

Every Day is an Adventure:

What Parents and Caregivers Need to Know About Fetal Alcohol Spectrum Disorder (FASD)



Healthy Child Manitoba
Putting children and families first

Manitoba 

ACKNOWLEDGEMENTS

Healthy Child Manitoba leads our province's prevention and intervention strategy to achieve the best possible outcomes for Manitoba's children.

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- Housing and Community Development
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- Justice
- Labour and Immigration

Special thanks to the members of the development team and the parents who shared their experiences to help others.

"The best strategy that we have used is the day to day or moment to moment experience. You have to take each day and each moment as it comes."

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Introduction

This booklet is for parents and caregivers of children and teenagers with Fetal Alcohol Spectrum Disorder (FASD) to provide you with ideas about caring for your children to help ensure they have the best lives possible. Note: This booklet refers to anyone who is caring for, or involved in the care of a child with FASD, as a parent or caregiver.

This booklet was written by parents as well as professionals who work with FASD in the community. Included in each strategy section are comments from parents who are caring for children with FASD. These are parents who understand some of the challenges you are going through and want to help by sharing their experiences, from one parent to another.

Caring for a child with FASD is both rewarding and challenging for so many reasons. Parenting, in general, is hard work. When parenting a child with FASD, you need information about the disability as well as support and ideas about how to accommodate your child's unique brain differences.

This booklet includes information about FASD – what it is and what it means for your child. A number of strategies will be provided. You may want to try some of these as you learn more about your child and how the disability has affected them. Since every child, parent and family is unique, not every strategy will work for everyone. You will likely find that the best strategies are built on developing a good relationship with your child and getting to know your child's strengths.

“My biggest struggle is that my children have a hidden disability because you can’t tell by looking at them. People look at their behaviour and say why are they doing this? Always having to explain to others in your own family. You feel like you always have to explain to everyone why you are doing what you are doing as a parent.”

What is FASD?

The term fetal alcohol spectrum disorder (FASD) describes the range of physical characteristics and brain disabilities that may affect a person whose mother drank alcohol while pregnant. Often, there are no physical characteristics to show the person has FASD, but the brain can still be affected. FASD is a hidden brain-based disability.

Each individual is unique with their own strengths and challenges.

Fetal Alcohol Spectrum Disorder (FASD)

An umbrella term that represents three medical diagnoses:



Fetal Alcohol Syndrome (FAS)

Brain Based Injury

Physical Indicators

Small for age,

Distinctive facial appearance

- Small eyes
- Smooth philtrum (area between nose and upper lip)
- Thin upper lip

Partial Fetal Alcohol Syndrome (pFAS)

Brain Based Injury

Physical Indicators

Presents with some, but not all, of the physical signs of FAS

Alcohol Related Neurodevelopmental Disorder (ARND)

Brain Based Injury

Physical Indicators

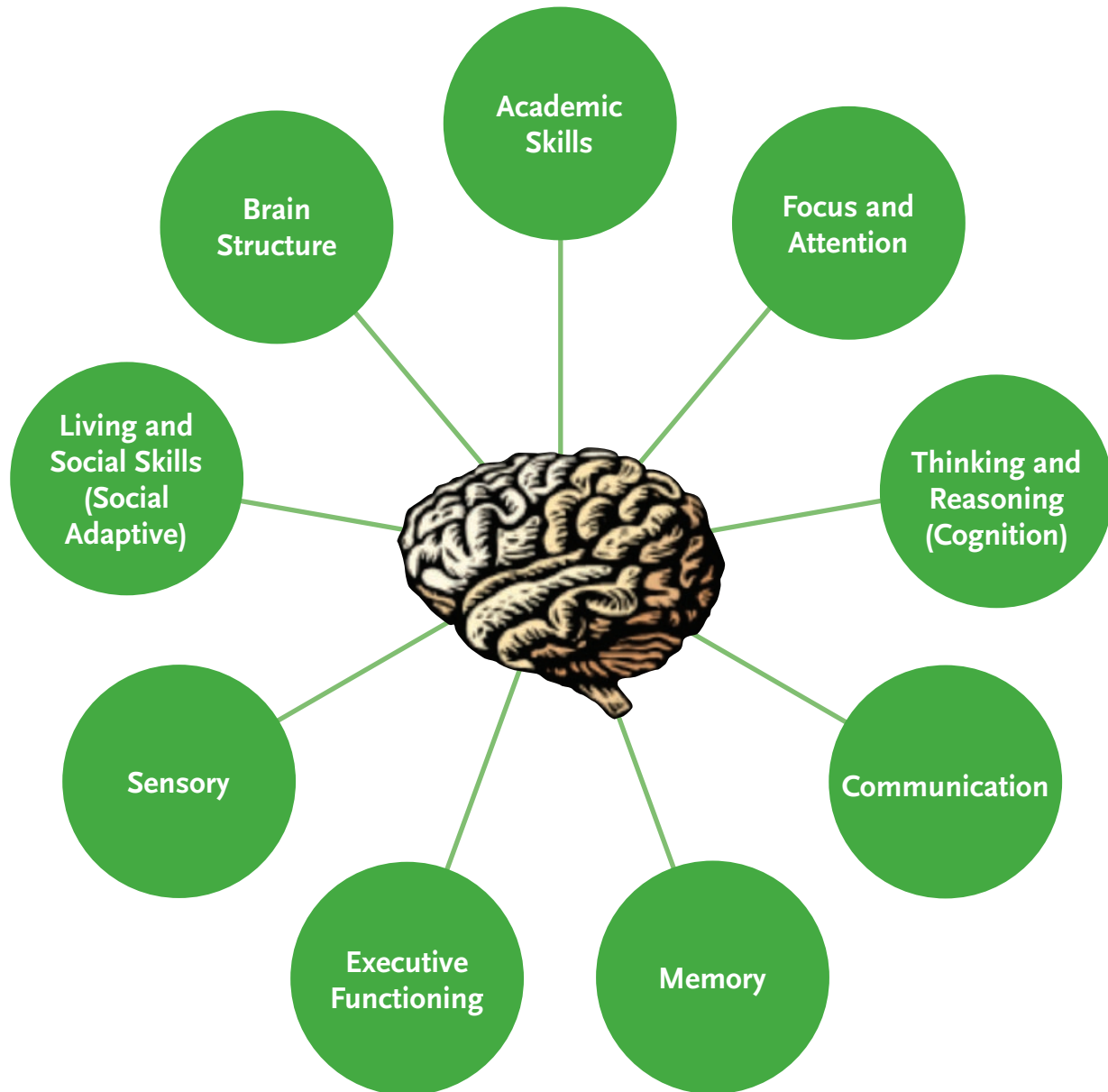
None of the physical signs of FAS

Source: Manitoba FASD Centre

Facial features and small size are associated with FAS and pFAS but ARND has no physical indicators. As a result, ARND is often referred to as an “invisible disability”.

Nine Brain Domains (Functions) Affected by FASD

There are nine brain domains* that are potentially affected by alcohol use during pregnancy that can lead to a diagnosis within the FASD spectrum. They are:



* Please note that revisions are currently being made to the Canadian Diagnostic Guidelines for FASD, which will include changes to the brain domains. These revisions will be included in the next edition of the *Every Day is an Adventure: What Parents and Caregivers Need to Know About FASD*.

ACADEMIC SKILLS

- may have difficulty in school (ex: reading, math, comprehension, organization and abstract concepts)
- benefits from visual and hands-on approach

FOCUS AND ATTENTION

- can be easily distracted, over-stimulated, inattentive, hyperactive

THINKING AND REASONING (COGNITION)

- difficulty reasoning, planning, solving problems and understanding complex ideas
- a wide range of IQ scores possible

COMMUNICATION

- may speak well, but not fully understand the meaning
- delayed language development
- difficulty understanding long conversation and instructions
- can repeat instructions or rules accurately, but may not follow through

MEMORY

- difficulty with long-term, short-term and working memory
- may appear to lie, but is filling in the blanks when unable to remember
- trouble memorizing and may seem forgetful
- difficulty accessing, selecting and organizing information

EXECUTIVE FUNCTIONING

- may have trouble planning, sequencing, problem solving and organizing
- may be impulsive, have difficulty understanding cause-and-effect and controlling emotions
- challenges with transitions and change
- often repeats mistakes
- difficulty with concepts, abstract ideas, consequences and managing time

SENSORY

- inability to accurately sense what is going on around them
- sensitive to light, noise, touch, smell and/or taste
- may under- or over-respond to stimulation

LIVING AND SOCIAL SKILLS (SOCIAL ADAPTIVE)

- may not understand personal boundaries and have difficulty reading social cues
- may be socially vulnerable and easily taken advantage of
- difficulty seeing things from another's point of view
- socially and emotionally immature and may behave younger than actual age

BRAIN STRUCTURE

- could have a smaller brain and head circumference

It is important for parents to understand how the injury to certain brain domains from FASD is often the underlying reason for the most difficult behaviours of children and teenagers with FASD

Source: The Hidden Disability

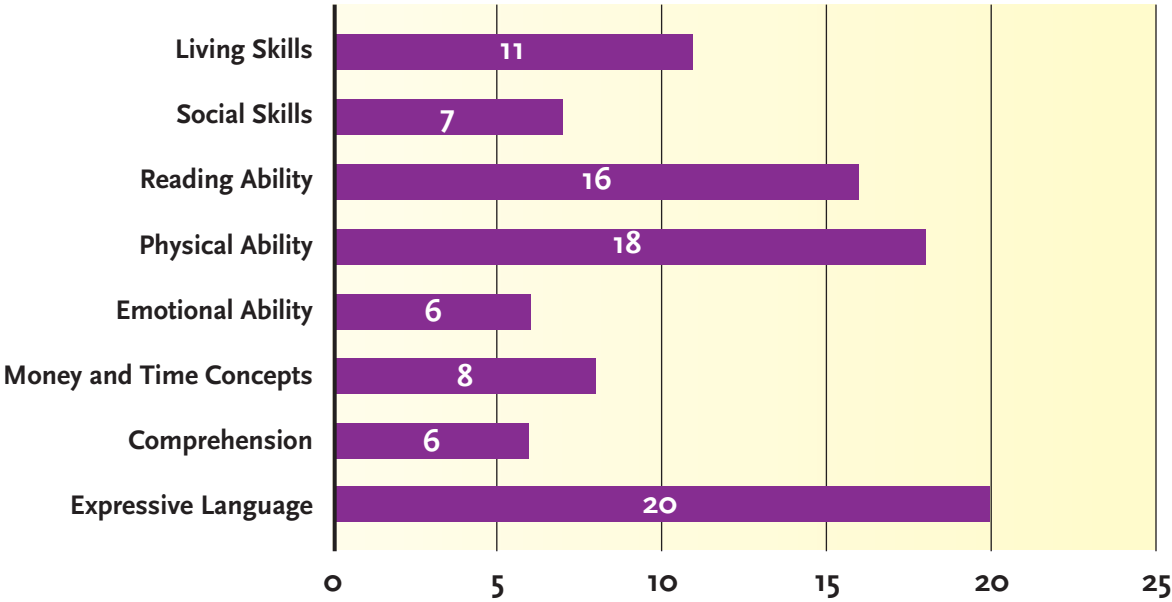
Developmental Age and FASD

As parents, we have expectations for our children based on their age (ex: “Susie should be able to clean her room without help because she is old enough”). This thinking assumes that your child is developmentally “on track.” Research shows that children and teenagers 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 following chart was developed by Diane Malbin, a researcher and author in the field of FASD. This chart shows a common developmental profile of a teenager with FASD. In some ways, the person may be on time or even ahead of their age peers, yet, in other ways, they may be behind. Imagine how problems could be avoided if expectations were adjusted to match a child’s ability.

When you look at this profile, 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 is described as a “poor fit” between the abilities and the expectations placed on a person with FASD. This poor fit can lead to other problems in addition to the brain-based injury, often referred to as secondary impacts or disabilities.

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

**DEVELOPMENTAL AGE EQUIVALENT
ACTUAL AGE OF INDIVIDUAL – 18**



Source: Trying Differently Rather Than Harder (2002) Diane Malbin

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, but perhaps, at a slower pace and not always in line with their age peers.

Adjusting your expectations and support does not mean that your child will not be held accountable. It just means that your expectations for accountability should match your child’s developmental age.

It is common for children and teenagers 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 willful behaviour. It would be helpful to think of these inconsistencies as “FASD days” or 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.

**“Thinking younger”
reduces the frustration
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expectations are not
being met.**

Cultural Belonging

Successful parenting of a child with FASD often includes many considerations including thoughtful exploration of various strategies and environmental adaptations, accessing and advocating for appropriate service provision as well as nurturing connections with supportive friends, family and community.

Cultural belonging – the feeling of being connected and accepted in one’s family and community – is another important consideration if the child you are caring for is from a different ethnicity. It is essential to healthy human development, building positive self-esteem, creating a sense of well-being and developing the ability to relate to others.

Reflecting the culture of the child you are caring for into your family’s day-to-day life is the best way to make this happen. Here are some suggestions:

- Take time to learn about your child’s culture. Books, the Internet and visiting a local culture centre or cultural community are all good sources of information. If you know about your child’s culture, you’ll be better prepared to answer questions and find opportunities to add these cultural practices into your life and daily routine.
- Participate in cultural experiences for your child and your family, so everyone learns to embrace the culture. Think about these opportunities when you choose what to do on family outings, where your child goes to school or when making vacations plans.
- Talk openly about race and culture. If you need help, look for a resource and/or find someone in the community who can help.
- Help your child and family make friends with adults and other children from your child’s culture. These friends can become natural mentors for your family and your child as he or she matures.
- Take lots of pictures of your family participating in various cultural activities. Put together a scrapbook, photo album or video of these celebrations.
- Find toys, books, and games that are part of your child’s culture.
- Display art from your child’s culture in your home, along with other art work.
- Make food that reflects your child’s culture. Let your child help pick out recipes and prepare meals.

- Seek out museum exhibitions that your whole family can attend to celebrate your child's culture.
- Celebrate holidays that are significant in your child's culture.
- Acknowledge your child's differences, while working to encourage a sense of belonging in your family.
- Even if your child seems uninterested in the culture, continue to explore it. Your child will learn that you respect and cherish his or her cultural background as part of your own.



Strategies for Parents of Children and Teenagers with FASD

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. The following list of strengths is not unique to people with FASD, but it does show areas where your child may excel:

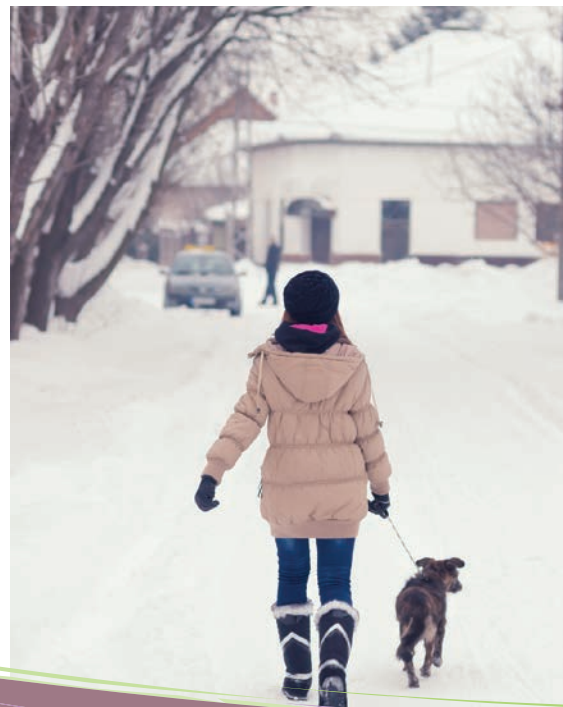
Affectionate Trusting
Wonderful story tellers
Strong visual memory
Friendly, loyal, loving
Eager to please
Creative Musical
Artistic
Good with animals
Determined Active
Learns best by doing
and more!

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 (ex: 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, they could rake the lawn or shovel snow. If they like to work on the computer, they could look up times for the movies or directions when you are going out.

“We focus on the positive things in life. One of the things we did when the kids were young is we created 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.”

- Build on these strengths by developing plans to prevent or resolve problems. Let’s say your teenager is getting into trouble because they have too much unstructured time available after school (ex: hanging out with friends who are smoking pot or drinking). Let’s also say that your teen loves horses and loves to ride. Reduce the amount of unstructured time by getting your teenager involved in horseback riding lessons or helping out at the barn.
- Try to reframe behaviour problems. This can be easier said than done, so it does require intention on your part as a parent, as well as 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.”
 - How can I mentor my child or connect them with a mentor in the community?



- Invite the child/teenager with FASD 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.
- Have you ever heard of the term “anticipatory parenting”? This term was presented in a new online curriculum for caregivers in child welfare (www.fasdchildwelfare.ca). Anticipatory parenting suggests that you, as a parent, know where your child faces challenges so you organize the environment to minimize these challenges. You anticipate problems, based on past experience, and intentionally change the situation to avoid challenges wherever possible. For example, if you know that your child is easily over-stimulated, gets wound up and runs off at the grocery store, then plan to go to the grocery store when you have respite or when your child is at school. When you are shopping with your child, think of strategies to help minimize challenges. Bring a support person with you to help supervise, or try giving your child some responsibility (ex. they can help you push the cart, help put items in the cart, etc.).

“When I asked my nine year-old who has an 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’”.

Structure, Routine and Consistency

All children do better with structure in their lives. This is especially important for 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 realize 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 new cupboard, can create major confusion for a child.

To help your child or youth succeed with everyday activities, make sure you have a consistent daily routine in place at home. Provide them with a structured schedule, whenever possible. Here are some examples:

- Meal times should be at the same times every day, whenever possible. For example, breakfast is at 7:00 a.m., lunch is at noon, supper is at 5:30 p.m. This will help your child prepare for meals and a sense of control and predictability.
- Structure routines into each day. (ex: after school, have a snack, go for a walk, do your homework and then, have a half hour of TV before supper).

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 and youth with FASD are 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. You can then post these pictures so your child can refer to these visual steps every morning – a fun and easy reminder.
- 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 (ex: 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 (ex: bathroom, kitchen, etc.).
- While structure and routine help children and teenagers who have 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.”

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. Nerves throughout our body take in the information and our brain processes the information and tells us what to do with it (ex: respond or ignore).

FASD and Sensory Processing

Children and teenagers 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 and they are busy and actively seeking sensory input. Their reactions to everyday sensations can be either too strong or not strong enough. Many children and teenagers also struggle to keep their sensory systems balanced. It is difficult for them to adjust and adapt to different environmental expectations (ex: 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

- get 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
- cover their ears, overreact with anger or bolting when they hear loud noises (ex: fire alarm at school)
- may create noise to drown out other upsetting noises
- misinterpret a regular speaking voice as yelling

Touch/Tactile

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

Taste/Oral

- fussy eater
- chew on clothing
- put everything in their mouth
- overstuff mouth with food

Smell/Olfactory

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

Joint Sense and Movement

- becomes motion sick easily
- fears their feet leaving the ground
- struggles with co-ordination, may be seen as clumsy
- has poor danger awareness
- has trouble with pressure and movement, may be too rough during play
- has poor body awareness (ex: stands too close to others, tend to get “in your face,” constantly touching others).

Children and youth 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. For example, a child can manage all the conversations at a dinner table one day, but be upset and unable to eat with the family the next day.

Helping Children and Teenagers with Sensory Processing Difficulties

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 (ex: a child crawling behind a piano may be telling you that this is a safe quiet space for them to calm down).

At first, as a parent, you act as an “external brain,” recognizing the needs of your child or teenager. By working together, and with time

and lots of practice, your child or teen will be better able to participate in daily activities and some self-regulation will develop.

Practical Sensory Solutions and Strategies for Everyday Activities

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 – “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 “brain tools” to help get calm, settled, and focused (ex: “You seem quite upset right now. I think a brain 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 or list of acceptable things they can do in their bedroom. You could provide an oil-and-water toy to watch, stuffed animal or a picture book.
- Think of 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 “electronic caffeine” 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 that 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.
- Avoid having them sit in front of a TV in the bedroom.
- Alert their senses with inputs such as turning on upbeat music, opening the bedroom curtains to let sunlight in and immediately giving them a glass of juice.
- Help with organization. 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 a homemade wiggle cushion (ex: a partially-inflated beach ball).
- 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 during supper, then have the child eat ahead of time and join the family for dessert.

Clothing

Children with FASD who are oversensitive will, at times, 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 (ex: "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 Chewlry, a chewable jewelry available online and in some local stores. Another option may be letting your child chew gum where permitted.

Shopping

Malls 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.
- Let your child push the grocery cart. Pushing a cart is a heavy work activity and can provide a calming sensory input.



- Have your child wear a ball cap or hoodie, this will help reduce some 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 (ex: 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. As a general rule, children with FASD are only able to 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 (ex: a clean table, away from TV, family or pets).

- Have fidgets (ex: 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 (ex: 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 neighboring 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 (ex: celery stick) to help extend focus.
- Try gum. The flavor can help 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.

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 (ex: "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 teenagers. 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 them proper menstruation hygiene.

Restaurants

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

Community

- Have fidget devices (ex: 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 a neighboring room.
- Have the child wear a backpack or fanny pack 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 (ex: 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 gas station, the grocery store 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, available in stores, 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 (ex: 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 teenager needs time to calm down, then look for a quiet place (ex: sit on a bench, go for a walk, 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 recognize 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 teens 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 organize themselves.



Praise

- It can be easy sometimes to place more focus and attention on the child's sensory processing difficulties, rather than focus on what the child has done well. When you see that your child or teenager has been able to successfully self-regulate, make sure to provide them with praise. This type of "positive reinforcement" is very effective. It helps them to recognize that they used a self-regulation strategy, it helps build their self-esteem, and it helps to build the parent-child relationship.

Transitions

Children and teens with FASD often have a hard time with transitions or shifting from one activity to another. They may also have difficulty stopping an activity or starting a new one, moving to a different place 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 teens with FASD need more time in the morning to wake up. It helps if there is a consistent wake-up time and morning routine. Some children like to wake up to the sound of a person's voice, while others may prefer music or a certain alarm sound. After the first wake-up call, it usually helps to wait a few minutes before doing another one. Sometimes, pulling the blankets back and providing a robe can be a way to cue them for the next step in the 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 (ex: really interested in the current activity; do not want to do what's coming next).

Strategies to Try

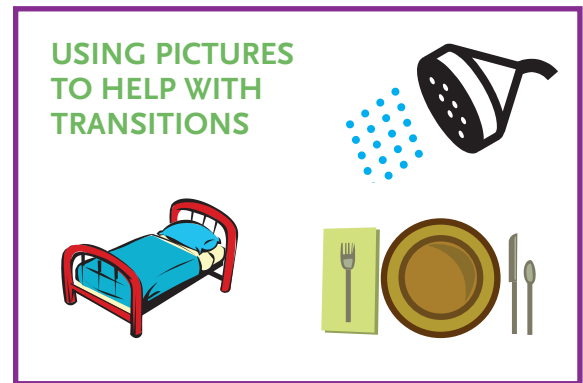
- Give a verbal warning the activity is about to change. Some kids need the verbal cue well ahead of time and some kids are okay with a warning right before the activity is changing. Example language to use: “It’s time to get up now.” “It’s time to put your toys away.” “It’s time to leave for school.” “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.” “When the big hand gets to 10 and the little hand gets to 9, you will leave for school.”
- Because time is an abstract concept, using a visual timer (ex: hourglass) sometimes helps because they can see how much time they have left before they have to transition to the next activity or location. 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, (ex: a book when it’s time for a bedtime story, a snack at snack time).
- Visual schedules can help children see what happens next. For teens, a visual schedule on a computer device (ex: tablet) can be helpful.

The *Visual Schedule Planner* is a customizable visual schedule iPad application, designed to give an audio or visual representation of the events of the day. Events that require more support can be linked to an activity schedule or video clip to help model the task even further.

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 teenagers with FASD often have trouble with:

- learning from consequences (ex: connecting cause and effect)
- applying learning from one situation to another
- remembering things (ex: short term memory)
- setting goals and following through on them
- organizing 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 above average. Also, there does not seem to be a pattern of deficits within this range. 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 teenager 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. “

Strategies to help your child learn:

- 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’ (ex: “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 math and science. Children may also benefit from using technology to help them learn.
- It may also help to rehearse a new skill in advance (ex: how to greet others or how to co-operate during a soccer game).

- Get creative to help your child learn. Instead of using numbers on paper to teach math 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 teenagers with FASD have trouble controlling their impulses. This often looks like typical Attention Deficit Hyperactivity Disorder (ADHD) type behaviours (ex: fidgeting, can’t sit still, acts before thinking) and is one of the brain “functions” that can be affected by FASD. Some children and teenagers may benefit from medication for these ADHD-types of behaviours. You can also help your child manage their impulses in many different ways.

Managing Their 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 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.
- Other sensory activities, such as chewing gum or playing with a bean bag or a fidget toy can help your child focus and calm themselves (see sensory section).
- Children and teenagers 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. There are some great social story cards you can buy to help your child practise positive social interaction. Social stories are a tool to help your child understand social cues and 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, follow this link www.thegraycentre.org/socialstories

Controlling Your Child's Environment

- When your child's impulsive behaviours lead to hurting others or placing themselves in danger, look at what is triggering these behaviours. For example, if your child is lashing out at their sibling while shopping at the mall, it may be that your child is too stimulated by the lights and activity at the mall. Understanding this can help you decide whether or not to take the child to the mall.
- When you see your child or teenager 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 teenager how to recognize when they need to take a break.



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-organize. 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 teenagers with FASD include:

- difficulties falling asleep (ex: 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 (ex: tossing and turning)
- sleep-walking or sleep-talking

Strategies and Solutions

Sleep Environment: As many children and teenagers with FASD have trouble processing sensory information, it is important to create a calming environment to promote sleep:

- 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 pajamas and use bedding that feels soft. Know your child's material preference (ex: 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 teenagers 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 (ex: video games, computers, phones) in the bedroom. For younger children, toys should be cleared and put away at bed time.
- Keep the bedroom layout consistent and uncluttered.

Sleep Routine: Many children and youth with FASD have poor organizational skills and an impaired sense of time. Caregivers find that rules, structuring, routines and consistency are helpful:

- 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 (ex: 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/quiet adult child snuggle/together time or a snack. Listening to soft music can also be calming.

Sleep-Promoting Activities: Many children and teenagers with FASD are very sensitive to their environments, so they are easily over-stimulated.

- Avoid screen time (ex: 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 (ex: watch time on homework and keep in mind that activities, such as rough-housing, may cause over-stimulation).
- Avoid food (ex: chocolate) and beverages containing caffeine (ex: soft drinks).

Medication: Some children and teenagers can also benefit from medication. Melatonin is a common, over-the-counter medication that can help establish a sleep schedule. Talk to your doctor to see if this is a suitable option for you and your child.

“You will not be able to have the perfect girl’s bedroom – deal with it and move on.”

Your 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. The term “environment” refers to many things, including where the child lives or goes to school.

Environment includes:

- physical environment
- family, friends and the community
- expectations and rules
- schedules and routines
- language and communication

Here is a quote from Diane Malbin in her book *Trying Differently Rather Than Harder* (2002):
“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” (pg.38).

Following are some tips about adapting your environment to meet the needs of your child or teenager:

Physical 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 mall, a loud and busy birthday party or a crowded theatre. If your child often has tantrums or meltdowns in these kinds of settings, they may need help. Think about bringing ear plugs for your child when it is too noisy, sunglasses in the mall 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 extras 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 (ex. 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, out of sight place. 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.”

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.

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.
- Use calendars, sticky notes and visual cues as well as social stories to help your children understand what to expect each day and what is expected of them. Visual cues can include photos of step-by-step instructions, picture books of places and people, charts or lists with tasks identified or appointment books.
- 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.”



Schedules and Routines

- 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 organized, 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 teenager's free time as much as possible. This helps prevent them from having the opportunity to make poor choices.
- Transitioning can be hard for children with FASD. You can help by using timers (ex: sand or egg) or provide reminders and preparation when your child is transitioning from one activity to another. The more visual, the better.



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 getting the lecture, 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.

*“I hear and I listen, I see and I learn, I do and I understand.”
(Anonymous)*

Ownership

Children and teenagers 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 teenager 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.

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 teenagers 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 teenagers 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 teenagers with FASD to tell stories (or "confabulate") to fill in the blanks in their memory.

Children and teens 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 teenagers with FASD are lying to them, when, in fact, the child or teen 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 teen with FASD is that when they are storytelling, they are not trying to be dishonest.

Some children and teens 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 teen with storytelling and lying:

1. 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.
2. 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.
3. If your child or teen 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.
4. Try to avoid punishing an impulsive child with FASD for lying. Instead, try using strategies to help your child manage their impulsive behaviour (page 27 for section on Impulsivity).

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 teenagers 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 similar to a three-year-old, the other children may stop playing with the child or start teasing the child. Or the child with FASD may become impulsive and/or invade the other children’s personal boundaries. Or maybe the child is influenced by the other children. These scenarios make it easy to understand how social lags 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 (ex: please, excuse me, no, thank you).
 - Practise how to handle frustration, disappointment and hurt feelings (ex: time outs, count to ten).
 - Practise how to manage someone bothering your child (ex: walk away, speak to an adult).
 - Practise appropriate body contact and personal space.
 - Practise taking turns and sharing activities.



- Also practise appropriate behaviour with your child through role playing (ex: “Charlie, can we play with you?”).
- Practise the behaviour with guidance. (ex: “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 organizing and planning for peer-related activities. Your child may be younger in their social skill development than their age. Note this trait for teaching skills.
- 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 (ex: 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.
- 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.

“Our daughter is such a giving person; she spends a lot of money on friends. Her friends will call her just to fill up the car with gas. I have a rule that whatever friend she is going out with they need to come in and say hi. This has helped me to evaluate her friends and guide her.”

Communication

It is common for children and teenagers 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 teens with FASD.

Children and teens 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 teens with FASD who struggle with expressive language may use the wrong word to describe someone or something (ex: 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 teens with FASD may have problems understanding language because they have difficulty processing information (ex: 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 realized 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 teens 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 teen 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.”

What Doesn't Work and Why

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 (ex: sticker charts)
- verbal consequences (ex: 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 recognize the brain differences of people living with FASD. They fail to consider that some brains have difficulty storing and retrieving information, forming associations, generalizing, 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 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 timeouts, 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."

Finding Support

Within your family

Family members and close friends can be a huge source of support. You can help them understand your child by doing the following:

- Give them 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 (ex. saying “the child can't”, instead of “the child won't”) in terms of brain function.

Most importantly, focus on strengths and celebrate their successes!

Within the Community

Being out in the community is not always easy when there are others who do not understand your child's challenges and struggles. There may be people in school, church, the grocery store or even your neighbourhood who have unkind words and thoughts 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 than yours.”

You may want to give them more information in the form of a flyer, card or booklet.

Advocating for Your Child

You may need to advocate for your child or teenager 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.

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

1. 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 behavior. This may mean trying different approaches to managing behavior.
 - 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.
 - Understanding how your child is affected, their learning style and strengths, as well as your rights and responsibilities under the law.
 - 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.
2. 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?
3. Avoid being adversarial 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.
 - Go into meetings armed with facts.
 - 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!
 - 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!
 - Make requests in writing to make it easier to remember and respond.



5. Share information – Recognize 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.
- An FASD information sheet that explains your child’s disability can be very helpful. A sample sheet is on the next page. 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.

6. 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 (ex.ADHD), feel free to join those groups too.

“Being okay with the fact that I am going to try this and if it doesn’t work, I am going to talk to other parents with children with FASD and see what works for them. I don’t know it all and I am willing to listen and try new things.”

7. Find additional secondary advocates, if you can. A good role model at school, church, child care centre or the community can be helpful.
8. 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.
9. 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.



WHAT YOU NEED TO KNOW ABOUT ME (FOR THOSE 13 AND OVER-ADOLESCENTS AND ADULTS)

I have Fetal Alcohol Spectrum Disorder (FASD). FASD is a term used to collectively refer to a range of disabilities caused by prenatal exposure to alcohol. Because FASD is an organic brain disorder that affects the central nervous system and involved permanent chemical damage to the cells and to the connections between those cells in the brain, the effects last a lifetime. However, that doesn't mean that I cannot be successful in life. Here are some things you need to know about the way my brain works and how to understand my reality.

■ Repetition of directions, instructions and concepts is very important because it allows information to be stored in the habit area of the brain (the right hippocampus) where it will be remembered more easily.

■ Routine and consistency help me to make better sense of the world. Establishing a routine and sticking to it helps me to function more effectively.

■ I can be impulsive at times and this

can affect my relationships. Role modelling and visual cues can help enhance my interactions with others.

■ You may need to adjust some of your expectations to my developmental age, which may be different from my chronological age.

■ My receptive and expressive language may not be the same. Often, I can repeat something back but may not fully understand it. It is very important to follow through with me and ensure that understanding is reached.

■ I often have sensory issues that lead to sensory overload. I may also become overwhelmed if too much stimulus or information is entering the brain at once. This may show itself through intense frustration, anger or other emotional outbursts. I need a safe place of my choice to calm down when I'm feeling overloaded or overwhelmed.

■ I have a unique level of sensitivity to criticism. I can become very upset with a sigh or angry glance. It

helps to be aware of my sensitivity and to act accordingly.

■ Learning and retention of information is accomplished in small steps or stages. I may need you to guide me through a task in simple steps, one step at a time.

■ I can have difficulties with time and money concepts, so I may show up late or miss appointments and forget to pay bills. It helps to have things like reminder phone calls before appointments and assistance with budgeting and due dates for household bills.

■ I may request that a parent or support person accompany me during appointments, meetings and job interviews so that they can help to interpret information.

■ I have many strengths and things that I am good at. Take the time to find out what I can do, and emphasize the positive!

USE REVERSE SIDE FOR OTHER NOTES

LET'S TALK FASD | 20a

Source: Let's Talk

Fetal Alcohol Spectrum Disorder:

Parent Notes for Teacher

To my child's teacher, _____:

My child _____ has been diagnosed with fetal alcohol spectrum disorder (FASD). This is a medical diagnosis and is an invisible neurological disability which impacts the brain, causing the child to learn and think differently. Because of this, my child may act or react in ways that surprise or confound you.

My child can easily become over-stimulated. His/her nervous system overreacts to stimuli that other people barely notice. You and I can filter out extraneous sounds, colors or activity and still focus on a task to be done. But "filtering" requires ongoing, conscious effort on my child's part. My child is distracted by everything around him/her and has a hard time "switching gears" from all the classroom stimuli to focusing on what's important or required in class.

In addition, the "different brain wiring" in my child's nervous system makes it extremely difficult for him/her to follow directions when they are given verbally and all at once. My child works best when you give only the first step of the instructions, let him/her do that step, then proceed to the next step. Modeling, demonstrating or giving visual cues can reinforce what needs to be done. That can range from simply pointing to something you've written on the board to an actual checklist for my child to follow. This checklist can be in print form or in visual form. Instructions need to be articulated in very simple, concrete and literal terms. Usually his/her behavior is a way of communicating to you that something is not working for them. It is not willful, deliberate or intentional.

I realize that this can sound somewhat intimidating. Children with FASD don't respond like other children to traditional teaching methods or behavior modification methods. I want to give you as much information as you need to feel comfortable with my child. Your comfort level helps immensely in creating an environment in which my child will want to learn.

**Please consider writing these interventions into my child's Individualized Education Plan so all his or her instructors can be aware of the interventions and put them into practice.

| What can Over-Stimulate my child | Warning Sign(s) | What helps bring my child back to a "Just Right" state |
|----------------------------------|-----------------|--|
| | | |
| | | |

School is a highly unpredictable environment for a child with FASD. It can be a very frustrating experience regardless of how hard he or she tries. If my child wants to call me during the day, please allow this. It's a good way for him/her to touch base, and will help him/her stay grounded in a "just right" state.

Regular communication between home and school can help ensure that my child is working to his/her potential. With your permission, I would like to propose the following:

Let's try this for _____ weeks/months; then we can talk to see how effective this was for all of us.

My child also has some amazing strengths. Capitalizing on these can help you as well:

FASD can make it hard for my child to trust a teacher or to make friends- not from lack of wanting to or trying, but from not being able to understand the nuances of communication (like interpreting body language, reading facial expressions and intonation of voice). My child's social skills are usually at a lower developmental level than their peers. Structure, repetition, and patience are key elements of creating an environment in which my child can learn. Let's work together to come up with the "best fit" possible for my child.

Thank-you for taking an interest in my child.

Sincerely,

Adapted from FASD: Parent Notes for Teachers, fasd.brighttomorrow.com

Helping Your Pre-Teen and Teenager with FASD

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

*"She needs unconditional love.
She needs to know the door is
always open"*

Understanding and Minimizing Secondary Impacts

Secondary impacts are those problems that arise later in life, often during the teen 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 worrisome, but the good news is that in many cases they can be minimized. As a parent, you can do several things to help your child/teenager 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
- justice involvement

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

School Disruptions

School can be challenging for any teen. There are often higher expectations on students and less support available to them when entering junior high and high school. Teens with an 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 teen gets proper support:

- Share the diagnosis and information about the primary disability with teachers and support staff.
- Communicate your teen's strengths and challenges.

- Ensure that the school is aware of other service providers/supports in your teen's life.
- Provide additional resources such as *What Educators Need to Know about FASD*.
- Advocate for your teens as you know them best (refer to section on Advocacy).
- 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.
- Recognize that transition times may be especially sensitive and difficult, such as moving from elementary to junior high, junior high to high school, summer break to first day of classes and starting with a new teacher or support staff.

Mental Health Concerns

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

1. **Addictions:** There are many reasons why your teenager 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/teenager about substance use and your family expectations about using alcohol and other drugs.
 - Be curious when asking your teenager about their substance use but do not judge. Staying neutral will encourage your youth to be honest with you.

- If you suspect your teenager has substance use problems or has developed an addiction, contact Addictions Foundation of Manitoba (AFM) Youth Services for support and information about how to talk to your child or teenager 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 for your teenager's learning style.
- Get involved to help your teenager at home and in the community with the goals they set during counselling sessions.
- Provide reminders and/or transportation to appointments.

2. **Poor Self-Esteem:** Most people, at some point in their life, struggle with low self-esteem. This may be especially true for a teenager with an 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 teenager feel good about themselves, such as:

- Create opportunities for your teenagers 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 teen involved in organized 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.

3. Self-Harming Behaviours: Self harming behaviors 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 teenager 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 teenager is already feeling badly. Ask professionals for more ways you can help your teenager overcome self-harming behaviors and develop healthy ways of coping.

- Explore healthy coping methods your teenager can use, such as writing their feelings in a journal, listening to music, drawing and other artwork or exercising.
- Use feelings charts to help your teenager normalize all feelings including anger, sadness and joy.
- If you find your teenager “getting stuck” in a negative emotion, try to steer them toward something positive.

High Risk Sexual Behaviours

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

- Talk to your child/teenager 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 teenager 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/teenager attend medical appointments about their sexual health.
- Even though your teenager may have a desire for independence, supervision and support is crucial to help them handle social situations, such as not recognizing a potentially dangerous situation or befriending a stranger.
- Be mindful of your child/teenager’s Internet usage and learn more about how to safeguard against online predators.

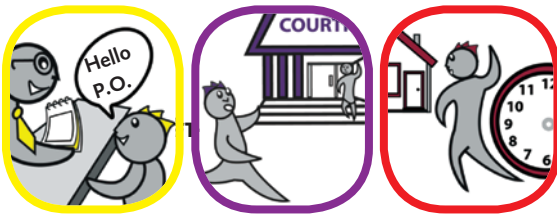
Justice Involvement

In some cases, teenagers with FASD can find themselves getting in 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 teenager get through this challenging time. Many of the processes and the language can be complicated. Asking questions will help everyone understand the process. Following are some ways to help with communication:

- If your teenager is in police custody, inform police of the FASD diagnosis and areas of challenges for the teenager. Ask that they not be interviewed for a statement until a lawyer or guardian is present.
- If your teenager is detained in custody, inform the corrections staff of the FASD diagnosis. Tell them about your teenager’s

strengths and challenges to help the corrections staff better understand them.

- Tell the teenager'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 teenager is assigned to a probation officer, parents are encouraged to communicate with that person. If possible, go to appointments to ensure the teenager 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 teen is more visual, ask about visual tools, such as probation icons.



Transitioning Your Teenager to Adulthood

Transition planning is an important step to help the adjustment to the next phase of your child's life. Your teen 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 their teen'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 teenager has been assessed by an appropriate professional and has all current diagnostic assessments in place. The assessment results will determine whether or not your child qualifies for Adult Services. These include Community Living DisAbility Services or the MarketAbilities Program. Begin submitting applications for these services when your teenager is 15 or 16. http://www.gov.mb.ca/fs/pwd/supported_living.html
- If your child is considered a Vulnerable Person under *The Vulnerable Persons Act*, contact Manitoba Family Services to determine if your teen would benefit from having a Public Trustee.
- Find out what your teen's hopes and dreams are for the future.
- If your teen has a support system in place at school or through other services, include them in the transition planning. Help your teen gain more understanding and acceptance of the type of support they may need in adulthood.
- Consider if your teen would benefit from living at home as an adult or if they need supported living. If your teen 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 (ex: direct payment for rent, utilities and other monthly bills).

- Keep in mind that your teens may be very generous with their money which leaves them vulnerable to financial victimization. Do what you can to protect them from this because it can happen more than once due to difficulty with generalizing from one situation to another, as well as understanding cause and effect.

- When your teen 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 teen to discuss their strengths and challenges with their employer, as well as ways to increase success in the workplace.

“It has been an interesting journey for me. It has been a big learning experience. I have definitely learned more from him than he has learned from me. He is graduating from grade 12 next week – it is a huge accomplishment for him and I feel as though it is a huge accomplishment for our family, because it’s not something he did by himself. We are just so proud of him and so excited to celebrate with him next week.”



Talking with Children and Teenagers About FASD

It is important that your child or teenager 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 to 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 teenager about their FASD. Maybe you are worried about:

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

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. 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 (ex: a picture of the brain) to help your child understand what is happening for them. Try to normalize 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.

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 teenager 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 realize 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 teenager'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 teenager understands their disability, it can open the door so that you can work together to find ways to address their challenges. Many children and teenagers 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, your teenager will develop positive coping strategies because of their understanding of FASD and will be better able to advocate for themselves in the community.



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 recognize 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.”

Taking Care of Yourself

“There are days I have pushed myself to the limit and I am starting to shut down. Finding the best strategies for self care for me is important.”

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 – get 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 (ex. 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 organizations and from personal supports.

“People who have children with FASD are exhausted. Sometimes we are scared to say that we are tired. But it’s okay”

- 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”:
“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...at least the car is not running...at least it is a nice evening to sit outside. 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.”

Though parenting is hard work, it can also provide indescribable joy. Laugh at the many hilarious ‘FASD moments.’ Be grateful for your children. Keep yourself strong enough to recognize the joy.

FASD Resources in Manitoba

If you have more questions about FASD, please visit the Healthy Child Manitoba website at www.manitoba/healthychild/fasd/resources for a list of Manitoba resources in the following areas:

- FASD diagnostic services
- outreach and support services for children, youth and adults
- family support services
- FASD prevention services
- FASD information and resources

FASD Websites

Manitoba FASD Centre

www.fasdmanitoba.com

This website gives information about assessment and diagnosis processes and referrals for Manitobans, education and training opportunities and local FASD research.

Manitoba Coalition on Alcohol and Pregnancy (MCAP)

www.capmanitoba.ca

MCAP is a province-wide, collaborative network of individuals and organizations, from across all sectors, committed to supporting prevention, education, research and intervention activities in the area of FASD. This website has local information on FASD programs, services and resources.

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