, Determination. He has produced many videos on YouTube.



Jessica Birch is an adult who was diagnosed with FASD later in life. She now advocates for FASD awareness and diagnosis. You can follow her on Twitter @JBirch_FASD.



Emily Travis is a FASD consultant and motivational speaker who talks about Thriving with FASD. With Myles and CJ, Emily is working on research about health issues for adults with FASD.



Nicholas is a young man living with FASD. He has spoken at conferences and you can find his videos on YouTube – search for "Nicolas Age 9 living with FASD" and "Nicolas speaks about living with FASD (aged 12)".



CJ Lutke is a young adult with FASD. She is part of an Adult Leadership Committee of FASD Change Makers in Canada and speaks about FASD at conferences and events. CJ writes a blog which you can find on the NOFASD website.



Liz Kulp has written books about FASD as a young adult and has also produced YouTube videos.

Strategies for Parents of Children and Young People with FASD

Eight Magic Keys



The Eight Magic Keys are principles which are helpful in working out ways to support children and young people with FASD. [*Eight magic keys of success.*](#)

1. **Concrete** – children and young people with FASD need those around them to use concrete language rather than abstract or idioms. For example, “Please take a seat” may not mean “sit on the seat” to a child with FASD.
2. **Consistency** – people with FASD struggle to generalise from one situation to another. Keeping things consistent with few changes will benefit them.
3. **Repetition** – children and young people with FASD may have memory impairments and need to learn information and practice skills many times.
4. **Routine** – stable routines that don’t change day to day will benefit individuals with FASD.
5. **Simplicity** – keep it short and simple. Single step instructions may be needed. Too much information and the person may shut down.
6. **Specific** – say exactly what you mean. Don’t expect your child or young person to ‘fill in the blanks’. Give specific directions and use concrete language.
7. **Structure** – this is the “glue” that allows the world to make sense for a person with FASD. A child or young person with FASD can achieve with enough structure to support them.
8. **Supervision** – a child or young person may need constant supervision to develop habits of appropriate behaviour, and to keep themselves and others safe.

Building on strengths

Every child with FASD has their own set of unique strengths. Unfortunately, many children with FASD are defined by their problem behaviours or their disability. While it is important to understand and accept the disability and focus on solving problems related to behaviours, this approach falls short of appreciating your child as a whole person. Focusing on problems limits possibilities and can sometimes overshadow your child’s amazing strengths.

Focusing on strengths can help your child be more successful in school, will help you appreciate your child as a whole person, not just a person with a disability, and could also decrease other secondary challenges by maintaining a positive focus on what they do well. This focus will help you build a strong relationship with them, enhance their self-esteem and decrease their stress levels as well as yours.

Identifying strengths and talents in children with FASD is a very helpful strategy. Understanding your child’s strengths allows you to change your environment to build on these strengths.



Strengths of children with FASD may include:

- Having good verbal skills
- Cognitive strengths in some areas
- Enjoying art, music, dance or singing
- Sport
- Being friendly, outgoing, affectionate and loving
- Enjoying social contact

- Having interests that absorb them – art, Lego, building things
- Being generous and willing to help
- Doing well in structured activities
- Good with younger children
- Enjoying 1:1 adult contact
- Enjoying being around animals
- Every day is a new day!

A Focus on Strengths: Useful and Practical Tips.

- Focus on prevention and ‘a great life’
- Make a list with the person of what they are good at
- Be creative!
- Select the best ideas and decide what to focus on
- Make a plan for new opportunities for the person to use their strengths.

Gary Radler gradler.com.au/my-approach/ talks about developing behaviour support plans, which focus on improving living environments, building on strengths, teaching skills, improving health, fostering friendships, increasing opportunities for exercising control, and other things we can do to promote physical, psychological, and social well-being and happiness.

Strengths vs talents

Your child may have talents in some areas – music, dance, art – and it is important to keep activities fun and manageable. There may be pressure for your child to do exams or competitions, which may turn them off the thing they enjoy. If they love something, keep it fun!

“We focus on the positive things in life. One of the things we did when the kids were young was create a wall of goodness. We had a wall downstairs with a light on top of it so whenever we saw something good, we took a picture of it and put it in the wall. We kept changing the photos on a regular basis. They could go down and look at the positive accomplishments that they had made.”

- Use your child’s strengths to try to prevent problems. Let’s say your young person is getting into trouble because they have too much unstructured time available after school (e.g. hanging out with friends who are smoking pot or drinking). Rather than focus on what you don’t want them to do, find something they enjoy and are willing to do, and try and occupy the hours after school.
- Try to reframe behaviour problems. This can be easier said than done, so it does require planning

Family or friends also want the best for our children and might suggest that your child’s interest could become their future career – they like cooking, maybe they can be a chef one day! You will need to manage the expectations of others – your child likes cooking and that is a strength in itself. Being a chef is a high-pressure job and may not be the best fit for your child, but they can learn to cook a range of meals at home and feel proud of themselves, as well as developing important life skills.

Building on your child’s strengths may require ongoing supervision to keep everyone safe and avoid failure. A child who loves animals might always need supervision to ensure that they don’t hurt the animal, or that they don’t react badly if accidentally scratched, for example.

How do you build on strengths?

- Start by identifying your child’s strengths, talents and potential interests. Consider things that help them get active and use their body because most children with FASD need a lot of physical activity to help them manage their day (e.g. swimming, time on the treadmill, biking, playing at the park, etc.).
- Incorporate your child’s strengths, talents and interests into everyday tasks. For example, if your child likes to be active and wants to help out at home, have a list of jobs they can help with like raking the garden. Choose jobs that are still helpful if not finished – raking half the garden is ok, but half-washing the dog is not so helpful. If they like to work on the computer, they could look up movie reviews or create a shopping list.

and practice. For example, when your child has trouble getting ready in the morning and is bothering everyone in the household, they may need more specific direction, either from you, or by using visual cues to help them get ready. If they are very active, your child may need to expend some of their energy every morning before being able to focus. Perhaps your child could walk the dog every morning. This also presents an opportunity for your

child to be praised, to feel productive and contribute to the family.

- Use a strength-based vocabulary when thinking about solutions or working with your child. Here are a few examples of what a strength-based vocabulary sounds like:
 - What does my child do well?
 - "I believe in you."
 - How can I get my child involved in what is going on?
 - How can I support my child when he/she is struggling?
 - "I am listening."
 - "I understand how you are feeling."
- Invite your child into the process. Ask them what will work. Help them discover their abilities and have some input into their surroundings. You may be surprised to hear that your child has a creative solution to a behaviour problem.
- Use your child's strengths when planning ahead. If you are planning strategies to manage supermarket shopping (see p 30) make sure you build on strengths. If your child likes visuals, create a picture shopping list and give your child responsibility to tick off items. If this is too easy, give them another task such as writing down the aisle number next to the item. If they like typing on the computer, help your child re-write the list with items in order for next time.

Avoiding failures

Many children with FASD experience difficulty making friends and may feel lonely and isolated. They may also experience a lot of what we call "social failure". Think back to a time when you had a "social failure" – maybe you made an embarrassing mistake, forgot someone's name, said something inappropriate, or maybe lost your temper in public – you probably felt embarrassed, ashamed, and hoped that you would never see those people again. For children, social failures occur in situations like:

- Producing schoolwork that is of a noticeably lower standard than their peers or needing help with tasks other children can do independently.
- Not handing in homework or not completing work which will be on display.
- Running out of the classroom or having a meltdown that scares other children.

- Having a meltdown in a supermarket or in a public place.
- Being excluded from an activity due to unsafe behaviour or not enough supervision.
- Not being invited to play dates or parties.

We usually expect children to learn from their behaviour and this includes learning from negative consequences. However, if a child with FASD has an impairment that means they don't learn from past experiences, we need to reduce negative effects by preventing or avoiding social failure as much as possible. Long-term experiences of repeated failure lead to poor self-esteem, disengagement and can contribute to anxiety and depression.

Avoiding failures involves:

- A focus on accommodations e.g. at school, adjust the task and/or the environment so the child can experience success.
- Avoiding situations where you know the child won't be able to self-regulate.
- Providing the support and scaffolding for success – e.g. homework emailed to parents as well as given to child, supervising your child's play date so you can provide support with social interactions.

Family, friends or even professionals may criticise your approach. Parents may be criticised for being over-protective or somehow holding the child back by not letting them learn. The reality for many families is that if children don't learn from experience, there is no point setting them up to fail over and over again – instead, we need to prevent the damage to self-esteem that repeated failure can cause.

Structure, routine and consistency

All children do better with structure in their lives, but especially children with FASD. They need structure to help them with daily activities because their brains have trouble figuring out the steps needed for each activity. We don't realise how much planning our brain is doing every minute of every day, just to do simple things like brushing our teeth, getting ready for work or making it to an appointment.

Change can be confusing for children with FASD because their brains have trouble adjusting to change and making transitions. Even the most minor changes, such as putting the cereal in a different cupboard, can create major confusion for a child.

- Routine and schedules help your child predict what comes next. Create an activity routine throughout

the day or the week. Some children need a lot of detail. Having an organised, predictable routine can also help ease the child from one activity to another.

- Try to be as consistent as possible with the schedule (do the same thing every day of the week, such as laundry on Fridays). Provide gentle reminders, including the use of visual or auditory cues.
- Monitor your child or young person's free time as much as possible. This helps prevent them from having the opportunity to make poor choices.
- Keep meal-times at the same time every day. This will help your child prepare for meals and have a sense of control and predictability.
- Create routines each day. (e.g. after school - have a snack, go for a walk, do your homework and then, have a half hour of TV before dinner).

Expectations and rules











It is very important that your expectations for your child are realistic and in line with their abilities. This will enhance your child's feelings of success and will prevent problems down the road. It can also be helpful to "think younger" when you are frustrated that your child is not living up to your expectations. Perhaps your 12-year-old with FASD is acting more like an eight-year-old. How can you change your response to fit your child's developmental age, rather than their actual age?

- Rules in your family or household should be clear, concrete and as consistent as possible. Maintain firm limits that are consistently applied. Do not do the "just this once" routine as your child may be unable to see this change as a one-time thing. Don't debate, negotiate or try to over-explain rules. Just do it.
- In any shared parenting or care giving situation it is important that everyone is using the same strategies and routines with your child.

"My most helpful strategy has been to constantly be developing circles of support that are appropriate for the needs of the child or young adult – from day care, through school and beyond. I have continued to build his circles of support whether he is aware of it or not."

Visual schedules

VISUAL SCHEDULE

AFTER SCHOOL				
				
Lunch bag	Back pack	Coat	Shoes away	Snack
AFTER SUPPER				
				
Dance class	Bike ride	Homework	Watch TV	Bed time

- Use picture or visual cues as well as calendars or whiteboards to post your routines at home. Children with FASD are often best at visual learning, so it is easier for them to figure out their day with visual help. Depending on their reading skills, they also may find calendars and lists very helpful. Another idea is to take pictures of your child doing each step necessary to get ready in the morning and create visual lists, so your child can refer to these visual steps every morning.
- Break down everyday tasks into simple, easy-to-follow steps. For example, try teaching your child to put away their toys by using easy steps (e.g. all the blocks go in the red bin, the puzzles in the blue bin, etc.). Easy steps can be made into visual cues and posted in the appropriate areas (e.g. bathroom, kitchen, etc.).
- While structure and routine help children with FASD, remember to be flexible, as sometimes strategies lose their effectiveness over time and new ones need to be rotated in. Be ready to switch things up, depending on what is happening for your child on any given day. Even the best ideas may not work for everyone all the time.

"My son got a new job. When they hired him they said: here is the schedule and you work these days. He went for the first day and never went back because they didn't teach him how to read the schedule. So he lost his job. He didn't think to ask or say please help me with that. So then we worked out a system for him. But for me it was hard to realize that...what was I thinking? He is very good at the job but hides his challenges."

Managing family life

Some of the suggested strategies in this section may seem like hard work and you might wonder how you will find time to fit them into your family's day-to-day life. Keeping structure and routine consistent, preparing visual checklists, or avoiding things like shopping centres can feel like a burden at times. It can also feel like an imposition on other family members when one child's needs require a lot of attention.

Parents and carers tell us that putting proactive strategies into place has long term benefits for the whole family. A child who understands the daily routine is likely to be better regulated and this will benefit the whole family. Some ideas to consider in implementing strategies include:

- Planning might require time – labelling shelves, making visual schedules or creating routines – but you are likely to gain time in the future by being well organised.
- The morning routine might require the family to wake up a bit earlier. Some parents wake their children an hour and a half before they leave for school so that the morning routine works well. This might mean moving bedtime to be a bit earlier which might also take some planning.
- It might be hard to alternate jobs between parents as this disrupts routine – e.g. the same parent driving to school each day. It's important to find other ways to share the parenting so that one parent doesn't carry all the responsibility. If one

parent is working, they might take responsibility for organising online grocery shopping on their lunch break, for example.

- You might need to actively plan to spend time 1:1 with your child's siblings. For example, if your child is dysregulated after school, a calming activity like sitting in a bean bag with headphones or a warm bath might give you a chance to spend time with another child, doing homework or catching up about their day.
- It can be frustrating to have to limit your activities to accommodate your child – like skipping the shops to avoid stopping on the way home from school even though you really need milk. Online grocery shopping, fruit and vegetable deliveries, or stocking up on essentials can reduce some of the frustration of not being able to change routine in the way other families take for granted.
- Being spontaneous may be very difficult. Try and use opportunities in your day to do things that don't require planning – have a spontaneous coffee after school drop off so you can take time out from the structure of the rest of your day.
- Spend as much time as you can with your children doing things that they enjoy where you don't have to constantly monitor them. Go for a regular walk in a park or on a beach if this is something your child enjoys - find opportunities to spend time together where you don't have to keep correcting or checking them.

"When I asked my nine-year-old who has a FASD diagnosis what she thought other parents should know about parenting a child with FASD, she replied, 'Kids with FASD have some difficulties, parents need to stay calm and just talk about it'."

Sensory Processing and Everyday Activities

What is sensory processing?

Every moment of every day we are taking in information through our senses; sight, hearing, touch, smell and taste. Our senses also help us with movement and body awareness. Nerves throughout our body take in sensory information and our brain processes the information and tells us what to do with it (e.g. respond or ignore).

FASD and sensory processing issues

Children and young people with sensory processing difficulties have trouble managing information from their senses. Their brains either do not understand or the incoming information is mixed up. This is because sensory processing in the brain has been affected by alcohol exposure. Some people with FASD feel bombarded by sensory information and they tend to shut down or tune out. Others may need more input, and they are busy and actively seeking sensations.



Children with sensory processing difficulties might need to touch or taste the object. Their reactions to everyday sensations can be either too strong or not strong enough. Many children and young people also struggle to keep their sensory systems balanced. It is difficult for them to adjust and adapt to different environmental expectations (e.g. gearing up to play basketball, calming down after a party or adjusting to reading a book or getting ready for bed).

Here are some examples of sensory processing difficulties:

Sight/Visual

- gets easily upset in a busy place, such as a mall
- frequently can't find their belongings

- frequently distracted

Hearing/Auditory

- easily upset by noise from appliances, such as a vacuum cleaner or blender
- covers their ears, overreacts with anger or bolting when they hear loud noises (e.g. fire alarm at school)
- may create noise to drown out other upsetting noises
- hearing a regular volume speaking voice as yelling

Touch/Tactile

- bothered by tags on clothing
- overreacts when touched, especially if it is unexpected (e.g. may respond by hitting, or report being hit and pushed)
- may not feel hot or cold (e.g. goes outside in winter without a hat or mittens and does not feel cold)
- constantly exploring their environment (e.g. touching every button on appliances, flicking switches, touching other people's belongings)

Taste/Oral

- fussy eater
- chews on clothing
- puts everything in their mouth
- overstuffs mouth with food

Smell/Olfactory

- strongly dislikes smells that are often undetectable by others
- tells others they smell bad
- refuses certain foods because they "smell bad"

Movement/Vestibular

- poor coordination, difficulty using both sides of the body
- difficulty tracking an object such as a ball with the eyes
- difficulty following the steps to a physical activity
- difficulty walking on surfaces like gravel, textured surfaces of metal grates, fears their feet leaving the ground.

Body Awareness/Proprioception

- becomes motion sick easily
- has poor danger awareness
- has trouble with pressure and movement, may be too rough during play
- has poor body awareness (e.g. stands too close to others, tends to get "in your face," constantly touching others)
- prefers tight clothes
- chews on objects.

Children and young people who are struggling with sensory processing differences often communicate these challenges through their behaviours as they often do not have the language to tell you how they feel.

Remember: Children can have a mix of sensory behaviours. They can be sensitive to auditory input but seek out movement. They also may be okay managing sensory input one day but are distressed the next day. Every day is a new day.



Practical Strategies for Daily Life

Your child's behaviour is trying to tell you something. It is up to the adult to try and determine what they are trying to tell you (e.g. a child crawling behind a piano may be telling you that this is a safe quiet space for them to calm down). Sometimes they might simply be telling you that they can't handle the situation they are in, and something about it overwhelms them.

First, as a parent, you act as an "external brain," recognising the needs of your child or young person. By working together, and with time and lots of practice, your child or young person will be better able to participate in daily activities and some self-regulation will develop.

When trying any new strategy keep in mind your child's unique strengths and challenges. You may need to try a new strategy for a while before knowing whether it works for your child.

Self-regulation

- Help your child develop a way to express emotions when feeling upset or overwhelmed. Name the feelings you see, e.g. "Look how relaxed you are, your breaths are nice and slow, your voice is quiet..."
- Help your child identify and talk about an emotion. Sometimes, using a simple visual showing five or six feelings is a good tool. This tool could be posted on the fridge door for easy access. Websites, such as www.do2learn.com have lots of free artwork for visual schedules and feelings charts. Real photos of the child, or people around them, are often even more effective than picture symbols.
- As you adapt different environments and begin using various self-regulation strategies, point out to your child how they are using tools to help get calm, settled, and focused (e.g. "You seem quite upset right now. I think a calming tool could help calm you down. Let's go to your Calming Fort.").
- If a self-regulation program, such as "How Does your Engine Run" by Mary Sue Williams and Sherry Shellenberger, or "Zones of Regulation" by Leah M. Kuypers, is being used in the child's school, use the same language and strategies at home.

"When my child has messed something up he is often in an anxious state. I find if I just leave the issue for a while and let him calm down he is more open to having a conversation. When we have a conversation later I am far more successful."

Bedtime

- To help a child transition from an alert and wakeful state to a calm and restful state, try applying calming practices, such as a back rub or some gentle squeezing of the feet, legs, hands and arms.
- An auditory-sensitive child may need total quiet to fall asleep. If this is not possible, try some alternative white noise. Try having a fan turned on or set up an aquarium that has a pump operating.
- Give older children a light snack before bed. Oral input is often calming in nature. Find out what kind of snacks help settle versus ones that are alerting. Oral inputs that are spicy, sour, cold and chewy tend to be more alerting tastes and textures.
- For the child who needs time to settle or wakes up during the night, have a basket/list of calming tools/activities in their bedroom. You could provide an oil-and-water toy to watch, stuffed animal or a picture book.
- Treat activities between dinner and bedtime as a time for your child to begin winding down. Try to avoid activities that are exciting and alerting, such as rough-and-tumble play.
- Remember that deep pressure touch is calming. Have blankets and pillows on your couch available for them to tightly wrap up in and snuggle. This type of calming touch could be used while a bedtime story is read, or when talking about the day.
- Avoid screens a couple of hours before bedtime. The lights from video games, computers and TV affect the ability to fall asleep.
- Use a visual schedule to help your child learn pre-bedtime routine.

Mornings

- Make mornings predictable by following a routine.

- With children who have a hard time getting up, make sure they are sitting up in bed, with their feet on the floor, before you leave the room to continue with your morning activities.
- Help them move to an alert state by turning on upbeat music, opening the bedroom curtains to let sunlight in and giving them a glass of water or juice.
- Avoid TV or screens in the bedroom.
- Help with organisation. Set out belongings, such as back packs and clothing in the same location. Always have a child get ready for school in the same location. This works well if the household is busy and everyone is getting ready to leave at the same time. Surprise touches and bumps are also avoided when the child has a quiet spot to get ready for the day.

Mealtimes

If your child:

- has trouble with personal space at the dinner table - use placemats to designate their space.
- has difficulty sensing fullness - the parent should serve food portions for the child.
- has trouble sitting at the table - let them stand or try having them sit on an exercise ball or chair that allows movement.
- is easily overwhelmed by auditory sensory information - have them wear headphones at the table to reduce auditory input and eliminate TV, radio and any other audible distractions.
- becomes overwhelmed by the smell of food - let them eat their meals in a different location or turn on a fan to eliminate the food smells.
- is a fussy eater - experiment with new foods to find out what works best for your child. Some children respond well to highly acidic/spicy/hot foods, others may do better with bland foods.
- has trouble sitting at the dinner table - use a visual timer to let them know how long they should sit there.
- is too easily distracted by conversation at dinner - have the child eat dinner early, and join the family for dessert.

Clothing

Children with FASD who are oversensitive may find their clothing distracting or upsetting. Here are some strategies you could try to help your child get dressed:

- Turn your child's socks inside out to avoid a seam rubbing against skin.
- Help them express their discomfort by giving them appropriate words (e.g. "I do not like how my shirt feels.").
- Have them wear soft clothing. Avoid clothing with scratchy nylon threads and remove tags from clothing.
- Tight or loose clothing? Some children prefer very loose clothing, while others like the deep pressure that comes with the feel of tight clothing, such as spandex.
- If your child is chewing through shirts, try adding a better option, such as chewable jewellery available online or through an Occupational Therapist.

Shopping

Shopping centres are a visual wonderland, with many people moving about, bright lights, changing noises, and the opportunity for unexpected bumps and touches. Shopping can be a very stimulating and overwhelming environment for many children with FASD. Here are some strategies you could try with your child when you go shopping together:

- Shop during off-peak hours when the store is less crowded and noisy.
- Avoid going to the shops straight after school, as your child may already be over-stimulated after a busy school day.
- Let your child push the grocery trolley. Pushing a trolley is a heavy work activity and can provide a calming sensory input.
- Have your child wear a cap or hoodie to reduce visual information. Some children find the slight pressure from a winter hat calming.
- Have your child help find groceries in the store. For non-readers, you could use a visual (e.g. picture of the food item). For children who are constantly on the move, having a job helps them to stay regulated.

Homework

A number of challenges can make sitting down to do homework very difficult for a child with FASD. Some people recommend no homework for children with FASD. Others suggest children may handle 10 to 20 minutes of homework per evening. Here are some strategies you could try with your child when doing homework:

- Set up a homework routine – same place, same time.
- Create a homework station that is visually quiet (e.g. a clean table away from TV, family, or pets).
- Have fidgets (e.g. small, moving objects held in the hand, such as a stretchy bracelet) available to help with focus. Remember: If a fidget looks too much like a toy, it may be distracting.
- Use a visual support (e.g. visual timer or a schedule) that can help your child track time and tasks.
- Provide quiet to help your child with focus and attention. For those with sound sensitivities, even sounds such as a conversation in a nearby room can be distracting. Turn off the TV, radio, and phone.
- Let the child wear headphones to decrease environment sounds.
- Have a glass of water with a straw or a crunchy or chewy snack (e.g. celery stick) to help extend focus.
- Try gum. The flavour can help the child stay alert, and chewing is muscle work that can help with focus.
- Some days just might not work for homework. Accept this and let school staff know.

“My teenage child has to swing on her swing listening to music through her headphones for at least an hour after she gets home from school to de-stress before starting her homework”.

Bathing and hygiene

- If your child doesn't like slimy soap or shampoo, try foamy soap. Foam soap is also good for tactile play.
- If children avoid bathing because they don't like the feeling of being rinsed with water, try using a large container of water. The extra weight of the water might provide a soothing feel. Such children might be more comfortable if they feel they are in control of the water. In this case, provide a watering can (beach or garden toy) or a hand-held shower attachment; count down together when doing the rinsing (e.g. “1, 2, 3, rinse”).
- If your child wants to keep their eyes and face dry, try using a foam visor or holding a washcloth over the child's face when rinsing. This is good for a child who doesn't like to tilt their head back for rinsing. You might also have to dry the child's face

immediately after washing it, even if the child is still in the shower or bath.

- To promote independence, use visuals, such as a reminder list of the washing to be done in the shower. This can work very well for young people. This may be as simple as a written list that says 1) Soap/wash body parts and privates, 2) Shampoo hair and rinse 3) Use conditioner and rinse. Check in with your child to make sure they know what to do.
- With girls, teach proper menstruation hygiene using simple language and concrete instructions.

Restaurants

- To help with sitting and waiting, have some fidgets available (e.g. pencil and paper for doodling).
- Set up an interactive fidget activity (e.g. tic tac toe game using cutlery, sugar, salt and pepper packs).
- If the environment is too noisy, have your child use hearing protectors (e.g. wear a hat or use headphones to listen to calming music).
- Take a movement break (e.g. trip to the bathroom for a hand wash).

In the community

- Have fidget devices (e.g. small toys and items) to hold and touch.
- If possible, get your child to take pictures at events to keep eyes and hands busy and focused.
- Calming and focusing snacks include crunchy foods, drinks with straws, or chewing gum.
- Be aware of triggers that may negatively affect your child, such as the size of crowds, smells, touches and noise. Adjust your plans as needed. Have a Plan B in case an activity becomes too much. Discuss potential challenges and strategies with an older child, so that they may be able to help make the outing successful. For example, if the games or general excitement of a birthday party are too much for your child, then plan to take a break in another room.
- Have the child wear a backpack or bum-bag with items in it. Carrying this extra weight can be calming.
- Try aroma therapy. Scents that might be calming are: lavender, chamomile, orange and rose. Alertness and attention aromas could be: peppermint, basil, lemon, cinnamon and rosemary.

Car rides



- Use a visual schedule to help your child understand the car routines (e.g. buckling up, keep hands to yourself) and the schedule of which stops will be made. For example, your schedule might show a stop at the petrol station, the supermarket and then, going for an ice cream. Have some car activities available to help with restlessness.
- Allow the child to use headphones and music.
- Try to offer enough seating space to help reduce the chances of the child feeling overwhelmed by touch, or a sensory-seeking child touching and bothering their neighbour.
- Sometimes extra child-proof buckles may be needed to help a child stay safely in a seat.

General calming

- Avoid or limit time in situations where your child will become over-stimulated.
- Have a quiet or calming place for your child to go, not as a punishment, but as a place to be calm. Make this area quiet, with pillows and blankets available, and soft lighting. In your house, this could be a bedroom, a corner of a room, a special chair, a play tent or an area under a table.
- Playground swings can be calming. Deep pressure (e.g. bear hug or being tightly wrapped in a blanket) can be calming. Some children like light head massages. Always first ask the child if it is okay to be touched.
- If you are not at home and your child or young person needs time to calm down, then look for a quiet place (e.g. sit on a bench, go for a walk, or find a playground swing).
- For younger children, calming can also be accomplished with some distraction. Try changing the focus and the activity.

- Always point out to your children when they are calm (or regulated), so they can recognise how their body feels.
- Be specific by pointing out how their breathing is slower and their voices are at a good volume.
- When your child is upset, limit how much you talk – less is more. Children and people with FASD often have difficulty understanding language.
- Be calm and regulate your own breathing. Children will feed off the energy of the people around them. If a parent's energy is agitated, children will have a harder time calming. If a parent is calm, children can better organise themselves.

Praise

When you see that your child or young person has been able to successfully self-regulate, make sure to provide them with praise. This can help them to recognise that they used a self-regulation strategy. It helps build their self-esteem, and it helps to build the parent-child relationship.

Transitions

Children with FASD often have a hard time stopping an activity, starting a new one, or shifting their thinking from one thing to another. Transitions are a large part of the day. When the day is structured with a great deal of consistent routine, transitioning becomes easier.

Think of all the transitions that happen in a day. For example, the first transition is the shift between sleeping and waking. Many children and people with FASD need more time in the morning to wake up. It helps if there is a consistent wake-up time and morning routine.

Most children with transition challenges will need a reminder about what comes next in the routine. Visual routines or schedules can be useful if the child has challenges processing what they hear.

Many children with FASD miss the subtle cues that a transition is about to happen. They may not notice everyone has finished eating or all the kids at the playground are going home for supper. A child's interest level in an activity may also affect their ability to shift (e.g. really interested in the current activity and do not want to do what's coming next).

To help your child with transitions:

- Give a verbal warning the activity is about to change. Some children need the verbal cue well ahead of time and others are okay with a warning right before the activity is changing. "It's time to get up now." "It's time to put your toys away." "It's time

to leave for school.” “In 10 minutes, it will be time to put your coat on.”

- Try using the “first and then” approach: “First we will go to the bathroom, and then we will get dressed.”
- Because time is an abstract concept, using a visual timer sometimes helps because they can see how much time they have left before they have to transition to the next activity. A visual timer shows the passage of time. “When the red is gone, you move on.”
- Counting down a transition is a good strategy when the timing of the transition needs to be flexible: “I’m going to count down from five, then it will be time for bed.”
- Use pictures to show where the child is going to next.
- Give the child an object that represents the next activity, (e.g. a book when it’s time for a bedtime story or a snack at snack time).
- Visual schedules can help children see what happens next. For teens, a visual schedule on a computer device (e.g. tablet) can be helpful.

Not every strategy is going to work perfectly the first time. Often, you must change a strategy to meet your child’s needs.

Learning

Because FASD is a brain-based disability, your child is living with unique challenges. Children and young people with FASD often have trouble with:

- learning from consequences (e.g. connecting cause and effect)
- applying learning from one situation to another
- remembering things (e.g. short-term memory)
- setting goals and following through on them
- organising themselves
- keeping up with their work at school
- figuring out how to get started
- following a detailed list of instructions



Children with FASD have a wide range of IQ scores, with some in the disability range and others in the average range. A child’s IQ alone isn’t a good predictor of how they will cope in day-to-day situations. For example, you may have a child who has above average use of language, but gets lost going from one classroom to the other. Other children may be talented artists, but may be unable to explain their painting.

People with FASD tend to be visual learners and even better hands-on learners. They usually don’t do as well with auditory learning. The FASD brain has to work harder than other brains, so it may take your child or young person longer to complete assigned tasks. They may just run out of steam earlier than everyone else. That is normal for them, so try again the next day or try a different strategy.

“The struggle with homework: I could not stand it anymore sitting at the table for an hour. In grade 9 she had spares, so what they did every spare there was an arrangement for her to do her homework. She did her work at school. She was happy she never had homework. It was so nice that she could come home we could have special time and we did not have to struggle anymore.”

To support your child’s learning:

- Use step-by-step instructions and visual cues. A picture is worth a thousand words.
- Use simple language, not a big elaborate explanation. Children will tune out if the explanation is not clear.
- Tell the child what ‘to do’ rather than what ‘not to do’ (e.g. “sit on the chair” rather than “don’t stand on the chair”).
- Use repetition and re-teaching because they may need more practice to master a skill.

- Use calendars, written schedules and lists to remind your child about what is happening that day, or what they need to remember to take to school.
- Focus on practical functional maths and science. Children may also benefit from using technology to help them learn.
- It may also help to rehearse a new skill in advance (e.g. how to greet others or how to co-operate during a football game).

behaviours. You can also help your child manage their impulses in many different ways.

Managing physical activity

Allow a good balance of rest times and activity. Some children need more activity than others to manage their behaviour or more rest than others to keep from becoming overwhelmed. This all depends on your child's particular profile. As noted earlier, all children with FASD are unique. If you know that your child is better able to

AFTER SCHOOL				
				
Lunch bag	Back pack	Coat	Shoes away	Snack
AFTER SUPPER				
				
Dance class	Bike ride	Homework	Watch TV	Bed time

- Get creative to help your child learn. Instead of using numbers on paper to teach maths skills, use objects that the child can relate to, such as building blocks. Make lessons relevant to something they are experiencing in their lives.
- Praise and encouragement along the way will help your child build bridges to success.
- Work closely with your child's teachers to make sure that you know your child's learning goals. Ask teachers to modify expectations, based on the child's abilities and break down assignments into smaller tasks.
- Focus on your child's strengths.
- Slow down the pace to allow your child time to process. Author Diane Malbin has a saying about children with FASD: "They are 10-second children in a one-second world."

Impulsivity

Many children and young people with FASD have trouble controlling their impulses. This often looks like typical Attention Deficit Hyperactivity Disorder (ADHD) type behaviours (e.g. fidgeting, can't sit still, acts before thinking) and is one of the brain "functions" that can be affected by FASD. Some children and young people may benefit from medication for these ADHD-types of

control their impulses after physical activity, such as swimming or jumping on a trampoline, then this will be a strategy to help your child manage their behaviour - something you will need to program into their daily schedule. Sensory activities can help your child focus and calm themselves (see *Sensory Processing* page 27).

Children with FASD tend to need more down time than others, because their brains have to work extra hard to understand and respond to day-to-day activities. Becoming overwhelmed may lead to meltdowns if the child doesn't have any other options. It is still important to keep their down time structured. For example, after school can be scheduled time for playing outside, doing chores or watching TV. But, remember to monitor what they watch as they may model the behaviour they see on TV and misread the social information they are absorbing.

Teaching and rehearsing with your child

Teaching positive strategies can help your children prepare for situations where they might struggle. For example, when they feel hurt or judged by friends, they might lash out physically. Over time, strategies like counting to 10 when they are upset, or redirecting them to ask a question or use their words may help your child

learn impulse control. For social situations, try role playing with your child to help them practise using their words to express themselves, rather than responding to their impulses.

Social stories are a tool to help your child understand social cues and responses and practice positive responses. Carol Gray first developed social stories for children with autism. However, they are also very useful for children with FASD who need support with social skills. To find out more about creating your own social story with your child, visit:

www.carolgraysocialstories.com/social-stories/.

When you see your child or young person start to escalate because of their frustration or lack of understanding, try to redirect them to another activity or to a calming activity before the outburst occurs. This will save you both from dealing with the outburst. Over time, it may help to teach your child or young person how to recognise when they need to take a break.

Your child's environment

One of the best ways to think about strategies for children with FASD is to think about changing the child's environment, rather than changing the child's behaviour (see *Understanding FASD* page 12). Diane Malbin in her book *Trying Differently Rather Than Harder* (2002) says:

"In parenting children with FASD, it seems the harder we try to change behaviours, the worse they become. The shift in the definition of the source of the problem provides a different focus for interventions: from trying to change the child to changing elements in the environment".

Children with FASD often struggle with loud, overly-bright, over-stimulating and cluttered environments. This is because their brain has trouble filtering out outside stimuli. Consider a busy, bright shopping centre, a loud and busy birthday party or a crowded cinema. If your child often has tantrums or meltdowns in these kinds of settings, they may need help.

If your child is lashing out at their sibling while shopping at the shopping centre, understanding the impact of their environment can help you decide whether or not to take the child to the shops.



Some tips about adapting your environment to meet the needs of your child or young person include:

- Think about bringing ear plugs for your child when it is too noisy, sunglasses in the shopping centre or only staying for a short time at the busy birthday party. In some cases, these kinds of environments may need to be avoided until your child shows signs of being able to tolerate them better.
- Other ideas include using calming paint colours, such as pale blues or other pastels, removing extra items from the child's room so that it is less cluttered and keeping the volume down at home or in the car. Remember every child is unique – sometimes, the only way they can study is when the music is turned up loud. Give your child a place to calm down when needed.
- Changing the environment may not bother most people, but moving the furniture around at home, a new person coming to stay over, or having a substitute teacher at school may overwhelm your child to the point where they are unable to tolerate the change. The challenge is to identify where the poor fit is for your child with FASD and adapt the environment to create a better fit whenever possible. This may be as simple as giving the child advance notice about rearranging the furniture. It might also mean that you will want to keep your child at home on days when there is a substitute teacher.
- Making space "visually concrete" helps the child to better understand their environment (e.g. labelling the containers for toys). Try using labels for clothes or other belongings. Use visual cues as needed in the bathroom, kitchen and other rooms to help the child clean up or take care of themselves.
- Sometimes things need to be kept in a safe place, out of sight. A locked box or cupboard keeps dangerous items out of reach and takes away another source or stress for you as a parent.

“We re-built the bedroom entirely – she was climbing the walls so we built a climbing wall in the bedroom – there is a swinging chair, monkey bars off the ceiling, she can dangle, climb the walls and do what she needs to do. It takes a huge amount of time, energy and brainstorming to figure out how to implement those accommodations, but once you have gone through the effort of doing it and it works, I no longer worry.”

FASD and sleep

Sleep issues are common among children with FASD. There are many causes for this. FASD can cause permanent change to the structures of the brain that can affect sleep. Sleep is also affected by other health problems, emotional issues, social issues, sensory processing difficulties and impaired abilities to sense time and self-organise. Sleep disturbances make behavioural, emotional and cognitive difficulties worse. Poor sleep for a child can also mean poor sleep for the parent, which can also lead to stress and frustration for the whole family.

Common sleep issues for children and young people with FASD include:

- difficulties falling asleep (e.g. taking more than 20 minutes to fall asleep)
- frequent awakening during the night for minutes or even hours
- early morning awakening
- trouble getting out of bed in the morning
- tired, hyperactive or irritable during the day
- restless sleep (e.g. tossing and turning)
- sleep-walking or sleep-talking.



Sleep strategies

As many children and young people with FASD have trouble processing sensory information, it is important to create a calming environment to promote sleep.

Sleep Environment:

- If possible, a bedroom should be totally dark. Use of light-blocking window shades can help. If a child needs some light, use a night light and make sure that it is not shining towards the child's eyes.
- Be aware of sensitivities to touch. Cut tags off pyjamas and use bedding that feels soft. Know your child's material preference (e.g. flannel vs. cotton, loose-fitting versus snug).
- A quiet environment is best for sleep. Some people benefit from ear plugs, sleep machines or other white noise machines. Carpeting will also absorb sound.
- Some children and young people find alternative bedding that provides deep pressure helps with sleep, so try using oversized quilts, heavy blankets or a sleeping bag.
- Make the child's bedroom for sleeping only. Avoid TV and all electronics (e.g. video games, computers, phones) in the bedroom. For younger children, toys should be cleared and put away at bedtime.
- Keep the bedroom layout consistent and uncluttered.

Many children and young people with FASD have poor organisational skills and an impaired sense of time. Caregivers find that the following rules, structuring, routines and consistency are helpful.

Sleep Routine

- Maintain a consistent bedtime and wake-up time.
- Establish bedtime routines. Some children also benefit from the use of a visual schedule to help reinforce the structure, routine, and expectations (e.g. pictures of having a bath, brushing teeth, story time, etc.).
- Include a scheduled wind-down time for about 30 to 60 minutes before bedtime. This can help reduce the time needed to fall asleep. Calming activities can include a warm bath, stories, massage, a quiet adult/child snuggle or together time, a snack. Listening to soft music can also be calming.

Many children and young people with FASD are very sensitive to their environments, so they are easily over-stimulated.

Sleep-Promoting Activities:

- Avoid screen time (e.g. no TV, video games, etc. for an hour or two before bedtime). Studies have found screen time can make it harder to fall asleep.
- Limit activities that increase stress or excitement (e.g. watch time on homework and keep in mind that activities, such as rough play or wrestling, may cause over-stimulation).

Medication: Some children and young people can also benefit from medication. Talk to your doctor to see if this is a suitable option for you and your child.

- Avoid food (e.g. chocolate) and drinks containing caffeine (e.g. soft drinks).

Language and communication

- Make sure your child understands you. Remember that children with FASD struggle with auditory learning so, while you are busy talking, they may not be able to interpret what you are saying in a meaningful way.
- Keep your instructions short, clear and concrete. If your child is not understanding your message, use fewer words or be clearer. Try to use the same words for the same instruction every time.
- Use visual reminders whenever possible. For example, thumbs up or thumbs down signs can help to let the child know, right away, what is good or bad behaviour. Ensuring you have eye contact with your child can help them better understand your words.
- Keep your tone as calm as possible.
- Slow the pace down to allow your child more time for processing.
- Always state what you want your child to do rather than what not to do. For example, if you want your child to stop running, ask them to walk instead.

Ownership

Children and young people with FASD often have trouble understanding ownership for many reasons. Most likely, the child does not have the ability to understand an abstract concept like ownership, especially when the object is not attached to a person. For example, if a child with FASD sees a bike on the sidewalk that no one is using, the child may think it doesn't belong to anyone. The idea that somebody not in sight actually owns this bike is abstract in nature, so the child may not be able to make the connection. You may also notice that your child is very generous and shares easily with others. This is a strength that you want

to encourage. This tendency towards generosity contradicts the idea that your child is stealing. It is more likely that they just don't understand ownership.

A child or young person with FASD may have memory problems and forget who owns a particular object. They may have thought it was theirs or that someone had given it to them.

They may also have trouble understanding when something is loaned to them. In their minds, it may seem like the person gave them the item. They may not be able to understand that the item must be returned at some point. At the same time, they might be very definite about something that they do own, and this can give others the impression that their actions are voluntary as they do seem to understand ownership when things clearly belong to them.

It can be hard for parents to know what to do in these situations. Your child may be accused of stealing from others. This can create consequences that are confusing for the child and are rarely effective. There are also times when children and young people with FASD do steal intentionally, which makes this even harder to figure out. Use your best judgement about how to interpret their behaviour and how to deal with it.

Here are some tips for responding to your child's "taking" behaviour:

- When you have discovered something that doesn't belong to your child, simply and calmly say that the item needs to be returned to its owner. Watch for items that appear in your home that may not belong there.
- If your child has taken something that doesn't belong to them, make sure they return it with an apology. Avoid lecturing on the topic of stealing. The action of returning the item with an apology will be more effective than any explanation you may have about the idea of stealing.
- You can teach ownership in creative ways. Label your child's items in your home. If something doesn't have a label on it, then it is easier to explain to your children that it doesn't belong to them.
- Keep your environment de-cluttered so that other people's belongings are not lying around and available to be taken.
- Supervision and redirection of your child are the best ways to prevent opportunities for taking things that don't belong to them.



Storytelling/filling in the blanks

Many children and young people with FASD have problems with memory. Because of this, they may find it difficult to remember events in the correct order in which they happened or they may not remember what someone has asked them. Their memory problems may also cause them to confuse what really happened with things they have imagined, heard in a story, or seen on TV. This can cause children and young people with FASD to tell stories (or confabulate) to fill in the blanks in their memory.

Children and people may also tell stories if they struggle with communication skills. In this case, they may not have the ability to properly explain what has happened.

This storytelling (confabulation) often causes people to assume that children and young people with FASD are lying to them, when, in fact, the child or young person is not able to properly recall what happened. It is important for parents to learn the difference between when their child is telling a lie and when they are storytelling. The difference between lying and storytelling for a child or young person with FASD is that when they are storytelling, they are not trying to be dishonest.

Some children and people with FASD may struggle with lying if they have trouble controlling their impulses. They may tell a lie when they think it is what the person wants to hear, when they do not want to disappoint someone or if they are trying to get someone's attention. With impulsive behaviour, it might seem like a good idea to tell a lie at that moment, but they have not thought ahead to the consequences of telling the lie.

Here are some strategies to help your child or young person with storytelling and lying.

- Help your child figure out the difference between storytelling and the truth.

- Give your child positive opportunities to tell stories and then, help them practise learning the difference between reality and fantasy/fiction.
- If you suspect your child might be telling a story, ask "truth or story?" This will cue your child to stop and think before continuing to tell you what happened.

Try not to punish your child for storytelling. By providing a consequence for storytelling, the child is being punished for having short-term memory problems. Instead, praise them for having a good imagination, while also teaching them when it is appropriate or not appropriate to tell stories. Try using real-life examples to help them understand.

If your child or young person is impulsive, reduce the number of opportunities for them to lie.

- Instead of asking them if they did something, ask them to show you instead. For example, ask your child to show you that they cleaned their room instead of asking, "Did you clean your room?"
- Try to avoid asking unnecessary questions, such as "Are you sure that happened?" These types of questions may cause the child to tell you what they think you want to hear. If the child is contradicted, they may become angry or upset.

Try to avoid punishing an impulsive child with FASD for lying. Instead, try using strategies to help your child manage their impulsive behaviour (see *Impulsivity* p 34).

Getting along with others

The gap between chronological age (how old they are) and developmental age (the age of their developmental level) is important to note for all people with FASD. This gap is particularly important to consider for the social relationship challenges that children and young people with FASD often experience.

For example, imagine supervising a seven-year-old child with FASD in a playground full of other children the same age. You may have similar expectations for all of these children because they are the same age. When the child with FASD begins playing and behaving more like a three-year-old, the other children may stop playing with the child or start teasing the child. The child with FASD may become impulsive and/or invade the other children's personal boundaries. They might make rude or direct comments and upset another child. These scenarios make it easy to understand how social delays may be one of the biggest frustrations for both children with FASD and their parents.

Here are strategies and tips to help your child get along with others:

- Before arranging a play date or visit, begin to practise important social skills with your child:
- Practise how to communicate what your child wants and the appropriate answers (e.g. please, excuse me, no, thank you).
- Practise how to handle frustration, disappointment and hurt feelings (e.g. time-outs, count to ten).
- Practise how to manage someone bothering your child (e.g. walk away, speak to an adult).
- Practise appropriate body contact and personal space.
- Practise taking turns and sharing activities. For example, if your child is looking forward to playing Lego with a friend, set out two Lego stations and allow your child to choose the Lego they want to play with before the friend arrives.
- Also practise appropriate behaviour with your child through role playing (e.g. "Charlie, can we play with you?").
- Practise the behaviour with guidance (e.g. "What will you say when your friend doesn't want to share the train set?").
- Reinforce your child's success in getting along with others as often as possible



- Consider developmental age, rather than chronological age when organising and planning for peer-related activities. Your child may be younger in their social skill development than their age. For example, toddlers don't understand sharing, so parents with toddlers have multiples of popular toys so that each child can have one.
- Choose activities where your child is likely to have the least experience of making mistakes. Think about the kind of games that children of different

ages can enjoy together (e.g. playing in a swimming pool with inflatables rather than a card-trading game).

- Try to understand what is happening for your child in social situations and where your child may be feeling vulnerable and unsafe. Create a safety plan with your child (e.g. develop a plan which can be followed when your child is feeling overwhelmed by peers, sound, light, movement and the environment).
- Many children with FASD like to be active. Sports and recreational activities may be a good place to channel energy and engage in social relationships. Games without complex rules will be more successful – you might need to adapt rules (e.g. tennis – ball is in if it goes over the net, rather than looking at the lines on the court).
- Maintain ongoing communication with your child's teachers, supports, neighbours, coaches and other caregivers. Discussing your child's social considerations will help your child to be included. It will also promote inclusion and appropriate behaviours in peer relationships and activities. Working with your supports, you can structure social environments and activities so that they are successful for all of the children and parents involved.

Communication

It is common for children and young people with FASD to develop language skills at a slower rate than their peers, which can affect their ability to communicate. The ability to communicate involves several different parts of the brain working together at the same time. This can be a difficult task for children and people with FASD.

Children and people with FASD often struggle with expressive language development and receptive language development. They may have difficulty understanding what someone is saying to them. They may also have trouble telling someone what they want, feel, or need.

Expressive language is a person's ability to put thoughts into words in a way that makes sense, using proper grammar. Children and people with FASD who struggle with expressive language may use the wrong word to describe someone or something (e.g. using "he" instead of "she" or describing toast as "warm bread"). Often, they know the word but, because of how their brain works, they are not able to retrieve it from memory.

Receptive language is a person's ability to understand language that they have heard or read. Children and

people with FASD may have problems understanding language because they have difficulty processing information (e.g. hearing someone speak, trying to figure out what they mean, remembering it correctly, and then, acting on that information). Because of these difficulties, they usually need more time to process information.

Your child may lead you to believe they understand when they really don't. They may be able to repeat instructions word for word but still not understand or have the ability to follow through.

"I realised how skilled our daughter is at faking it: faking that she understands what is going on. If you go back and have a conversation with her, you find that what she says is completely skewed, how much she has learned to hide her lack of understanding."

Children and people with FASD may understand language in a literal way and may not understand abstract ideas. They may have trouble responding to an abstract request because they do not know what is being asked of them. What may appear to be disobedience may actually be their inability to put instructions into action. They tend to experience more success when they are provided with simple, concrete instructions.

Some children with FASD struggle to pronounce words properly, which can make it difficult for them to be understood. This is usually identified before a child starts school. In some cases, the child may need speech and language therapy to help the child at home and in school.

Strategies to help your child with communication skills:

- When you start to speak, always use the child's name and make eye contact to help ensure that they are listening.
- Use simple, concrete language when giving instructions.
- Give instructions one step at a time and repeat instructions as needed.
- Use the same key words or phrases for tasks. This helps to place the instructions in the child's long-term memory.
- To help ensure that a child has understood verbal instructions, ask the child to show you what needs to be done, instead of just repeating the instructions.

- Use visual cues to help your child understand verbal instructions.
- Record stories so children can listen and read along.
- If your child or young person is unable to put their thoughts in the right order, ask some more questions to help figure out what the child is trying to say.
- When you and your child attend meetings with several service providers, make sure that everyone allows time for your child to process what is being discussed.
- Keep meetings with service providers to a reasonable length. When meetings are too long, children with FASD can get tired or overwhelmed when trying to keep up with the conversation.

"My son is very literal. One time after him being out of sorts and down for days I finally asked him what was wrong. He responded that he was worried that I was going to die. He said "I heard you talking on the phone to auntie and you said you nearly died laughing."

Within the Community

Being out in the community is not always easy when other people don't understand your child. People you encounter may say hurtful things about your child. Remember that these thoughts belong to someone who doesn't understand that your child has a different way of thinking and feeling. If you want, you can help them see things differently. However, be sensitive to whether this is appropriate to say when your child is present. Try saying things like:

"My child has FASD."

"S/he has developmental delays."

"S/he has special needs."

"His/her brain is wired differently to yours."

You may want to give them more information in the form of a flyer, card or booklet. NOFASD has cards available and these can be ordered at our website.

Sex Education and FASD

Because of the discrepancy between developmental age and social/emotional age, puberty can be a difficult time for children with FASD and their family. Children with FASD of all ages may exhibit inappropriate sexual behaviours if they have difficulties with impulsivity, social communication and in knowing what is appropriate behaviour, and being able to generalise from one situation to another.

A useful Australian resource is "Talk Soon Talk Often" which can be found at:

<https://talksoontalkoften.wordpress.com>. It contains some useful general tips such as talking to children early, before they are reluctant to discuss sex; not waiting for children to ask before you talk to them about sexual matters; talking often and repeating subjects many times, and practicing being comfortable using correct words for body parts so that you can talk comfortably with your children.

Your child may need explanation as for a younger child, using concrete, literal explanations of concepts around sex, relationships and appropriate behaviour. It may help to use social stories to talk about appropriate touching and about personal safety. Supervision will also be crucial if a child is showing sexually inappropriate behaviour, as the child may appear to take in what you are saying, but may not be able to change their behaviour "in the moment".

NOFASD's website has a link to a presentation titled: *FASD and Sexual Development* with resources for parents, carers and educators. It includes tools and strategies to support children and young people, and strategies for responding to inappropriate sexual behaviour:

<https://www.fasdwaterlooregion.ca/assets/images/genera/FASD-Sexuality-Carizon.pdf>

The Healthy Bodies Toolkit is a US Resource including a parent's guide to talking about puberty with children and young people with disabilities. You can find it at:

<https://vkc.vumc.org/healthybodies/>

Supporting a Young Person with FASD

The transition from childhood to adulthood can present some unique challenges for both the caregiver and the young person. All young people want independence and freedom to make decisions. As a caregiver of a young person with FASD, you may need to find ways to safely respect these wishes in tune with their strengths and challenges. In this section, we will discuss some of the challenges you may have and strategies to help navigate through these years.

Understanding and minimising secondary effects

Secondary impacts are those problems that arise later in life, often during the teenage years, but sometimes earlier. Secondary impacts are sometimes due to a poor fit between the person's needs, level of functioning and the environment. However, sometimes secondary impacts are directly linked to the brain-based disability. Secondary impacts may be concerning, but the good news is that in many cases they can be minimised. As a parent, you can do several things to help your child/young person reduce the risk of negative experiences. Streissguth and Kanter in their book, *The Challenge of Fetal Alcohol Syndrome: Overcoming Secondary Disabilities* (2002) describe some common secondary impacts or secondary disabilities for people with FASD as:

- school disruption
- mental health concerns
- addictions
- poor self-esteem

- self-harming
- high risk sexual behaviours
- being involved with the justice system.

It is important to note there may be other reasons your young person is struggling with these issues. The impact of trauma, poor attachment, genetic factors, and other conditions may be other factors to consider.

Education and schools

School can be challenging for any young person. There are often higher expectations on students and less support available to them when leaving primary school for secondary school. People with a FASD diagnosis may not want to ask for extra help because they don't want to appear different from their peers. Without help, they may end up feeling frustrated and fall behind in their schoolwork. This, along with other challenges, can lead to school disruption. Following is a list of ideas that can help you work with the school system to ensure your young person gets proper support:

- Share the diagnosis and information about the primary disability with teachers and support staff.
- Communicate your young person's strengths and challenges.
- Ensure that the school is aware of other service providers/supports in your young person's life.
- Provide additional resources (see Resources p. 65)
- Advocate for your young person as you know them best (See Advocacy p. 51).



Nature Girl by Jacob (16) who has FASD.

- Do your best to form a relationship with your teen's teacher and support staff to help ensure their individual learning needs are met and their strengths are developed.
- Recognise that transition times may be especially sensitive and difficult, such as moving from primary to secondary school, from school holidays to first day of classes and starting with a new teacher or support staff.

Sexuality and relationships

Like any other young people, individuals with FASD have the same need to explore their sexuality and engage in sexual behaviour and relationships. Lack of maturity can impact on their ability to keep themselves safe and they may need more support than others to navigate sexual behaviour and intimate relationships.

Many young persons with FASD have a strong desire to please others, which can make them vulnerable to peer pressure and sometimes, place them at risk. Young persons can be sexually curious and may misinterpret social cues such as a smile to mean someone is interested in them romantically.

- Talk to your child/young person about boundaries, relationships and personal space.
- Openly discuss sexuality, sexual health, birth control and safe sex.
- Consider the primary disability when thinking about birth control options for females. For example, if your young person struggles with memory, a birth control pill that needs to be taken daily may not be the best option. Discuss the options further with your medical professional.
- Help your child/young person attend medical appointments about their sexual health.
- Seek out specialist sex educators through organisations such as Family Planning who have expertise in communicating with young people with developmental differences.
- Even though your young person may have a desire for independence, supervision and support is crucial to help them handle social situations, such as not recognising a potentially dangerous situation or befriending a stranger.
- Be mindful of your child/young person's internet usage and learn more about how to safeguard against online predators.
- Like any other young person, your child may identify as same sex attracted, non-binary or transgender. If these issues arise it will be important that you seek

some support to educate yourself so you can respond effectively. You may feel that your child has enough on their plate – but it's important to accept and support your child in the way they want to express themselves.


- Young people who identify as LGBTQIA+ are at greater risk of mental health issues, so your unconditional acceptance is crucial to reduce the risk of anxiety or depression. Minus18 is an organisation that can support you and your child.

A parent blog on Gender identity, FASD and parenting in uncharted waters can be found here: <https://fasdlearningwithhope.wordpress.com/2018/07/16/gender-identity/>

Supporting the transition to adulthood

Transition planning is an important step to help the adjustment to the next phase of your child's life. Your young person may have a strong desire to live independently because they hear their peers talk about moving out of their family homes. Parents should consider several things when planning for a young person's transition into adulthood.

- Start planning well before they turn 18. Keep in mind that although 18 is often used as a benchmark for adulthood, you as a parent, must assess your teen's developmental age, as they may be developmentally much younger. When it is appropriate, there are steps you can take to prepare them for this transition period.
- Ensure that your young person has been reassessed in relation to their areas of capacity and impairment. A recent assessment will be important to ensure eligibility for NDIS funding, if possible.
- If your child has a cognitive impairment, you may wish to consider seeking Adult Guardianship for them, for example, in relation to financial management.
- Find out what your young person's hopes and dreams are for the future.
- If your young person has a support system in place at school or through other services, include them in the transition planning. Help your young person gain more understanding and acceptance of the type of support they may need in adulthood.
- Consider whether your young person would benefit from living at home as an adult or if they need supported living. If your young person is able to live independently, remember they may need extra support to be financially independent. Be creative in



coming up with ideas to help them with budgeting, so they can be successful in paying rent and fulfilling other basic needs (e.g. direct payment for rent, utilities and other monthly bills).

- Keep in mind that your young person may be very generous with his or her money, which leaves them vulnerable to financial victimisation. Budgeting support may be needed to avoid this.
- When your young person is looking for work, help them build on their strengths and abilities. Remember that a busy, high-paced work environment may not be a good fit. You may want to consider supervised work-placement options. Encourage your young person to discuss their strengths and challenges with their employer, as well as ways to increase success in the workplace.

Finding Support

Caregiving can be incredibly rewarding, but it can also cause emotional and physical stress. As a caregiver, you might be so focused on the person you're caring for that you don't even realise that your own health and well-being are suffering. It is important to know and watch for signs of caregiver stress.

Caring for someone living with FASD is very challenging. Understanding your own feelings and caring for yourself will help you to be able to take care of your child, particularly if your child requires considerable attention or supervision that leaves you drained and frustrated. NOFASD has developed a first aid kit for carers and a series of webinars by FASD specialist Eileen Devine. You can find them on the website under the heading "[Caring for You](#)".

If you feel overwhelmed, please don't feel you are alone – we're here to help you with practical support and advice. Just call us on 1800 860 613 (free call) or email enquiries@nofasd.org.au. The Australian Government website www.carergateway.gov.au has some great tips about caring for yourself. It also includes links to get practical support including financial assistance and respite care. You can call the **Carer Gateway** for support and advice **1800 422 737** (free call).

Family, friends and the community

People around your child with FASD are very important assets, often providing the supervision and structure that they need to function on a daily basis. Support people can guide your child on outings, at family events or at school. Whenever possible, think about ways to expand and nurture the supports surrounding your child, including grandparents, relatives, neighbours, family friends and support workers. This circle of support can make a huge difference in your life and in the life of your child. It may be hard to ask for help, but most people are willing to help when they know they are needed.

You can help them understand your child by doing the following:

- Give your support network basic information on FASD. Don't bombard them with information. Instead, give a quick summary, say you can talk more about the diagnosis or offer some reading material if they want. You can also say you are trying to learn more about FASD at this time. It might sound like this:

"My child has been diagnosed with FASD. It is a brain-based disorder that sometimes makes it hard for people to think and act in expected ways. It is caused by prenatal exposure to alcohol and the effects last a lifetime. There's more information in this guide/website, and I'm learning more about it as I go."

- Be open to share your fears and concerns, as well as theirs. They love your child and you!
- Give them time to absorb the information.
- Tell them what your child needs. You are the best guide for the kind of accommodations and support you and your child need.
- Teach them how to guide your child in the best way and explain that guidance is needed. Lead them by reframing actions (e.g. saying "the child can't", instead of "the child won't") in terms of brain function.

Support from other parents and carers of children with FASD

No-one understands what it's like to be the parent of a child with FASD like other parents of children with FASD. You can find communities of other parents through NOFASD and in the **Resources** section of this manual.

A wise quote comes from a carer Eileen Devine who said "When we're talking with others who have the same lived experience as we do, but there is no discussion about positive actions that can be taken to shift the tide of our emotional state, it can enhance and exacerbate our own feelings of burnout, instead of helping to alleviate them. Choose your support wisely." Read more of Eileen Devine's blog – eileendevine.com.

"People who have children with FASD are exhausted. Sometimes we are scared to say that we are tired. But it's ok."

Parenting can be hard work. Parenting through FASD behaviours can be extremely hard work. The hard work goes on and on, because it takes a long time to raise a child. Parents also continually deal with intense emotions, such as frustration, disappointment, and sadness, as they try to help their children manage the extra challenges FASD causes. Deliberately making time to take care of yourself will help you avoid the emotional fatigue that can take a toll on you and interfere with loving parenting. Being the best parents you can, for the

children you love so much, requires a focused effort on your own self-care.

- Be the strongest version of yourself. Look after your own physical needs – enough sleep, eat well, exercise. Nurture your spirituality. Invest in the relationships that give you emotional support. Remember the interests and passions you had before parenting a child with FASD and spend time enjoying them again (e.g. sports, music, art, etc.).
- Know yourself and your responses. Notice your strengths and resources and lean on these. Notice your limitations and find help in these areas. Be aware of your triggers and how to avoid them.
- Stay informed about FASD. Continue learning. Read research, go to workshops, join committees and connect with others who understand.
- Make use of respite and resources for your children. Learn what is possible and use help, both from organisations and from personal supports.

Self-care

- Be an active part of your community. Families affected by FASD risk isolation because of behavioural challenges. Embrace your community and enjoy the support it offers.
- Accept the challenges of FASD and adjust your expectations, both for your children and yourself. Don't worry about the little things. Know that there will be rough moments and decide to rebound from these even stronger. Have a long-term perspective, knowing it will be better tomorrow. Allow for mistakes from yourself and your children – and forgive.
- Try using "the positive game" – one carer wrote: "It's all about finding the positive in the FASD moment...for example; when our daughter locks

herself in the car in opposition to bedtime... we find the positive that at least she is sitting in the backseat, not in the driver seat cranking on the levers like the last time when it cost us \$300... It is a good time and it reminds us that there is always an upside, provides for a little humour, controls the stress levels, builds our marital relationship and gives us time to process and figure out an appropriate strategy while at the same time giving her time to process the situation as well."

Grief and loss

Many parents experience feelings of grief, loss and guilt along their journey with the child with FASD. These feelings are normal and natural. The feeling of loss for what "could have been" for the child can be overwhelming if it is your only focus. Hopes and goals can be adjusted to your child's strengths. Building on the possibilities can help to shift the focus from negative to a more positive, productive path.

The feeling of guilt for the effects of alcohol on the child can also be difficult for parents. No parent sets out to cause harm to their children. People consume alcohol for many different reasons and to various degrees. Because it is unknown how much alcohol produces what effects, no alcohol is the best practice when pregnant. Often, mothers are unaware that they are pregnant until several weeks after conception and have, unknowingly, exposed their unborn child to alcohol. Some have addiction issues. Whatever the reasons have been for the exposure, intentional harm was not what the mother had set out to do. It is important to recognise these feelings, seek appropriate support and help to understand your own feelings about this. You need to be well, physically and emotionally, so you can be the best parent possible for your child.

"The biggest struggle I have had is reconciling the discrepancies between the child you want to have and the child you have and learning to love and embrace the child that you have."

FASD Diagnosis and Assessment

If you suspect your child has FASD but hasn't yet been diagnosed, it's best to get advice and support early. Children with FASD can be very different from each other. In very young children, it can be hard to detect the early signs unless the child has very obvious physical indicators and one or more developmental delays. Some of these issues might not be noticed, or might not be a problem until they start pre-school or school.

It is important to consider having your child assessed for FASD if:

- there is a history of prenatal alcohol exposure during the pregnancy, and:
- there are concerns for your child's growth or development, or
- there are concerns for your child's learning or behaviour, or
- your child has facial or physical features which a doctor thinks might be consistent with FASD.

Australian diagnostic criteria

Australian Guidelines state that a FASD diagnosis can be made where:

- There is a history of confirmed alcohol exposure during pregnancy, and
- The child has significant impairments in 3 or more different areas of brain function.
- In addition, the child may have 1, 2 or 3 of the distinctive facial features, or may have no features.
- Sometimes other neurological or physical features may also be identified.

An individual may be diagnosed with either:

- FASD with 3 sentinel facial features, or
- FASD with less than 3 sentinel facial features.

In the past, the term "FASD" was considered an umbrella term for a range of conditions like Fetal Alcohol Syndrome. FASD has now replaced these other conditions and is the formal diagnostic term used in Australia.

These brain domains are typically assessed by a multi-disciplinary team, including a paediatrician, neuropsychologist, speech pathologist and occupational therapist (see 10 Domains of Brain Function on p 10).

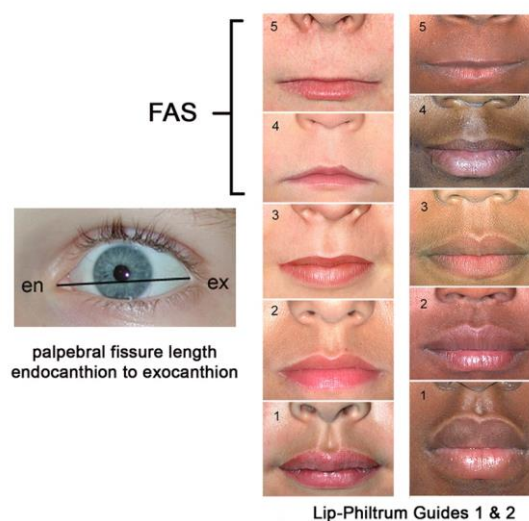
Facial features

There are 3 facial features that, when they occur together, are thought to be unique to FASD:

- small eye openings
- a smooth philtrum – the ridge between the nose and the top lip
- a thin upper lip.

The child's face is assessed by a paediatrician trained in FASD diagnosis. Paediatricians also look for other physical differences involving the ears, hands, fingers or toes, ears, eyes, spine, kidneys or heart.

A child with FASD may have 0, 1, 2 or 3 facial features. They are not required for a diagnosis.



Lip-Philtrum Guides 1 & 2



Reproduced with permission Dr Susan Astley, University of Washington.

Growth and sensory issues

- Under the current guidelines, poor growth is not a criteria. Paediatricians will still assess growth.

- Sensory issues are not included in the 10 brain domains assessed for diagnosis, but a sensory profile can be a helpful part of an assessment.

Getting a diagnosis

The [Australian FASD Hub](#) has a list of Australian clinics and professionals who can help with diagnosis. FASD diagnostic clinics are available in some parts of Australia and each has its own criteria and waiting times.

NOFASD Australia also maintains a current list of FASD informed professionals and service providers. Phone 1800 860 613 (free call) or enquiries@nofasd.org.au.

If there is no clinic in your area, you may be able to access a diagnosis through your paediatrician or other specialist who is familiar with the Australian Guidelines. If you are an adult seeking diagnosis, you may need to see a Geneticist or Neurologist. Your specialist can make referrals for a range of assessments including speech and language, occupational therapy, psychology and neuropsychology and can review the results to see whether the individual meets the criteria for FASD. There may be a cost for these assessments; some may be NDIS funded.

Your observations are important for the assessment, diagnosis and planning process. The NOFASD website has a simple tool - [FASD – A Checklist](#), to help get you started. We suggest you complete it and take it to your GP or Paediatrician. (For an overview of FASD indicators see *FASD Across the Lifespan* on p 13).

A diagnosis of FASD can only be made where there is evidence of prenatal alcohol exposure. Birth parents can provide this information, but if someone else is caring for the child, the information may come from:

- Family members or others who had first-hand knowledge of alcohol consumption during pregnancy
- Professional agencies such as Child Protection, medical or legal records.

If the birth mother can't remember, or reports she didn't use alcohol during the pregnancy, but there is other evidence of prenatal exposure, this may be enough for a FASD diagnosis to be made.

If the child is in your care and you are not the legal guardian, you will need the child's guardian to agree to the FASD assessment and for the clinic to access records relating to the pregnancy. If you are the child's legal guardian, you may need to request records from child protection or other services under Freedom of Information on their behalf.

Should you experience any difficulties accessing diagnosis please call NOFASD Australia. Phone 1800 860 613 (free call) or email enquiries@nofasd.org.au



The [FASD Hub](#) has more information about diagnosis including:

- What to expect
- What documents to take to the assessment
- What is involved and what happens next?
- What forms are provided by doctors and professionals to understand referral and screening criteria for FASD
- A video presentation from Professor Elizabeth Elliott from Australia on the diagnostic process - [The Story of Alcohol Use in Pregnancy](#).

After a diagnosis

The Australian Guide includes [Information for individuals and Caregivers after a FASD Diagnosis](#), which explains:

- The doctor will share and discuss with you the results of the medical and other assessments, including whether your child meets criteria for FASD, and/or other conditions.
- You should ask any questions you have and ask for a copy of the assessment findings. These may be in the form of a letter or a report and the doctor may be able to provide this to you at the appointment or if not, post it to you after the appointment. Ask how long it might be before you can expect a letter or a copy of the report.
- You can discuss with the doctor or another member of the team any specific goals you have for your family member and for the family as a whole. This is part of developing a management plan for the person with FASD.
- Depending on the person's specific needs, the doctor or another team member may make a referral to other health professionals for therapy. For example, to an occupational therapist, speech therapist or a psychologist.
- Ask about where to go for any therapy or other services and if there are any costs and waiting times to access these services. You may also want to ask about any private therapy services that are available locally and how much these are likely to cost.

- In the case of a child who is going to school, part of the child's ongoing therapy goals may involve the school. The doctor or another team member may be able to approach the school about this and provide the school with the report or a copy of the child's management plan.

Diagnosis FAQs

Is there an ideal age to be diagnosed? I know early diagnosis is important, but my doctor has said I should wait till my child is older.

FASD can be diagnosed at any age, but it can be more challenging to assess in younger children. If a young child has some but not all of the features of FASD they may be considered "at risk of FASD" and would require further assessments after age 6, or when their abilities have had more time to develop.

The diagnosis didn't cover all the 10 brain domains – do I need to get more testing?

Some domains may not have been tested because your child doesn't show delays in those areas, or because some skills have to be learned before they can be tested – such as academic skills. What's important is that you have enough information to support your child. If an area was missed that you think is important, talk to the diagnostic team.

My child didn't meet criteria but has been recommended for re-assessment in a few years. Does this mean they might have FASD?

If a child hasn't met the criteria in 3 domains of brain function, this might be because they were too young for

all the domains to be tested, or their scores may be borderline. If a child has moderate delays in some areas, they may need to be re-tested when older as the gap between them and their peers may increase over time, as expectations of them increase, for example, in executive functioning or academic work.

My doctor has ruled out FASD. Is this possible?

FASD is a condition that can't be ruled out just by assessing one or two areas of a child's development. In the past, some medical practitioners have said that a child doesn't have FASD because they don't have facial features – this is not correct under current guidelines. Unless a comprehensive assessment has occurred using the Australian Guide to Diagnosis, FASD shouldn't be excluded.

Making sense of a diagnosis

Once you have a diagnostic report, it is important that you really understand what it is saying about your child's particular strengths and challenges. It might be helpful to summarise these in a document you can share with your child's teachers and professionals. There is an example on the NOFASD Website <https://www.nofasd.org.au/parents-carers-and-families/resources/>.

Your knowledge of your child's specific strengths and difficulties will help you work out which of the strategies suggested for children with FASD might work better than others.

Getting Professional Support

FASD is still being recognised in Australia, which means that many professionals haven't had the benefit of specific training in FASD-informed supports. There are some FASD-informed evidence-based interventions which have been shown to have benefits for particular groups. These include specific programs to improve maths knowledge, improve peer interactions, improve behaviour regulation and parent effectiveness, reduce caregiver stress or improve skills in other areas such as language. A list of those therapies can be found on the NOFASD website under: [Evidence based interventions](#).

One of the difficulties in looking at evidence-based models overseas is that identical programs are rarely available in Australia. There are, however, many strategies that service providers and parents have found work well with children/adults living with FASD. Access to services will depend on where you live, whether you have funding (e.g. under NDIS) and your child's age. Some supports are only available to permanent Australian residents.

A multidisciplinary approach

It's important that your child receives coordinated services. You might be able to access a clinic where these professionals come together and meet to make a plan for your child. If not, you might need to be the one to bring them together so that everyone is on the same page.

[FASD Hub Australia](#) has a service directory with a listing of health professionals who have FASD experience and expertise.

NOFASD Australia maintains a current list of FASD informed professionals and service providers. Phone 1800 860 613 (free call) or enquiries@nofasd.org.au

Paediatric/GP care

Children with FASD usually require ongoing paediatric care and monitoring, which may be through a specialist developmental paediatrician, or through a GP. Adults with FASD benefit from the support of Physician or GP who is FASD informed and can take a holistic approach to their care. Paediatricians and medical practitioners can provide support in relation to:

- **Treatment of symptoms:** some children will benefit from medication to address specific symptoms; for example, attention, mood disorders or sleep. Not all children with FASD will have typical reactions to medication, so it is important to

regularly review these and discuss any issues with your child's doctor.

- **Advice and support:** carers often need to manage their child's dietary issues, sleep disturbances, toileting, and other issues which may benefit from specialist referral, for example to a continence clinic.
- **Other health conditions:** some children with FASD require monitoring of other medical issues, for example heart or joint problems. Children may have vitamin deficiencies which require management. Children with FASD often experience symptoms such as joint pain and it is important to have a doctor who understands the range of symptoms associated with prenatal alcohol exposure.
- **Access to funding:** your paediatrician or GP will be an important person to help you access funding, for example NDIS funding. Additionally, your child may be eligible for funding under a Mental Health Care Plan or a Chronic Disease Management plan. Each of these has specific requirements and you would need to discuss these with your child's doctor.

Allied Health services

There are many types of practical services that might help your child living with FASD. These can include occupational therapy, speech therapy and physiotherapy. Every child with FASD is different so if your child has a diagnosis, the health professional you consulted will help you work out which of these services may be necessary to best meet the needs of your child.

- **Occupational therapists** support children and young people to develop their fine and gross motor skills, cognitive skills, social skills and independent living skills in order to increase success in their daily lives. They can also provide strategies that can help with sensory processing issues.
- **Speech therapists** can support children with their speech development, receptive and expressive language development and visual resources and communication programs for children who are non-verbal or developing language. Speech therapists also run social skills groups for children.
- **Physiotherapists** can provide treatment designed to enable children to achieve their own level of functional motor skills like sitting or standing. Toys, games and specialised equipment are used to encourage the development of the child's motor skills, in conjunction with specific handling skills. The physiotherapy program becomes part of the child's activities during the day, as parents are shown the

best way to assist their child during day-to-day care and play.

Psychological and behavioural supports

Many families struggle with behavioural challenges. In the above section we talk about strategies for parents and carers, with a focus on making environmental changes to better support the child and reduce challenging behaviours. When behaviours reflect an underlying brain impairment, we may not be able to change the behaviour, but we might be able to reduce how often it happens or how difficult it is to manage.

There may be times when you need the support of a professional to help you in managing your child or young person's behaviours, and to implement strategies in the home or at school, particularly if your child is hurting themselves or others. These supports might include:

- **Social workers** – can support families in developing and implementing parenting strategies, provide counselling, education, advocacy and support access to other specialised services.
- **Positive Behaviour Support Workers** – funded under NDIS, positive behaviour support workers can support children, young people, and families to develop strategies to manage complex behaviours
- **Behavioural Psychologists** – provide support to families to reduce the impact of challenging behaviours.

There has been limited training in Australia for professionals in relation to FASD, so there is not a large number of skilled professionals, or FASD-specific services for families. When families need support in caring for a child with FASD, they may need to use services that were developed for children and young people with other developmental disabilities, such as Intellectual Disabilities, Autism Spectrum Disorder, or Acquired Brain Injury. Some of these children and young people have similar challenges, but there are also differences, and if professionals are willing to educate themselves about FASD and, importantly, your child's specific needs, you may be able to access helpful supports.

Some professionals may give you advice or suggestions based on typical behavioural strategies; for example, using rewards charts or praising positive behaviour. Traditional behavioural strategies are not a good fit if your child or young person struggles to:

- Learn from experience

- Change their behaviour as a result of positive or negative consequences
- Make different choices next time.

This can lead to frustration and a feeling that services are unhelpful.

"Positive" Behavioural support for children and young people with FASD might be better described as recognising when behaviour is involuntary, and promoting positive behaviours through clear instructions, reminders, repetition, prompting, role modelling and mentoring, with a focus on building self-esteem. Positive behaviour support recognises that changes need to be made in the child's environment to reduce unwanted behaviours, and that when these stressors are removed, the child will have the opportunity to be their best. Positive behaviour requires the child to experience warm, positive relationships with people who appreciate their strengths, keep them safe and recognise when they "can't" do something.

Trauma-informed care

Many children and young people with FASD have also had traumatic experiences such as:

- experiencing abuse or neglect
- being separated from their primary carer
- being exposed to violence or parents' mental health or substance use
- multiple placements.

Children need their carers to understand the impact of trauma in their lives. One of the challenges is that some of the indicators of trauma often overlap with the indicators of FASD. Sometimes your child or young person's behaviours may have been seen as due to trauma, but might be understood differently after a diagnosis of FASD. It can be helpful to understand the difference between trauma informed and FASD informed care so you can work out what your child needs. For more information about trauma-informed care for children visit <https://www.oohctoolbox.org.au/trauma>

Many trauma informed strategies can be very supportive for children with FASD – they promote safety, emotional connection and relationships over consequences or discipline. However, when considering any behavioural or trauma informed strategy consider:

- Does the strategy expect the child to learn skills (e.g. self-regulation, communication) in areas of the brain where they have impairments?
- Does the strategy expect the child to take responsibility for changing their behaviour?

- Does the strategy accommodate the fact that the child may not be able to control impulses or regulate their emotions?
- Does the strategy expect the child to learn from past experience and apply learnings to new situations?

If your answer is yes, you will need to think realistically about whether the strategy accommodates the child's impairments or expects them to overcome these challenges. The effectiveness of behavioural supports will depend on the professional's willingness to educate themselves about FASD and work in partnership with you and your family.

There are several behavioural consultants who specialise in FASD and who have produced online training resources. **Dan Dubovsky** is a behavioural consultant who has many YouTube videos on different aspects of behavioural management and FASD. You can follow his YouTube channel – POPFASD.



Dan Dubovsky - Comparing ODD, ADHD, and FASD

11,445 views • Oct 16, 2015

81 2 SHARE SAVE ...



SUBSCRIBE

Counselling and therapy

If counselling or therapy is something you are considering, or something that has been recommended, it will be important for you to understand the kind of approach a therapist is taking. Children with language difficulties might require a play therapy approach. Older children may benefit from talking to a counsellor, but if the child has memory or attention problems, or executive function difficulties, their ability to make changes between sessions, implement goals or remember strategies might be impaired.

Therapeutic approaches that might be helpful for children with FASD include those that:

- Accept that not all approaches may be effective with FASD
- Provide space for children to express emotions including non-verbally
- Don't require strong language skills
- Don't rely too much on intact memory
- Teach and re-teach skills, accepting that the child will require many repetitions
- Support parents with concrete, simple strategies in the home
- Teach parents skills to support the child, including managing emotions (self-regulation).

More information about FASD and Therapy is available on the NOFASD website.

Advocating for your Child or Young Person

You may need to advocate for your child or young person for needed services or other opportunities. There will be times when they will be misunderstood and they will not have the right words. When you are educating others and speaking up on your child's behalf, you are acting as your child's advocate. You are taking on the role of "interpreter," so everyone has the same information.

Communicating your child's requirements to educators, medical professionals, lawyers, and other professionals can be a daunting task, as they may have heard of FASD before, but do not truly understand what having FASD means. Some health professionals may feel you are "looking for" a diagnosis that they are reluctant to give. What doctors may see as seeking a diagnosis, parents experience as being an advocate for their child.

Remember to believe in yourself for you are the most important advocate your child can have, after all, who knows your child better than you do and who holds your child's problems closest to their heart? Being an advocate means representing your child and speaking up when your child can't. It's a demanding role but also a fulfilling one.

Although FASD awareness is slowly growing in Australia and resources are becoming more readily available, knowing about FASD is not the same as understanding FASD. Talk with your child's teachers and other professionals and find out if they are FASD-aware. It is important to try your best to develop a relationship with the professionals in your child's life, however if you think the professionals are not helping your child, do not be afraid to get a second opinion.

Below are a few ideas about how to become the best advocate for your child or young person:

- Know the facts: teach yourself, and adults around you, that FASD is a brain-based physical condition with behavioural symptoms. Invisible physical changes in the brain can affect behaviour. This may mean trying different approaches to managing behaviour.
- Understanding FASD can help you explain your child's challenges. In many situations, you are going to be the expert on your child. Don't assume everyone knows as much as you.
- Keep a file with all the information you have collected over the years including assessment

reports, personal notes and journals. This information is part of the big picture for your child and can help demonstrate your case.

- Take notes of phone calls and in meetings. Go into meetings armed with facts. Request to bring someone with you for support.
- Be specific about your concerns. What are you worried about? Having enough supervision? Having enough support? Or are you worried that others aren't seeing your child's talents along with his/her challenges?
- Avoid getting into arguments when meeting with others. Think solutions and team-work. Remind them the goal is to help your child reach his/her full potential and each person has an important part to play.
- It's okay to get angry, but vent your emotions with a trusted friend or family member instead of the professionals you are meeting with.
- Be ready to propose possible solutions. Give examples about what has worked in the past, or what you think might make a difference. It may be a good start to finding a great solution! Make requests in writing to make it easier to remember and respond.
- Instead of saying "I want..." say "My child needs..."
- Finding the right system or agency to help is part of the challenge so don't be discouraged if it takes a few tries to find the right people to help. Keep trying!
- Share information – recognise that FASD is a relatively new disability and it takes time for someone to understand your child. Keep lines of communication open. Listen and be visible.
- Use various ways to share information about FASD. Talk about it, provide handouts/booklets or refer them to online videos. Give them a copy of this guide or others in this series.
- A FASD information sheet that explains your child's disability can be very helpful. A sample version can be found on the NOFASD website under [Resources](#). You may want to add information such as the following:
 - "My child learns best when you use..."
 - "My child does not react well to..."
 - "When s/he is uncomfortable, s/he can..."
 - "When s/he is uncomfortable, you can try to..."

Success is more likely when all adults around your child are aware of your goals and strategies.

- Join support groups. Not only are other parents a source of strength, but together, you can find solutions, promote learning and increase awareness. Many disabilities have common challenges, so don't stick to just FASD groups. If your child has other disorders (e.g. ADHD), feel free to join those groups too. Facebook groups and Podcasts are good places to start.
- Find additional secondary advocates, if you can. There may be professionals on your team who can help you advocate for your child.
- Teach your child to advocate on their own behalf – help your child understand what is in the information sheet/cards and role-play how the child might explain FASD to others.
- Give yourself credit for doing all you can. Advocacy may be outside your comfort zone, but it will be worth it when you get the support you need.

The Raising Children Network has a helpful video [“Being an advocate for your child with disability: parent tips”](#). Parents talk about finding information, and planning and coordinating treatments for their child. Visit www.raisingchildren.net.au

Working with child protection and foster care services

When working with agencies such as child protection, foster care or adoption/permanent care agencies, your relationship with the agency can help you get the right supports.

- Treat your worker as a colleague. You both want the best for your child and your job may be to help your worker understand what you and your child need and why.
- Seek permission for assessments and provide reports back to the agency. Don't assume that the worker will have read every diagnostic report at the level of detail you have. Keep communication open – let them know the good as well as the bad.
- If a professional recommends something for your child (assessment, aids, therapies) make sure you get this in writing and ask them to get in contact with the agency themselves if possible, to explain why it's important and what the impact will be if it doesn't happen.
- Be aware that the professionals you work with may be overwhelmed by their workloads and by the issues they are dealing with. A new case worker

might not have had time to read your child's entire file – make it easier for them by summarising and be ready to repeat yourself.

- It's frustrating when your child is on their fourth – or fourteenth – case worker. Focus on building relationships with workers and don't let your frustrations spill over. You need the worker to trust your judgement and be willing to go into bat for you and your child.
- There will always be cancellations and rescheduling when child protection workers have high caseloads. However when you really need an urgent response, or are not safe, make sure you communicate this. Let the worker know you understand their priorities but this is an emergency and ask who else can help.
- It helps to acknowledge professionals when they do something to help. If your worker has obtained funding for some of your child's needs but not everything, it may not be within their control.
- Be solution focussed. If you are overwhelmed, chances are your worker is too. Try and think what you need to help you in the situation. If it's advice, be prepared to listen. If it's funding, be aware that there may be guidelines. If it's respite, make your request clear. Be willing to be creative and to compromise.
- If you disagree with a decision, ask about the process for appealing a decision. There will be a way for you to have any decision reviewed. Manage things up when needed. If you need help, talk to your foster care agency or an agency supporting carers in your state or territory.
- If you have a complaint about your worker, raise it appropriately through official channels. Try to keep complaints factual and clear, rather than personal.

Advocating for your child at school

If your child is attending pre-school or school, it is important to make an appointment to meet with their teacher. Depending on the age of your child and previous school experiences, you have valuable information that educators require to formulate appropriate programming and behavioural strategies that will ensure your child's progress both academically and socially.

NOFASD has an Introduction to Teachers booklet online you can download and complete with your child's information to provide to their school. It is available at <https://www.nofasd.org.au/parents-carers-and-families/resources/>.

There are a number of helpful resources for educators in relation to FASD (see *Resources* p67). You might like to print one out and provide it to the school when you tell their school about the diagnosis.

Your child may be eligible for school support. Government, independent and Catholic schools all have support and funding for children with disability. The type of education or school support your child can get depends on the school and the state or territory you live in. You can find more information at www.raisingchildren.net.au – [School support: Children with disability](#).

Unfortunately, many teachers do not have a good understanding of FASD and often misinterpret the symptoms of FASD as intentional or as poor behaviour. You are likely to have to work closely with the school to help them understand your child and what they need to succeed. Having supportive professionals in your team to support your engagement with the school, such as a psychologist, OT or speech therapist will be important.

Home schooling

Educating a child with FASD has many obstacles, many which often cannot be accommodated in the mainstream school environment. Before beginning their educational journey, children with FASD are already struggling with processing information, interpreting body language of others, following instructions and many other skills are not developing in the same way as their peers. Fitting in at school can be a challenge and school refusal or challenging behaviour may be the result.

Home-schooling, or home education, can be a viable option for some families. While it does require commitment and has challenges, for those caring for a child with FASD who is struggling in a mainstream school environment, it may be an opportunity to provide learning opportunities for their child in a quiet, calm, home environment, with a learning plan tailored to the child's specific needs. Some families find home schooling significantly reduces the anxiety and distress that can accompany school attendance and can lead to better outcomes for their child.

Each state and territory has its own rules regarding the requirements both to register and the ongoing commitments for home-schooling - see the list of contacts in *Resources* (p67)

Education department disability policies

If you feel the school does not understand your child, it is important to know your rights. You will need to communicate with staff at your child's school to find out what policies are in place for children with extra support needs. To get a head start, you can research some of this information through the School and the Department of Education in your state – see *Resources* (p67) for more information.

National Disability Insurance Scheme (NDIS)

The goal of the NDIS is to shift support funding from being based on labels and diagnoses to being about a person's individual needs in gaining independence and integrating into the community. Both children and adults with FASD should be eligible for support through the NDIS as they most likely will have significant and permanent disability that reduces their functional capacity, or psychosocial capacity in undertaking one or more of the following activities:

- communication
- social interaction
- learning
- mobility
- self-care or
- self-management

The NDIS supports your child, as well as you and your family, and eligibility for services will be determined by the National Disability Insurance Agency (NDIA).

Although a diagnosis of FASD may not be necessary to qualify for support, supporting documents will be required. This means you will need to have assessments from allied health professionals, for example, psychologists, neuropsychologists, speech therapists or occupational therapists that demonstrate your child's needs.

In order for a support to be deemed reasonable and necessary by the NDIA it must:

- be related to the participant's disability
- not include day-to-day living costs unrelated to disability support needs
- represent value for money
- be likely to be effective and beneficial to the participant; and
- take into account informal supports given to participants by families, carers, networks, and the community.

These are the support categories the NDIS will fund:

- Assistance with daily life at home, in the community, education and at work
- Transport to access daily activities
- Certain independent living supports

- Daily living skills training/therapy to assist independence
- Social skills and behaviour support
- Improved living arrangements
- Improved health and well-being through dieticians, personal trainers, or exercise physiologists
- Psychology services for anger management for those with cognitive impairment or autism
- Learning improvement support
- Finding and keeping a job
- Increased social and community participation
- Improved life-choices
- Assistive technology
- Vehicle modifications; and
- Home modifications.

The NDIS will **not** cover the following:

- Supports unrelated to the disability.
- Rent, groceries, utilities, etc.
- Something funded elsewhere – for example, school support or mental health services covered by a Mental Health Care Plan (MHCP).
- Paediatricians' consultations and medication management; or
- Psychology services for anxiety.

Planning tips

Because FASD is a disability that is not well understood in the community, individuals with FASD may require more support coordination than people with other disabilities. They may require more hours of in-home support than anticipated. Finding the right supports takes time, and it is important to make sure professionals have a good understanding of FASD. Provision of FASD training and meetings between professionals and the family may need to be included in the plan.

Support for NDIS planning

There are a number of guides that have been published to help families of people living with disability understand the NDIS:

Getting ready for the NDIS - NDIS Planning Workbook
- workbook provided by the **Association for Children with a Disability**: <https://www.acd.org.au/>

The aim of this workbook is to help you prepare for your child's planning meeting with the NDIS:

<https://www.acd.org.au/acd-ndis-planning-workbook/>

The **Raising Children Network** provides information that may be helpful. Visit: www.raisingchildren.net.au and browse to the [National Disability Insurance Scheme: FAQs](#)

The **Endeavour Foundation** has a range of NDIS planning guides online. Visit:

www.endeavour.com.au/ndis/resources

Their *Discover Guide* is a practical, comprehensive and up-to-date guide to the NDIS, prepared by La Trobe University in conjunction with Endeavour Foundation. It aims to help people understand the various components

of the NDIS and how to access them. It also includes additional legal information on whole-of-life planning for people with a disability.

[Reimagine](#) - one of the primary categories under the NDIS where people with FASD should be eligible to qualify for services is Psychosocial Disability. Although this website has been designed for people with a mental health condition, it has excellent information about psychosocial disability and how to apply for services under the NDIS.

NOFASD Australia is here to support you so please contact us if you need any help with completing forms for the NDIS. We may also be able to help if you have been denied NDIS funding. Please phone 1800 860 613 (free call) or email enquiries@nofasd.org.au

Should your child for some reason be ineligible for NDIS funding please don't despair! There are a range of supports available to carers that are not part of the NDIS, including respite support, counselling, education, training, peer support and advocacy. For information about what supports and services are available in your area, call the **National Carer Gateway** on **1800 422 737**.

When Things Get Tough...

Managing extreme behaviour

Despite parents' best efforts to adopt positive behaviour strategies, children with FASD may still escalate and their behaviour can pose a risk to themselves, family members or others.

Specific resources can be found at:

<https://www.nofasd.org.au/managing-challenging-and-or-extreme-behaviour/>

Tips:

- Recognise when the person is becoming anxious – look for early indicators
- Use as few words as possible
- Clearly state what you want to happen – the desired behaviour
- Don't argue, debate or negotiate
- Be direct but not authoritarian
- Don't expect the person to be reasonable or act their age
- Ask a few questions to which the person will answer 'Yes', to break the 'No' cycle
- Pay attention to your verbal and non-verbal communication
- Keep the brain injury in mind to help you stay detached.

Nathan Ory has written: [How to divert someone you cannot confront without an explosion?](#) He suggests:

- Avoid pressuring the person for a response
- Try to give them a way out of the situation
- Instead of reacting to threats or aggression, use strategies to divert and defuse the situation, for example:
- Use modelling – say "I'm ok, but I need a break"
- Give them a way out of the situation with a physical prop. For example, hand them an item (e.g. shopping list) and ask what they want for dinner
- Pre-rehearse a way to get out of a stressful situation to practice for when the situation arises – e.g. hand them a card which says "go and hit the punching bag" or "go for a walk".

See the full article on the NOFASD website for more details.

Nate Sheets is a behavioural consultant with Oregon Behavior Consultation. He has produced a number of YouTube videos focussing on behavioural issues and FASD, and you can subscribe to his YouTube channel. Episodes include:

[Handling Escalation: From Anger to Out-Of-Control 5 Unhelpful Responses We Have to Escalated Kids and Adults.](#)



Crisis intervention

There may be times when you need help from emergency services, to assist if your child is having a crisis. Remember:

- Your safety is important – it's ok to call for help if you or your child is unsafe
- Police or ambulance officers may not know a lot about FASD. You will need to tell them about your child's FASD and what it means for them.
- Tell emergency services that your child has a disability, and what their symptoms are. If you are under pressure you might need to explain quickly that FASD is similar to an intellectual disability or autism and they will need to use a similar approach as with these individuals, as they are likely to have had some training.
- If you are dealing with these behavioural issues, try to plan ahead for the next crisis. Write down the information you want police, ambulance or emergency department to understand.
- For example: My child has anxiety and they are likely to be aggressive when overwhelmed. Loud noises and flashing lights will frighten them. They will not understand long sentences and will not be able to answer questions. They will not be able to explain why they did something and will not

respond to someone explaining why they did the wrong thing.

- Let emergency services know what you need, for example:
 - I am scared/overwhelmed/at my wit's end and need help to get my child to calm down.
 - Once they are calm I won't be worried about my safety. **OR** I am concerned about my safety and need help.

Let them know what will help, e.g.

- someone to stay with you until your child falls asleep;
- someone to give you a break so you can regroup;
- someone to take your child overnight for respite;
- hospital admission or a mental health assessment.

Let them know what you do/don't want. For example:

- A mental health assessment – this may be useful if your child's doctor thinks medication or an admission will assist in a crisis, but won't always help when the behaviour is related to their disability.
- Safety planning – let them know your child will not be able to enter into a safety plan with a mental health service. If they are at risk they need others to keep them safe.
- Child protection involvement – this may be helpful or necessary if you need respite or don't feel safe at home.
- Your child to be charged with an offence – criminal charges are unlikely to make a difference to the person's behaviour, but there may be times when you need your child's behaviour dealt with in the justice system if it means your family can access resources or get the person into a service.

After a crisis

Individuals with FASD may feel guilt, shame and embarrassment after an outburst, meltdown or aggressive behaviour. Some individuals won't feel any remorse and this can be difficult to handle, as it may feel like they don't care or are "getting away with" their behaviour. It's very important at these moments to get help from others who understand about the brain injury of FASD. Your child is not able to see or understand the impact of their behaviour.

After a crisis it is important to:

- Get back to normal as quickly as possible. Familiar routines will reduce anxiety and the risk of further meltdowns.
- Show your child unconditional positive regard. They need to know you love them. Promote their connection with you over discipline or consequences.
- Do fun, soothing and comforting activities. Go out for ice cream, go to the park, make them a warm bath, or let them play on their favourite device (as long as it doesn't increase aggression).
- Don't listen to family members who tell you your child shouldn't be given a reward for bad behaviour. Providing your child with a positive experience after a crisis has nothing to do with whether they will learn consequences from their behaviour and everything to do with making your child feel safe and connected to you.
- Don't talk about what happened in any detail. Your child is unlikely to be able to remember accurately what happened, and referring to the incident may raise their anxiety and increase the risk of further incidents.
- Do not talk about things they did such as self-harming or making suicidal threats, or threats to hurt you and remind them of their behaviour. Reminding them can unintentionally reinforce behaviour.
- Use natural consequences in a non-blaming way. "We can't use the x-box because it's broken. But we can watch a movie."
- Resist the urge to remind them of the consequences of their behaviour later: "You could play on your x-box if you hadn't broken it". This is likely to be interpreted as criticism and lead to further aggressive behaviours.
- Ask for your child's help to clean up a mess, patch a wall or throw out broken items, if they are calm and seem able to do so. But if they get agitated, don't involve them in cleaning up or repairing the mess.
- Keep yourself emotionally calm and regulated, even if you don't feel it. Seeing you upset can raise your child's anxiety. Keep a neutral tone and be matter of fact about things. Meltdowns happen!
- Let the professionals involved with your child know what happened. Use this time to reflect and plan for the next time. What early indicators did you notice? Could you do something differently next time? Focus on prevention.

- Reflect on emergency services involvement. What happened with the police/ambulance/hospital? How can you be prepared for the next incident? In the following days you could write notes to help manage the next incident.

Getting in trouble with the law

Sometimes young people with FASD can find themselves getting into trouble with the law. If this happens, it is very important to talk to professionals working in the justice system to ensure they can help both the parent and the young person get through this challenging time.

- If your young person is arrested, inform police of the FASD diagnosis and areas of challenges for the young person. Ask that they not be interviewed for a statement until a lawyer or guardian is present.
- If your young person is detained in custody, inform the corrections staff of the FASD diagnosis. Tell them about your young person's strengths and challenges to help the corrections staff better understand them.
- Tell the young person's lawyer about the FASD assessment and if possible, provide a copy of the diagnostic report. This information will help the courts understand your child.
- The parent or caregiver's attendance in court is important to help answer questions and consider community supports.
- If your young person is assigned to a youth justice or probation officer, parents are encouraged to communicate with that person.
- If possible, go to appointments to ensure the young person understands the information. This will help them comply with a probation order. Probation orders can include language that is hard to understand, so ask questions. If your young person is more visual, ask about visual tools.

Mental health concerns

Some young people may struggle with mental health issues which need professional help. Following are some of the more common concerns that young people may experience and how you can support them.

Addictions

There are many reasons why your young person may experiment with drugs or alcohol, such as low self-esteem, peer influence, a need to fit in or as a way to cope with their feelings. Following is a list of strategies that may help you to support your teen.

- Talk to your child/young person about substance use and your family expectations about using alcohol and other drugs.
- Be curious when asking your young person about their substance use but do not judge. Staying neutral will encourage your young person to be honest with you.
- If you suspect your young person has substance use problems or has developed an addiction, contact an Alcohol and Drug Youth Service in your area for support and information about how to talk to your child or young person about substance use.
- Connect with your child/teenager's school about what addiction/counselling resources are offered in their school.
- Provide the counsellor with information about your child/teenager's primary diagnosis to ensure the service provided is best suited to your teenager's learning style.
- Get involved to help your young person at home and in the community with the goals they set during counselling sessions.
- Provide reminders and/or transportation to appointments.

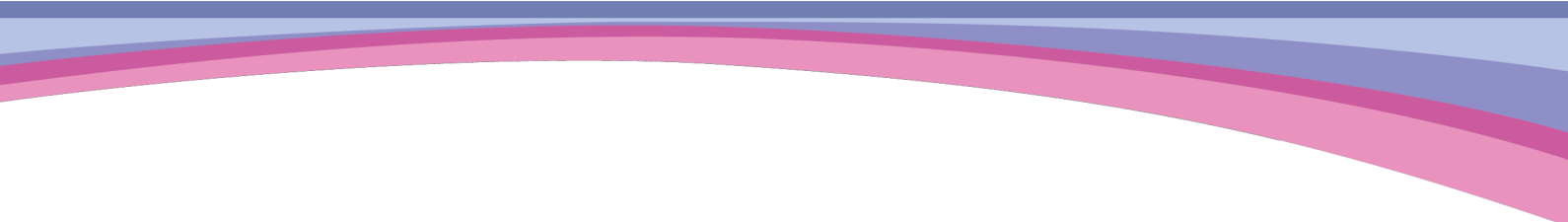
Poor Self-Esteem

Most people, at some point in their life, struggle with low self-esteem. This may be especially true for a young person with a FASD diagnosis because they may feel different, have trouble socially or struggle in school. As a parent, there are things you can do to try and help your young person feel good about themselves, such as:

- Create opportunities for your young people to build on their strengths, talents and interests.
- Celebrate even the smallest of successes with your teenager.
- Highlight your teenager's strengths at the school, and with other service providers, to ensure they use and build on them.
- Get your young person involved in organised recreational activities that can provide opportunities for building friendships and experiencing success. Remember that they may need reminders about rules, practice and game times, as well as transportation to get to the activity.

Self-Harming Behaviours

Self-harming behaviours may take many forms, such as cutting, scratching, not eating, vomiting after eating, not allowing wounds to heal, burning or hair pulling. It is important to know that self-harming is most often used as a way of coping.

- 
- It is best to get professional help to find out if your child is using this as a way to cope with feelings. If that is the case, try to react calmly, without judgment or blame and be aware of your body language. Remember that your young person is already feeling hurt. Ask professionals for more ways you can help them overcome self-harming behaviours and develop healthy ways of coping.
 - Explore healthy coping methods your young person can use, such as writing their feelings in a journal, listening to music, drawing or other artwork, and exercising.
 - Use feelings charts to help your young person normalise all feelings including anger, sadness and joy.
 - If you find your young person “getting stuck” in a negative emotion, try to steer them toward something positive.

Talking with Children and Young People About FASD

It is important that your child or young person understands that they have FASD. Your child needs to know about themselves, who they are and how their brain works. Without this information, there is no way for a child with FASD to understand what is happening for them or why their brain works differently than others. We all have a need to make sense of ourselves. Understanding how FASD affects your child will help them do that.

As a parent, you may be worried about talking with your child or young person about their FASD. Maybe you are worried about:

- making things worse
- your child being stigmatised
- your child being treated differently by others
- your child feeling negative about themselves
- your child being angry about how this happened to them.

If your child is not your biological child, you might be worried about whether they will blame their birth mother for consuming alcohol during the pregnancy and worry that this will damage their relationship. Some of this may happen, but working through these questions and feelings can lead your child to a better understanding of themselves – and even empower them to face the world with more confidence.

How do I talk with my child about FASD?

It depends on the age of your child. Even young children can benefit from information about their diagnosis if it fits with their age and stage. It is usually better for children to be told difficult information early in life, and have this repeated at different ages and stages, rather than suddenly finding out at age 10 or 14. If a child grows up knowing they have FASD, it will be a normal part of life and something they have always known about themselves.

- Prepare yourself in advance by getting information about FASD, its diagnosis and the words you will use to explain it.
- Use concrete, simple terms and try to keep your explanations short – at least at first. You may want

to use visual cues (e.g. a picture of the brain) to help your child understand what is happening for them.

- Try to normalise what is happening for them as much as possible, such as “all of our brains are different – we all have different strengths or learning styles.”
- Talk about your child’s unique strengths and reinforce their worth and abilities. FASD is only a part of who they are.
- Be curious. Ask your child – what are you good at? What are your strengths? Then ask “what things do you struggle with? Are there things that are harder for you than for other kids your age?” It’s likely your child will have noticed that they have difficulties in some areas.
- Prepare yourself emotionally. Try to have supports in place, for both you and your child, before having your talk. Choose the time and place for this talk when things are quiet, stable and there is enough time. You should follow-up at another time to see what your child understood from the talk and to answer any questions. Make sure their support system also knows about this talk, so that they can support your child and reinforce your supportive messages.

You may need to help your child or young person deal with anger about having FASD. No one drinks during pregnancy to harm their child. There are reasons why women drink during pregnancy. Some mothers:

- don’t know they are pregnant right away
- don’t realise that drinking will harm their baby
- have an addiction to alcohol or other drugs and need help to quit or cut down on their drinking.

Acknowledge your young person’s feelings of anger, fear or confusion about having FASD. Help them work through these feelings to come to understanding and acceptance over time.

Once your child or young person understands their disability, it becomes easier to work together to find ways to address their challenges. Many children and young people say that they feel relieved when they find out that this is a medical condition, rather than feeling like they are “stupid” or “bad.” Over time, you can support your young person to develop positive coping strategies based on their understanding of FASD.

It's likely you will have many conversations about this over the years with your child. Be prepared to bring it up in non-threatening ways so that your child becomes comfortable. For example, commenting "you forgot your hat today, I think it's the memory problem we talked about." This gives your child permission to also notice their behaviour and understand why they struggle in some areas.

Find positive role models

Have a look on the FASD Hub and on YouTube for videos of children living with FASD (see **Success Stories**). It's important to watch videos first before sharing with your child to make sure the message is appropriate – your child may take things literally. Find examples of other children living with FASD who are doing positive things – see Red Shoes Rock for example.

Talking to children about their sibling who has FASD

Talking to other children in the family about their brother or sister who is living with FASD will help them to develop an attitude of understanding, inclusion and acceptance.

[*My Sibling Has a Fetal Alcohol Spectrum Disorder \(FASD\). Can I Catch It?*](#) is aimed at children who have a sibling with a Fetal Alcohol Spectrum Disorder (FASD). It answers questions a child might have, focusing on the feelings of the sibling. It also contains a resource guide, games, and activities: This is available on the site yumpu.com - search for the title. If you create a free Yumpu account, you can download and print a copy. There are also lots of other useful FASD publications shared on Yumpu including some of those listed in our resources.

A [Language Guide](#) has been developed to promote the dignity of those with FASD and their families. We have also included some additional suggestions:

Instead of....	Use....
Suffering from FASD FASD kids	Person/Child with FASD Person/Child living with FASD
Brain damage Brain injury	Brain differences Areas of impairment/challenges Neurodevelopmental impairment; Neurodevelopmental disorder; Intellectual disability
People with FASD have challenges, impairments	People with FASD have both challenges/impairments and strengths/abilities
People with FASD are likely to...(be involved in the justice system/develop mental health issues, etc.)	Without a diagnosis and appropriate supports, people with FASD are at greater risk of
FASD is caused by drinking in pregnancy; FASD is caused by women drinking in pregnancy	FASD is caused by prenatal alcohol exposure; FASD occurs when alcohol is consumed in pregnancy
Women who choose to drink	Person who drank alcohol; Parents drinking during pregnancy
100% preventable	Preventable
Just one drink can cause FASD	Not drinking alcohol during pregnancy is the safest option

Adults with FASD

Adults with FASD need:

- recognition that they have the same hopes and dreams as everybody else;
- understanding that the way they experience FASD is different from others, and they have their own unique responses to stress, fatigue, distractions and different environments;
- respectful supports that recognise their individual vulnerabilities and provide safeguards;
- people around them to understand that their symptoms are indicators of underlying brain differences that need accommodation, rather than problem behaviours that need to be eliminated.

FASD Diagnosis for Adults

Under the Australian guidelines, a FASD diagnosis can be made by a medical professional with some assessments completed by others (e.g. speech and motor skills). An adult seeking a diagnosis would need to find a professional willing to co-ordinate the FASD diagnostic process. This could be a physician, neurologist, geneticist or other professional.

Although the need exists, there are currently very few Australian health professionals who offer assessment/diagnosis of adults who may have FASD. Visit the FASD Hub Australia website to see if there is a clinician in your state who can help with Adult FASD diagnosis. If there is no clinician available in your state, please call us on 1800 860 613 (free call) or email enquiries@nofasd.org.au as we may be able to provide further suggestions.

Adults who have a known history of prenatal alcohol exposure and where FASD is suspected may benefit from a neuropsychological assessment. The results of this assessment can be used to inform service providers and ultimately affirm and support adults who have FASD. Such an assessment may also lead to eligibility for NDIS support. It is also possible to arrange your own assessments for language and adaptive functioning with speech therapists and OTs.

The NOFASD website has a link to an article that you can give to your neuropsychologist:

[The value of the neuropsychological assessment for adults with Fetal Alcohol Spectrum Disorder: A case study](#)

Supporting adults with FASD

A strengths-based approach to supporting adults with FASD is important. Young adults with FASD have said that they gain strength through:

- asking for help
- having FASD-informed teachers
- being involved in school activities that fit their interests and abilities and create opportunities for friendship
- participating with youth groups
- engaging in elder support
- reaching out to help others
- gaining self-insight through FASD diagnosis.

Things that they found helpful included:

- knowledgeable and caring teachers
- supportive caregivers and adults
- youth groups and community programs.²

One young man with FASD who shared his experiences in a Photovoice project noted that his personal strengths included visual and hands-on learning, spatial memory, as well as being adaptable and observant of others. Being aware of these strengths helped him set career goals, be motivated, and remain optimistic and persistent.³

FASD and employment

It can be challenging for a young person or adult with FASD to obtain employment, and sometimes even harder to keep it. Because many adults with FASD often have good verbal skills, their difficulties are not obvious, and they may be successful in finding employment. However very often the demands of the job are challenging for an adult with FASD, as they may involve

² S. Knorr, L., & McIntyre, L. J. (2016). Resilience in the face of adversity: Stories from adults with Fetal Alcohol Spectrum Disorders. *Exceptionality Education International*, 26(1), 53-75.

³ Brenna, B., Burles, M., Holtslander, L., & Bocking, S. (2017). A school curriculum for Fetal Alcohol Spectrum Disorder: advice from a young adult with FASD. *International Journal of Inclusive Education*, 21(2), 218-229. doi:10.1080/13603116.2016.1193565

following complicated written or verbal instructions, being expected to think on your feet, or being expected to remember information and learn quickly. To achieve success, adults with FASD will benefit from someone who can advocate for them and provide support in the workplace. Disability Employment Services (DES) can help people find employment and keep a job. Go here for more information visit: www.jobaccess.gov.au.

Parenting with FASD

There are very few published resources available on this topic. A study of parents with FASD identified a number of challenges for parents with FASD, including reluctance to seek support for difficulties like substance use for mental health issues, for fear of being labelled a 'bad parent'. Extended family networks are particularly important for children of a parent with FASD, as the parent may be very capable in some areas but require support or assistance in others. Parents with FASD need longer term supports, and if the adult is eligible for NDIS funding they may be able to receive some funded support. Information and support is available from the NOFASD Parent & Family Support Team. Phone 1800 860 613 (free call) or email enquiries@nofasd.org.au

If you are an adult with FASD

If you need some help to work out where you can go for support, please give us a call on 1800 860 613 (free call) or email enquiries@nofasd.org.au

The Asante Centre in Canada has developed information cards for adults with FASD on topics including:

- Help me understand my assessment
- Help me to understand my FASD
- Things to know if you have FASD

HELP ME *understand* my FASD!

Advice from people with FASD...

1. Make sure you know me, and I know you before we talk. You have to be safe.
2. Be forthright and honest. If you beat around the bush I will get confused or learn to feel ashamed. I deserve to know why some things are hard.
3. Show me that FASD is not a death sentence. Some things will be hard, but with the right tools I can be a success.
4. Teach me how to help myself, because I will worry. Explain how nutrition, exercise, sleep, and relaxation help my brain and body stay healthy as I get older.
5. Look for teachable moments to help me understand myself. I might ask questions, or notice when something is hard.

See: <https://www.asantecentre.org/education-and-resources>

Your rights

If you have Fetal Alcohol Spectrum Disorder, it's important to understand that you have the same rights as everyone else. Because those rights are often not respected in the same way that they are for those without disabilities (particularly in the case of 'invisible' disabilities such as FASD), there are special protections for certain rights, such as the right to being supported in ways that meet your needs.

Human rights are rights that everyone has. Every person should be treated equally. Your rights and freedoms are be protected by our government.

Parent and Carer Support

The staff and family support team at NOFASD Australia understand the feelings of isolation sometimes experienced by families living with FASD. While we are unable to provide direct assistance such as treatment or legal services we do provide confidential telephone and email support to individuals living with FASD and their parents, carers, family members and service providers.

If you are seeking referral information to diagnostic and related supports throughout the country or would like the opportunity to share your experience or concerns with our staff or family support person, phone 1800 860 613 (free call) or email: enquiries@nofasd.org.au

Family support services are available in all states and territories for parents experiencing challenges. Visit your local Department responsible for children and families to see what parenting supports are available



Financial support

As a carer, you may be entitled to financial support depending on your specific family situation. If you are providing unpaid care for a child or adult with FASD there are options for support and respite through the Australian Government – visit www.carergateway.gov.au/ and follow the links to financial support including

concessions, carer payments, respite, and carer help and advice. You may also be eligible for a Companion Card – visit www.companioncard.gov.au and follow the links to your state or territory department.

If you are providing foster care, kinship care or permanent care for a child or young person, you should be entitled to a range of payments including a carer payment, a Health Care Card for the child, and other benefits depending where you live. Contact the support agency in your area or search online for foster care, kinship care or permanent care/adoption support services in your state or territory. It is worth joining your local carer peak body to ensure you receive newsletters and updates about new funding sources.

Support groups

Having your own circle of support is very important. NOFASD Australia offer parent and family support via 1800 860 613 (free call) or email: enquiries@nofasd.org.au

You may find it helpful to talk and share your experiences with other parents/carers in similar circumstances to yourself. There are some active FASD Facebook support groups and a small number of face-to-face groups in Australia. You can find contact details for these support groups on the NOFASD website <https://www.nofasd.org.au> or on the FASD Hub

[MyTime groups](http://groups.mytime.net.au/) are also active in every state and provide support for mothers, fathers, grandparents and anyone caring for a child with a disability or chronic medical condition. It's a place for you to unwind and talk about your experiences. It's a world away from appointments and therapy. It's support for you. Visit <http://groups.mytime.net.au/>

Resources

Stories of living with FASD

There are many resources to help you learn more about FASD. Watching videos and documentaries is a good way to:

- learn about how children are affected differently
- get ideas about how families have overcome challenges
- hear the language families use to talk about FASD
- hear children talk about having FASD
- hear birth mothers talk about their experiences.

NOFASD has links to many videos – visit

<https://www.nofasd.org.au/parents-carers-and-families/resources/#videos>

The FASD hub also provides links to videos – visit

<https://www.fasdhub.org.au/>

Tristan

Tristan is the story of a 12-year-old indigenous boy with FASD. You can order this DVD from Marninwarntikura Fitzroy Women's Resource Centre or contact the FASD Hub.



Other films relating to Aboriginal families and FASD can be found on the FASD Hub at

<https://www.fasdhub.org.au/help-me-choose-for-australian-indigenous-research-and-resources/videos/>

FASD: Finding Hope

This Canadian documentary follows the stories of four families of children affected by FASD with a focus on the education system. It is available on YouTube.



FASD: Recovering Hope

This Canadian documentary focuses on the experiences of birth mothers and their children. It is also available on YouTube.



Moment to Moment: Teens growing up with FASD

A film available for purchase at www.ntiupstream.com/videos. You can see a short clip on YouTube.



Fetal Alcohol Spectrum Disorder – two short films, one focussing on families and the other on two teenagers coming to terms with FASD. Available on [YouTube](https://www.youtube.com/) – search “FASD Attitude Live”.





The **FASD Hub** has a number of video stories including the story of Michael and Lina, who live with FASD.



Red Shoes Rock is an international community working to break down the stigma associated with FASD. You can see their work at: <https://redshoesrock.com/>



Information about alcohol in pregnancy

[Australian Guidelines to Reduce Health Risks from Drinking Alcohol](#) can be found online, with new guidelines released in 2020.

<https://alcoholthinkagain.com.au/> has information about alcohol use, health, risk factors and pregnancy – including a video for parents planning a pregnancy: [Alcohol Think Again](#)

The [Women Want to Know](#) initiative has information for professionals regarding talking with women about alcohol in pregnancy.

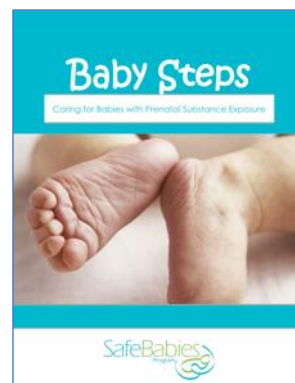
Parenting resources

These resources can be found online or via the NOFASD website.

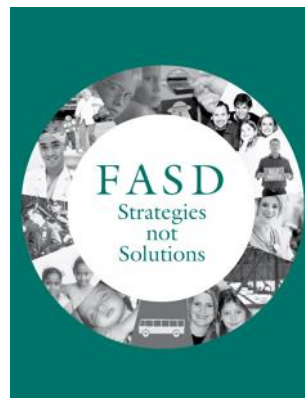
[Who has to change?](#) Trying their hardest, doing their best! - What it is like to live with Fetal Alcohol Spectrum Disorder is a fact sheet by Nathan Ory.

[NOFASD Australia fact sheets](#) for free download

Families Affected by Fetal Alcohol Spectrum Disorder (FAFASD) is a parent-run organisation with lots of tip sheets on parenting children with FASD including challenging behaviours. You can find their information at fafasd.org. One of their resources is a tip sheet: [Behavioural Symptoms & Accommodations for FASD](#) This can be a useful resource to print and share with others.



[Baby Steps: Caring for babies with prenatal substance exposure is](#) a Canadian resource for carers looking after babies and is helpful for foster carers.

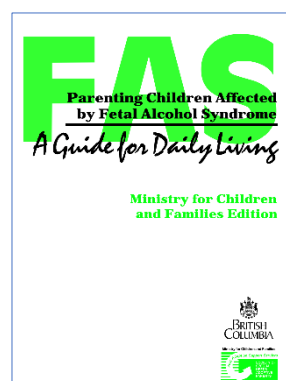


[Strategies Not Solutions:](#) A resource developed to educate caregivers and the community in managing the

behaviours associated with FASD throughout the lifespan. The project relied heavily upon caregivers and professionals who provided information, advice, and feedback.



[The FASD tool kit for Aboriginal families](#) for Aboriginal Families is a Canadian resource developed with First Nations peoples. It is aimed at professionals but has some useful information for families.



[Parenting Children Affected by Fetal Alcohol Syndrome](#) – *A guide for Daily Living* is a Canadian resource with many useful suggestions for daily life – managing money, teaching ownership, bathroom routines, etc.

Books

These resources can be found online to purchase:

“Trying Differently Rather Than Harder” – Malbin, Diane V 2017 (2nd ed) MSW)

“Foetal Alcohol Spectrum Disorders – Parenting a child with an invisible disability” Mather, Dr M. & Brown, J. 2017, available for purchasing online from various bookstores.

“The Perfect Love Story” This book written by Claire Gyde, Chairperson of FASD-Can New Zealand, is witty, wise and truly FASD-informed. It is not available to download but a printed copy is free for parents and carers by emailing enquiries@nofasd.org.au

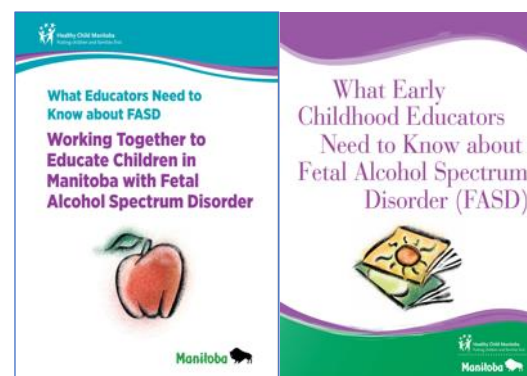
Education resources

The South Australian Department of Education has a website with information for educators about the needs of students with FASD. This is a great resource and one that you could provide to your child’s teachers. You can find it online by searching the terms [“SA Education FASD”](#).



New Zealand also has a website on FASD and Learning which has classroom strategies grouped by age level. It includes strategies to identify needs, provide support, support self-regulation and positive behaviours and includes helpful classroom strategies for years 1-8 and years 9-13

<https://www.inclusive.tki.org.nz/guides/fetal-alcohol-spectrum-disorder-and-learning/>



[What Early Childhood Educators need to know about FASD](#) and

[What Educators Need to know about FASD](#) are two useful resources with lots of practical kindergarten or classroom suggestions. These were produced in Manitoba and can be found online or at the NOFASD website.

Education department contacts

For general information visit these sites. A search of "home education" will bring up relevant details (except NSW and Tasmania which have separate websites, see below). You can also search for "Disability" to see relevant contacts.

Queensland: <https://education.qld.gov.au/>

NSW: <https://education.nsw.gov.au/>

NSW: <https://educationstandards.nsw.edu.au/> (home education)

Victoria: <https://www.education.vic.gov.au/>

Tasmania: <https://www.education.tas.gov.au/>

<https://oer.tas.gov.au/> (home education)

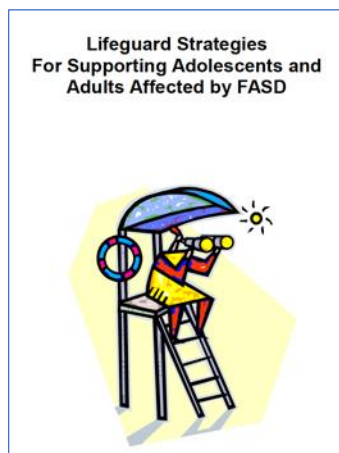
South Australia: <https://www.sa.gov.au/topics/about-sa/government/departments/education>

Western Australia: <http://det.wa.edu.au/>

Northern Territory: <https://nt.gov.au/learning>

ACT: <https://www.education.act.gov.au/>

Young people with FASD



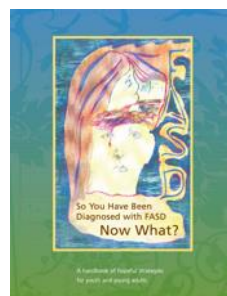
[Lifeguard Strategies](#) is a helpful publication focussing on supporting adolescents and adults with FASD.

[The SECCA App](#) is a digital app that supports the development of knowledge and skills in navigating sexuality & relationships across the lifespan. Each lesson

plan is linked to the Australian National Curriculum and the ABLE WA curriculum. Visit <https://app.secca.org.au/>



Adults living with FASD



[So you have been diagnosed with FASD – now what!](#) – A handbook of helpful strategies for young people and adults.



[Supporting Success for Adults with FASD](#) – This Canadian booklet has been developed with the support and advice of individuals with FASD and family members and professionals involved in the lives of adults with FASD.

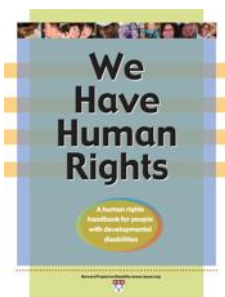


[FASD in the workplace](#) - This is a great publication written for employers by Claire Gyde from New Zealand and is suitable for downloading and sharing with employers in Australia.

If you have Fetal Alcohol Spectrum Disorder, it's important to understand that you have the same rights as everyone else. Because those rights are often not respected in the same way that they are for those without disabilities (particularly in the case of 'invisible' disabilities such as FASD), there are special protections for certain rights, such as the right to being supported in ways that meet your needs.

Human rights are rights that everyone has. Every person should be treated equally. Your rights and freedoms should be protected by our government.

You can find more information about your rights in [The Human Rights Handbook for people with developmental disabilities](#).



People with Disability Australia has a new website to help people with disabilities find the services they need. The Wayfinder Hub is at wayfinderhub.com.au.

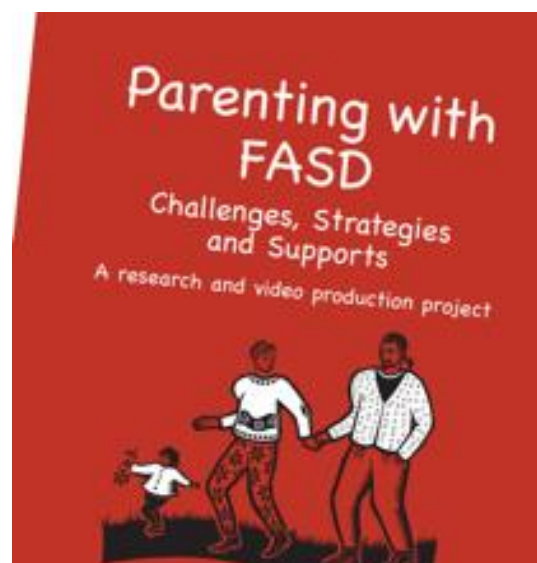


Helping you find your way through the Disability Maze

A Canadian [Guide for Employment Professionals Supporting Employment in Adults with FASD](#) has some helpful tools for employers.



A useful WA resource is [Kick Starting Your Child's Career Journey – A guide for families of young people with Disability](#). Written for families, this has some great tips and success stories.



Supporting Parenting with FASD – Challenges, Strategies & Supports is a video and booklet focussing on parenting challenges and strategies for parents living with FASD. It is available for purchase by emailing info@fetailcohol.com

You can find more information about your rights in The Human Rights Handbook for people with developmental disabilities.

NOFASD Australia

NOFASD Australia is working towards ensuring FASD is recognised as a disability in Australia, promoting social inclusion by advancing the rights and interests of people living with FASD, and providing the necessary supports to individuals and families at a grassroots level.

- Visit us online to subscribe to the NOFASD monthly e-newsletter.
- Follow NOFASD Australia on Facebook and Twitter to keep up to date with the very latest information and resources on FASD.

The NOFASD website is regularly updated and includes information about:

- Alcohol and pregnancy
- Information and resources for parents and carers
- Information and resources for service providers
- Education and training
- Extensive links to Australian and International FASD resources, services and research.

FASD websites - Australia

FASD Hub Australia

FASD Hub Australia is a website developed by an alliance of organisations working to provide a 'one stop shop' for information, tools and resources that are current and evidenced based. It provides information on FASD for Australian health professionals, teachers, justice professionals, service providers, researchers and parents and carers.



Telethon Kids Institute (WA) – Alcohol Pregnancy & FASD

The Telethon Kids Institute is one of the largest, and most successful independent not-for-profit medical research institutes in Australia, comprising a dedicated and diverse team of more than 500 staff and students. They have many FASD resources and research projects on their website – visit

www.alcoholpregnancy.telethonkids.org.au

Australian Indigenous Alcohol & Other Drugs Knowledge Centre

The AOD Knowledge Centre Fetal Alcohol Spectrum Disorder (FASD) portal – is for people working, studying or interested in addressing the harms of alcohol use in pregnancy. It aims to provide a central collection of policies and strategies, publications, resources and training materials supporting prevention and management of FASD in Aboriginal and Torres Strait Islander communities.

<https://aodknowledgecentre.ecu.edu.au/>

Drug Education Network (DEN)

A non-government organisation in Tasmania funded to deliver a range of health promotion, prevention, and early intervention programs to reduce the harm associated with alcohol, tobacco, and other drug (ATOD) use. <http://www.den.org.au/>

FASD C.A.R.E WA

The Fetal Alcohol Spectrum Disorder Collaboration for Assessment and Care, Research and Education are a team of health care professionals who aim to provide high standards of clinical care for children and young people living with FASD. <http://www.fasdcare.org.au/>

Synapse

Synapse is the national body for brain injury in Australia and provides research, specialist housing and support services for Adults with brain injury and disabilities.

<https://synapse.org.au/>

The CICADA Centre NSW

This specialist centre provides diagnosis and clinical care for children and young people affected by alcohol and drug use and supports leading research and education in key areas of need in Fetal Alcohol Spectrum Disorder (FASD), parental drug and alcohol use and adolescent drug and alcohol use.

A Glossary of Diagnostic Terms

We have compiled some simple definitions to help you understand the language used in your child's diagnostic report. It's important to ask professionals to clarify anything you don't understand in the report.

Adaptive Behaviour

The skills required for daily life including socialising, playing games, communicating with friends or strangers, self-care, keeping safe and doing things around the home like dressing, showering or cooking.

Affect Regulation

Affect (emotional) regulation is the ability to manage your feelings in different situations. It includes skills of coping with frustration or excitement, calming down after something upsetting or exciting, and learning to control impulses.

Auditory Processing

The way the brain makes sense of the sounds we hear, for example making sense of words, or knowing where a sound is coming from.

Bilateral Coordination

Bilateral (two-sided) coordination means the ability to use the left and right sides of our body together to do tasks like skipping, catching a ball, riding a bike or swimming.

Flexibility

The ability to think of different ways of doing things, integrating new ideas into your existing way of thinking and being able to let go of something if it isn't working.

Executive Function

A set of mental skills that we use to set goals, plan and get things done – the 'management system' of the brain. They include skills of staying on track, understanding other's perspectives, being aware of yourself (self-monitoring) and regulating your emotions.

Expressive Language

The ability to get your message across to other people through words or gestures. These skills are important for expressing thoughts or feelings, asking questions, providing information and having conversations.

Fine Motor Skills

Using your hands to manipulate things, particularly using the small muscles of your hands – for example - threading beads, holding a pencil, picking up small objects or tying shoelaces.

Gross Motor Skills

Using large muscle movements for activities like walking, jumping, climbing or ball games. Gross motor skills require balance, bilateral coordination, eye-hand coordination, postural strength, motor planning and sensory processing.

Hyperactivity

Being unusually active, including constantly moving; fiddling or fidgeting, talking constantly, having difficulty doing quiet activities such as reading. Hyperactivity can include impulsive behaviours.

Impulsivity

Acting without thinking about the possible consequences, including doing silly things to get attention, not following rules, having trouble waiting your turn, grabbing/pushing others, interrupting or blurting things out, or taking risks.

Inattentiveness

Having difficulty focusing on the task at hand, being easily distracted, not noticing when spoken to, having difficulty following instructions.

Organisational Skills

The skills needed to gather and store information, and retrieve it when we need it. Organisational skills are needed for self-care (getting dressed), following routines and knowing what to do next, and completing tasks like homework or projects. Telling a story in a logical way requires organisational skills.

Percentile

A measure of the percentage of people in the population performing at around the same level. For example, if a child is at or below the 2nd percentile on a test, it means that around 98% of children their age would score higher.

Phonological Awareness

The ability to recognise and use sounds in spoken language – for example, picking out words that rhyme, counting the syllables in your name, or noticing that words start with the same sound.

Postural Strength/Muscle Tone

Having the strength and control in our bodies, including our trunk, shoulders and back, to allow us to do other activities - e.g. able to sit in a chair without getting tired.

Pragmatic Language/Social Communication

Knowing what to say, how to say it, and when to say it in social situations, including reading body language and using gestures.

Praxis/Motor Planning

The ability to think of an unfamiliar movement, (like the first time you do a star jump), plan it in your mind, put the steps in order in your mind and then do it successfully.

Proprioception

Knowing where our body is in space, and what it is doing, without looking at it.

Receptive Language

The ability to understand what others are saying which is important for communication, engaging in conversation, understanding requests or following instructions.

Selective attention

Paying attention to a specific task, and filtering out distractions.

Self-monitoring

The ability to notice what you are doing, assess whether you are doing the task the way you planned to, and catching and correcting mistakes as they happen.

Sensory avoiding

When a child's brain has difficulty processing sensations, they may avoid sensory input more than other children – disliking bright lights, loud noises, avoiding foods or textures.

Sensory seeking

Children with sensory seeking behaviours need more sensory input to function – being attracted to bright lights, loud noises, crunchy food, rough play, touching things and people, and seeking out movement.

Sequencing

Planning and doing things in the right order – e.g. using words in the correct order in a sentence or telling a story with a beginning, middle and end.

Shift

The ability to "go with the flow" and think and adapt as situations change. Shifting allows a child to stop doing something quickly in order to start doing a different activity.

Sustained attention

Being able to focus on something for a stretch of time, even when there are distractions.

Visual Memory

The ability to remember what you have seen, recently and in the past.

Visual Motor Integration

The ability to use our eyes and hands in a coordinated way. We use these skills when we are threading beads, handwriting, cutting shapes or colouring in.

Visual Processing

Making sense of the information our eyes take in, such as distinguishing shapes or letters, or reading words or letters in the correct order.

Working Memory

The ability to remember information long enough to use it, such as verbal instructions.

While not specific to FASD, www.understood.org has some useful information in clear language for families of children with thinking or learning differences.