

TIPS

For Parents
& Caregivers

FASD 
NETWORK

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WHAT IS FASD?

Fetal Alcohol Spectrum Disorder (FASD) is a disability that can occur in children, youth, and adults when alcohol is consumed during pregnancy. It is a lifelong, brain-based, and often invisible disability. It is called a spectrum disorder because there are many different symptoms so no two people with FASD are the same. Primary disabilities are caused directly by exposure to alcohol during pregnancy. There is a wide variety of primary disabilities. They are organized under the following four categories: physical, cognitive, behavioural, and sensory.

Physical Disabilities

Prenatal exposure to alcohol can affect how a body grows and develops. People with FASD can have differences in how their bodies are formed and how they move.

Cognitive Disabilities

Cognitive functioning refers to intellectual tasks like thinking, reasoning, and remembering, which are crucial in our everyday functioning. People with FASD can have trouble with many cognitive tasks.

Behavioural Disabilities

Your brain controls your behaviour in social interactions. Individuals with FASD may seem to display strange or inappropriate behaviours because their brains do not process other people's actions and words in the same way. Research has found learning and behavioural differences between people with FASD and others in relation to their developmental age. Dysmaturity is when someone's developmental age is younger than their physical age, so they act and think younger than they are.

Sensory Disabilities

Every day, your senses take in a huge amount of information from your environment. Receiving and interpreting this range of information is called sensory processing. Because the brain takes in so much information, the sensory system works best when all senses work together, which is called sensory integration. Prenatal exposure to alcohol can damage the central nervous system and cause sensory processing or integration problems. This can result in sensory-seeking behaviours such as unusual hyperactivity or avoidant behaviours such as shutting down to any responsive actions.

Secondary Challenges

Secondary challenges are those difficulties that arise later in life due to a poor fit between the individual's needs, level of functioning, and the environment. Complications arise most often because of undiagnosed primary disabilities, lack of intervention, lack of services, ineffective strategies or unrealistic expectations. Many organizations and people are not educated on FASD and the brain differences that influence behaviours. Having FASD doesn't mean that these things will definitely happen. If we put the right supports in place early on, we can help to avoid secondary challenges.

TIPS FOR BEHAVIOURS

It is important to remember that if a child has FASD she has a disability. Behaviours she exhibits are quite often a result of the disability and her environment. The child's behaviours are not intentional. She is not doing things to purposely make you mad or frustrated; her behaviours are a direct result of the prenatal alcohol exposure and often become a way of communicating.

Once we understand and make sense of her behaviours it will be easier to put the proper supports and interventions in place.

- Adjust your expectations for the child's developmental level.
- Shifting our perceptions from the child "won't do something" to the child "can't do something" makes an incredible difference.
 - Making accommodations is supporting an individual, not enabling or excusing behaviours.
- Provide immediate feedback and recognition. Encouraging words work well to reinforce positive behaviours.
- Depersonalize behaviours, think of them as symptoms of the disability.
- Explore the factors that may be causing behaviours – behaviour records, such as journals, allow you to look back to see what was going on when certain behaviours have happened and what the common occurrence has been.
- Look at behaviours as an attempt at communication. Are they expressing fatigue? Fear? Failure?
- Discuss behaviours with your child, ask what they were feeling/experiencing at the time.
- Instead of trying to change the individual, change elements of their environment including physical elements affecting their senses, as well as the attitudes, expectations, and assumptions of the systems around them.
- Use strength-based approaches such as implementing different learning styles and kinds of intelligence (visual, auditory, hands-on, etc.) based on the child's strengths.
- Educate others in your child's life who may incorrectly see their behaviours as 'lazy, unmotivated or oppositional.'
- Traditional behaviour management techniques (such as token rewards and money) may not work.

TIPS FOR BEHAVIOURS

Examining the link between the primary disabilities caused by FASD, the expectations of most environments, and how we interpret the behaviours that are a direct result of the poor fit between individuals and their environments can allow us to think outside of the box to create accommodations that prevent challenging behaviours.

Our expectations	Characteristics of FASD	Resulting behaviours	Interpretation of behaviours	What we usually do	Accommodations
Think fast, timed tests, finish tasks in time allotted	Slow cognitive pace	Anxiety, frustration, tantrums	Avoidant, not trying, holding others up on purpose	Take away privileges, shame, ridicule	Give time, slow down, reduce work load, accept slow pace
Follow the rules, learn inferentially, 'get it' by watching	Difficulty generalizing, gets the piece not the picture	Fear, frustration, anger	Willful, on purpose, intentional, he knew what the rule was	Punish	Accept the need to re-teach concepts in different settings
Act your age, be responsible and appropriate	Dysmaturity: Developmentally younger than their age	Lonely, isolated, depressed	Poor social skills, acting like a baby, inappropriate	Teach age-based skills, punish behaviours	Think younger, base expectations on developmental age
Pay attention, sit still, ignore distractions	Sensory issues: over stimulated, overwhelmed, easily distracted	Agitation, anger, overactive, anxiety, avoidance, tantrums	Not trying, off task, undisciplined, ADD	Punish, more work, medicate, no recess	Evaluate environment, adjust accordingly, provide breaks
Learn the first time, remember from day to day	Memory problems, "on days and off days"	Anxiety, fear, no confidence, eroded esteem	Doesn't care, lazy, needs to try harder	Punish, ground, shame	Recognize and allow for variability, prevent anxiety
Think ahead, plan, set goals, rein in impulses	Impulsive, inability to predict outcomes, acts fast but thinks slowly	Avoidance, defiance	Willful, disobedient, inappropriate, doesn't care	Punish	Prevent problems, build on strengths, use visual cues

TIPS FOR COMMUNICATION

Because of the primary disabilities, communication can sometimes be a struggle for individuals living with FASD. A lack of comprehension can be caused by a variety of primary disabilities such as poor receptive language skills, confabulation, dysmaturity, sensory disabilities and a lack of understanding cause and effect.

If you try ensure communication is understood, consistent, and done in a way that supports the child, you will have more success with communicating.

- Individuals with FASD need more time to learn some things. You can help by being patient and explaining the same things multiple times.
- It is helpful if a person receives the same message in the same form from all of his or her support workers. It is important to repeat, repeat, repeat.
- Asking individuals with FASD to repeat instructions does not ensure that they understand the meaning of what they are saying. Requesting that they “show you” or explain in their own words will more accurately demonstrate their level of understanding.
 - Your child may develop a large vocabulary that makes it harder to notice communication difficulties but you may need to stop and ask if they know the meaning of new words.
- Re-teach rules in different settings. Use visual charts and reminders.
- Communicate while being mindful of an individual’s ability to process information, be aware of the pace and tone of your speech.
- Be consistent with visual, verbal or physical cues. Ensure everyone in your house is using the same strategies with the individual.
 - Using the same words for instructions can help with long-term memory.

TIPS FOR COMMUNICATION

- Use words or statements that are specific to the desired behaviour you wish to achieve. For example, say “walk” instead of “don’t run.”
- Avoid intonations and verbal tones that are attached to abstract meaning such as sarcasm, individuals with FASD may not pick up on the hidden meaning behind a change in pitch or intonation.
- Try to be aware of your tone of voice, it can be easily misinterpreted. Try your best to use gentle and calm tones.
- Allow extra response time. An individual with FASD is a “ten-second child in a one-second world.”
- Know their levels of expressive and receptive language and speak to that level. Try to mirror their vocabulary.
- Be concrete and use plain language.
- Making sure they maintain eye contact with you can help them focus. Get down on their level if needed.
- Try giving instructions without all the extra words.
- Open ended questions can seem abstract to an individual with FASD. Asking questions about the specific information you want may be a better strategy. For example, instead of asking ‘how was school?’ try ‘what did you do in gym class today?’
- Writing things down or using visuals can be a good way to assist with communication.
- Remember that individuals living with FASD may struggle to understand abstract concepts like jokes and figurative language. For example, “keep your shirt on.” Try to say exactly what you mean.
- Emotions can be hard to communicate. You can try practicing with your child to identify and label feelings using a chart or pictures of facial expressions demonstrating different emotion. Learning how to label their feelings may allow a child to express themselves verbally rather than through their behaviour.

TIPS FOR COPING WITH SENSES

Some children with FASD are very sensitive to touch, movement, light or sound. Because of the way their brains work, children with FASD may be so focused on what they hear, see, or feel on their skin that they can't focus on other things. When children have heightened senses, they may need to shut down or they might act out. This can be very hard for parents to cope with, especially when you are out in public.

It is important to remember that some children with FASD have sensory impairments. They may not know when they are hot or cold and some may not feel pain as much as other children can. Try to help these children dress in the right way for the weather and check them for illness or injury.

Example #1

A parent takes her child to a puppet show at the library. All week he has wanted to go, but when they get there, the room is noisy and crowded and the child gets nervous. He plugs his ears and as he gets more frustrated he starts to yell, "shut up" at the kids around him.

What you can learn:

- This child is over-sensitive to sound. The noise in a crowded room is too much for him. He tries to cope by covering his ears. His sensitivity to noise makes him frustrated and over-stimulated. Assess an activity before you plan to attend it. Think about what sense may be over-stimulated.

Example #2

A 7-year old child takes off her socks as soon as she gets home from school. Sometimes she takes her socks off at school. When the girl is asked why she takes off her socks she says, "I can't stand to wear them."

What you can learn:

- She is over-sensitive to the clothing she's wearing. She can feel even the small seam in a sock and can't 'tune out' that feeling. This means she can only focus on the clothes that bother her and nothing else. She needs to wear clothes or adjust clothing so that they are comfortable for her. You may want to turn her socks inside out so that the seams don't bother her.

TIPS FOR COPING WITH SENSES

- Try to find out what your child is reacting to so that you can avoid what's causing him or her trouble.
- Try not to go to places where your child may be over-stimulated by noise, light, etc. You may also want to be proactive and have sunglasses or headphones ready.
- If a child is showing signs of over-sensitivity to something, and heading to a 'meltdown,' try to leave before the meltdown happens. As the child gets older, he or she can be taught why they are feeling over-sensitive, and how they can avoid these situations.
- An occupational therapist may be able to suggest some exercises or ways to reduce the child's sensitivities.
- If you want or need to go to public places like malls or fast food restaurants, try to go at quiet times of the day. Fewer people go mid-afternoon or early in the day.
- Holding the child's hand will help him feel calmer and less confused by the hustle and bustle around him. Plan to stay for a short time only.
- If a child seems sensitive to light, offer sunglasses, tinted goggles, or a big sunhat. Use dim lighting when you can.
- Wash all clothing a couple of times before wearing and remove all tags. Turn things inside out so the seams won't bother your child.
- Bedding needs to feel comfortable for the child. Some children like heavy blankets on their beds (even in summer) and some like light blankets on their bed (even in winter).
- To some children, a firm touch feels better than a light touch. Some children like their hair stroked while other children like a firm backrub. Find out what kind of touch your child prefers.
- Provide breaks from things if it becomes overwhelming. Create a safe space for them where they control all the sensory input.
- Do audits of their environments, like bedrooms or classrooms, to see what may cause issues.
- Go to places/events early to allow them a chance to get a feel for the new place and get settled. Discuss what a new activity or place might be like and what to do/where to go if it's overwhelming.

TIPS FOR ROUTINES & STRUCTURE

Routines are important in everyone's life. Understanding that we do specific things at certain times every day helps keep us organized. Knowing what time the school bus comes on school mornings or what time we go to bed helps us feel secure because we know what to do.

Children and teens with FASD can have a hard time being organized. Parents or caregivers can help them by creating routines. Routines will help a child learn good habits and bring stability. A child with FASD may never fully understand why it's important to brush and floss his or her teeth everyday, but what is important is that they develop the good routine of brushing and flossing everyday.

Visual aids that show routines are very helpful. A chart with pictures of what a child needs to do can help the child see the steps needed to complete an activity. For example, a visual chart in the bathroom could include pictures of washing his face and hands, brushing and flossing his teeth, combing his hair, and putting on deodorant. Verbal prompts, when used with visual aids, are very helpful.

Example #1

Every morning Brad has trouble getting ready for school. When he goes to his room to get dressed, he needs to be called several times to hurry up and get ready for school. He forgets to brush his teeth and wash his face. Then he can't find his school bag. The more his parent or caregiver tries to hurry Brad along the more stressed and upset he gets. Brad often leaves for school in tears.

What is happening:

- To get ready for school, Brad needs to do many things. He doesn't have a routine, so he is very disorganized. He knows he needs to get ready and out the door by 8:40 a.m. but can't understand all the steps needed to get him organized. Brad shows his confusion and frustration by becoming emotional. He may even shut down because he feels so overwhelmed by everything and that he can't do anything right.

What you can do:

- With your child, make a plan of what needs to be done to get ready for school. The night before school, help him pack his book bag and get his clothes ready. Some children like to lay their clothes out in the order the clothes go on. This activity helps them stay on track when they are getting dressed. A toaster on the counter with the bread, butter, and jam beside it, or a cereal bowl and spoon on the table will remind him what he is having for breakfast. Pictures of his bathroom routine will help him to leave home clean and neat. Be sure to walk him through the steps a few times before you let him try on his own.

TIPS FOR ROUTINES & STRUCTURE

- Decide which parts of your day need routines. Some ideas are wake up and bedtime routines, mealtime routines, when to watch TV, play, or do chores. Simple routines like sitting in the same seat at the table or in the car are important.
- Keep routines simple and basic. Develop routines that build on your child's strengths.
- Keep the same activity patterns every day. Children with FASD thrive on routine and structure. School gives structure to the day. Staying up really late on weekends or holidays can make your child feel out of sorts. This can lead to poor choices and behaviours that are upsetting for the whole family.
- Think and plan ahead. Think about what could go wrong and make changes to the environment. For example, it can be noisy and confusing for a child when the entry bell rings at school. Having an adult routinely meet the child with FASD at the door to lead them through the maze of children to their classroom can be helpful.
- When asking your child or teen to do something use the same plain and simple phrase each time, such as "Sandra, time to get ready for bed."
- Teach the steps of a task in the same order every time. For example, when doing the dishes, teach the child to use 3 steps: scrape, rinse, and wash in hot soapy water. Your child may not understand why he should scrape the food off the plate, but he knows it's a good way to do dishes.
- Always plan for the future when you teach a child with FASD a new skill. They may not be able to change a routine once it is locked in their brains.
- When changing from one activity to another, children with FASD need time to adjust. Warn your child about a change in plans.
- A weekly calendar that has pictures can help children with FASD understand the days of the week. It is helpful to split the day into three parts: morning, afternoon, and evening. You can place a picture of an event on the day it will happen.
 - For example, a picture of a church on Sunday morning or a picture of a child in her Brownie uniform on Monday evening. This will help the child remember activities.
 - When your child keeps asking about an activity, have him check the calendar and then tell you what activity is on the calendar.
 - Family activities can be colour coded. All activities for Jamie are in blue and all activities for Anna are in red.
- Routines help children and teens with FASD to succeed and feel good about their lives.

TIPS FOR TRANSITIONS

Transitions can require a high level of executive functioning and flexibility. People with FASD can be 'thrown off track' when transitioning from one task to another as they may require more time to process information and complete tasks, which can result in behaviours such as frustration and defiance.

- Tell your child ahead of time if the routine has to change. Some children may need a full day's notice of change, and others may do best with just a few minutes' warning.
- Plan change occasionally. Talk with your child or teen about what might happen if the plan doesn't go the way you hope. For example, "What will we do if our car isn't fixed by tomorrow?"
 - Sometimes it makes sense to plan for problems. Talking about a plan B or C can teach your child or teen about how decisions need to be flexible.
- Break changes into small steps. For example, "First you need to put away your toys." "Okay, now let's go brush our teeth." "Good, here are your pajamas." A long list of things to do is very confusing for children and teens with FASD.
- A countdown may be helpful for younger children. For example, "Play for five more minutes and then it's time for your bath...three more minutes...time to put the toys away; your bath is ready."
 - Using an egg timer may help your child or teen 'see' how much time is left for a certain activity. For example, if you ask them to do homework for 15 minutes, they will hear the bell when the time is up.
- When you can, let your child finish the thing she is working on. Some children really like and need to take their time to finish things. They enjoy working on things at their own pace and like to finish a project.
- If a transition didn't go well, resulting in a meltdown or tantrum, you can try it again as a 'do over.' Go through the steps of the transition with your child, repeat as many times as necessary until they feel calm and know what to expect.
- Perseveration can occur during transitions between tasks. This is when the child is unable to let go of an idea or topic.
 - A child could be perseverating because the next task is too difficult, you can try to get them an easier task.
 - A child's pattern for perseveration can be predictable, if you learn what the pattern is you can prevent perseveration at the first sign.
- Use photos of real people and places to help prepare a child for moves from one grade to another or to a different school or home. For example, a 'transition book' can help get a child ready for a move to the next grade. This book can have pictures of the child with this year's teacher and pictures of the child with next year's teacher. The book can hold pictures of the child's new classroom, where he should put his boots, what door to come in, etc. This may make it easier for him to adapt to a big change in his life.

TIPS FOR TRANSITIONS TO ADULTHOOD

- Start planning for the transition to adulthood as soon as possible. Talk to the individual about their hopes and dreams for the future.
 - Create a transition team of people who will help support your child as they move into adulthood. Work with this team to create a life-plan of clear objectives and goals for the future, make sure to involve the individual in creating these plans.
- Don't make assumptions and generalize strengths. Even if your loved one demonstrates exceptional skills at home, it may not mean they can be independent and self-reliant. They may always need the same level of support.
 - Planning the transition into adulthood can help the individual develop understanding and acceptance if they need to continue living at home, receiving help for daily living, being financially inter-dependent or co-parenting their children, etc.
- Try to help them adjust for the transition from school into the workforce by focusing on life skills (job training, apprenticeships, etc) over academics. Work-ed programs at school can help with this adjustment.
- Ask your loved one to sign Freedom of Information disclosure letters. This will allow you to talk to service providers on their behalf.
- It can be very stressful to think of your loved one's future after you are gone, having plans in place can help ensure they are always looked after. Here are some places to start when planning for the future:
 - Disability Tax Credit - a tax credit for parents/guardians of a child who lives with a disability. To be eligible, a medical practitioner must confirm the disability and its effects on a form. The form is then submitted to the Canada Revenue Agency, who make the final decision about the child's eligibility. Applying for the Disability Tax Credit opens the door for the Child Disability Benefit, Registered Disability Savings Plan, and Disability Savings Grant and Bond.
 - Child Disability Benefit - a tax-free benefit for families who care for a child under 18 with a disability.
 - Registered Disability Savings Plan - a savings plan that is intended to help parents save for the long-term financial security of a person who is eligible for the Disability Tax Credit. Withdrawals from RDSP do not affect the person's social assistance amounts.
 - Canada Disability Savings Grant and Bond - these bonds are money the Government contributes to the RDSP of low and modest-income Canadians. Applications for the grant and bond can be made at the financial institution where your RDSP is.

TIPS FOR DECISION MAKING

Everyday decisions are sometimes difficult for people living with FASD to make because their brains work differently. Children with FASD may not be able to clearly understand the consequences of their actions. They may also have trouble sorting out the facts when they make decisions.

Decision making is a life-long challenge for people with FASD. They will need the aid of someone who can be trusted to help them make good decisions. But how do you help your teen or adult to be independent? Teens with FASD are like most teens: they want to feel good about themselves, have friends, and be independent. They are likely to act first and think later because of the way their brains work. They are often more impulsive than their peers and quick decisions can lead to trouble.

This sheet offers you some tips on how to teach your child about how to make good decisions and wise choices.

Example #1

It's a cold winter day and your child doesn't want to put on their coat, hat, or mitts.

How you can help:

- To understand your child's reasoning behind the decision you need to look at all of the factors affecting the decision. Is this a behaviour because of the disability? Your child may not feel the sensation of being cold. Therefore, he or she may not know to wear additional clothing as the weather changes. You could put up visuals showing the seasons and suggestions of what to wear. Your child may also be overwhelmed by the choices. Does he or she have more than one option for winter clothing? Is the closet cluttered, making it hard to tell what belongs to who? It also might be something as simple as the sensation of that clothing item. For example, if there is a tag inside of the mitten, it may be quite irritating if your child is over-sensitive.

Example #2

An adult is on her way home from work and she has just enough money for the bus. While she's waiting for the bus to come, she gets hungry. She goes into the store and buys a chocolate bar. Now she doesn't have enough money for the bus and she is going to have to walk home.

How you can help:

- A monthly bus pass, or enough bus tickets to last her the whole month, would help her get home safely from work. Help her to pack snacks so that she has options if she feels hungry.

TIPS FOR DECISION MAKING

- Offer only two choices at a time. For example, “Do you want to wear your blue sweater or your red sweater today?”
- Encourage your child when she makes a good decision. For example, “That was great that you stayed on the sidewalk when your ball went in the street.”
- Youth and adults with FASD need a long time to learn some things. You can help by being patient and explaining some things over and over again.
- People with FASD may need a lot of time to make good decisions. Try to give them plenty of time to make up their minds.
- Try to have fewer things to distract them when they have to make a decision. For example, before the family orders food in a restaurant, talk about what meals are on the menu and help them decide what they want to eat and drink. Then let them order food first from the waitress or waiter. If you go to the same restaurant every time, they may feel more relaxed and less confused.
- Help them understand that everyone makes mistakes and that it’s good to stay calm when you’ve made a mistake.
- Teach them to look around and see if there is someone they know who they can ask for help. If they don’t know anyone, teach them that it is always OK to ask for help from their caregivers.
- Talk about different situations and how what they decide to do could be a good choice or a poor choice. For example, what would you do if you missed the bus? Would you stay in the bus shelter and wait for the next bus? Or would you walk to work even if it’s really cold out?
- Point out how everyone has responsibilities to themselves and to others. For example, it is our job to keep our bodies clean and to wear clean clothes.
- Take time to explain what can happen when money is spent on the unnecessary things or when a job is not done right. For example, if all the money is spent on new clothes, how will the rent be paid and food bought?
- Make their chores and responsibilities habits in their lives. If they have good habits and clear routines they will have less decisions to make every day.

TIPS FOR UNDERSTANDING ABSTRACT CONCEPTS

Abstract concepts like time, math, or money can be difficult for people with FASD to comprehend. Individuals with FASD tend to learn best when things can be touched or seen since they are concrete thinkers.

Example #1

Your child asks you over and over again when an event is going to happen. “When is Barney on?” “When is it supper-time?” “When is Daddy coming home?” are just some examples. You are going crazy because he asks the same questions twenty times a day.

What is happening:

- A child with FASD has no internal clock. The passing of 10 minutes or 1 hour feels the same to him. He looks at the clock on the microwave and it says 8:00. He does not know if it means 8:00 in the morning or 8:00 in the evening. He needs help keeping his day organized. Many children with FASD get thoughts stuck in their heads (this is called perseveration). This causes them to ask the same question over and over again.

What you can do:

- A digital clock is much easier for a child to understand than a clock with hands. Be very consistent with how you say the time to your child. We understand that 2:45, fifteen minutes to one and quarter to one all means the same time. A child with FASD may think you are giving him 3 different times.

Example #2

A teen sells his new \$100 running shoes to a friend for \$5. He doesn't understand what he did wrong.

What you can do:

- Go with the teen and ask that his shoes be returned for \$5. Explain that we don't sell our things to other people without asking a parent or trusted adult. Try to explain the value of money in smaller things such as chocolate bars. “Your runners are worth 100 chocolate bars and all you got for them was 5 chocolate bars.”

TIPS FOR UNDERSTANDING ABSTRACT CONCEPTS

Tips for Help with Math

Mathematical concepts can be difficult for individuals living with FASD. Math often involves many symbols and terms, translating word problems into the correct mathematical sequences, and mental problem solving. Here are some basic tips to help your child or teen with their math skills.

- Search for FASD-aware tutors who don't rely on memorization to learn math concepts.
- Allow the use of calculators and technology to assist them.
- Try to find hands-on or visual ways to help them learn the basic concepts.
- Teach and continually review mathematic vocabulary like add, subtract, multiply, divide. etc.
 - Create a chart of different words that mean these terms. For example 'take away' means subtract, 'plus' means add.
- While working on their math skills, continuously stop at key points to check for comprehension.
- Reduce the number of math problems on the page to prevent them from becoming overwhelmed.
- Use a highlighter to help them identify the instructions of word problems.
- Allow them to have enough time to complete the questions.
- Try to use the same terminology and instructions being taught at school.
- Try practising math everyday for short periods of time.
- Focus on teaching practical math that the individual will need in their lives.
- Advocate to the teachers and school for your child to be allowed extended time on assignments and tests.

TIPS FOR UNDERSTANDING ABSTRACT CONCEPTS

Tips for Understanding Time

The concept of time can be difficult for people with FASD to comprehend. Some individuals with FASD may lack an internal sense of time and since FASD also causes faulty memory it can be difficult for someone to plan and anticipate events. Sometimes a person being late, or missing appointments, is misinterpreted as purposeful and lazy. In reality individuals with FASD are often unable to understand concepts of time and may need some assistance.

- Establish routines that will help to develop habits. The habits will serve in place of an inner clock.
- Use an egg timer for activities like showering and brushing teeth. Teach your child how to set the timer.
- Make the passing of time visual with a countdown clock or using plastic chains with each link representing five minutes, remove the chains as time passes so the child can see how much time is left.
- Write down what time the child is to leave for school. Tape this paper by the digital clock on the microwave. Tell your child, “When the numbers match, it’s time to leave for school.”
- Teach time by association, compare the passing of time to something the child might understand. “We will be at Grandma’s house in the time it takes to watch your favorite show.”
- Use the radio or TV to help the child understand when it’s time to do something. “It’s time to go when this episode is over” or “We will clean up for one more song.”
- Link the time of day to an activity such as brushing teeth before bed or washing the dishes after breakfast. This will help the child develop good lifelong habits.
- FASD can cause faulty memory. Teach your child to write down appointments and events in an agenda or daytimer and to refer to it often during the day.
- There are many ways to refer to the time of day, try to use the same words every time. For example always saying, “ten minutes after,” “fifteen minutes after,” instead of mixing it up with “quarter to,” or “half past.”
- Advocate with school, employers, or anywhere else for flexibility in the schedule as time is an issue individuals may struggle with their whole lives.

TIPS FOR UNDERSTANDING ABSTRACT CONCEPTS

Tips for Money Management

Managing money can be very confusing for people with FASD. Money and the value of money are hard to understand. Twenty dollars for a chocolate bar and twenty dollars for a pair of new shoes may both seem like good prices to the teen or adult with FASD. Money is an abstract concept. That means while you can touch money and hold it in your hand, what money can buy or what money can do are ideas. How much is something really worth? What happens if you don't pay your phone bill and your phone gets cut off? Why should we try to save money? How do you get out of debt? These are concepts worth discussing.

- You can help your child understand the value of money. Go shopping together. Give her a small list of items your family needs and tell her she only has \$20 to spend. Have her write down the prices of the items she puts in her cart and add the prices up on a calculator. This will help her understand that the food she puts in the cart all cost money.
- Teach the concept of money by relating it to the value of objects. For example: \$2.00 is a chocolate bar, \$20.00 is a new book.
- Do not give her large amounts of money to spend all on her own, help her spend it wisely. If the teen insists on an expensive item, have her save it in the bank for one month. This will allow her time to think things over. Praise her when she makes good decisions.
- Have her spend some of the money she earns or receives from allowance on the things she wants or needs. This will help her understand that shampoo, clothes, and treats all cost money.
- Have him pay for a magazine subscription or his own phone or internet bill. When the bill comes in the teen's name, help him read the bill and find out what amount of money must be paid and on what date it must be paid.
- Teach your child that it is cheaper to spend \$80 on food for 2 weeks than to spend \$5 a meal each day eating out.
- Give your child, teen or adult the freedom to make small mistakes without bailing them out. We all learn from mistakes.
- Find a trustee. It's better if the trustee is not a family member or friend. The trustee will give the person small amounts of money and supervise bill paying. There are agencies that act as trustees; call community organizations for ideas or referral to organizations that provide this service.

TIPS FOR DISTINGUISHING FACT FROM FICTION

All children tell stories. Children see the world differently from the way adults do; children with FASD have a hard time knowing the difference between reality and fantasy.

Children may story-tell, over and over again, about many things. They aren't doing it intentionally; they may be having trouble with short-term memory, so they are filling in the blanks. They may be trying to please you by telling you what they think you want to hear. They may be having trouble thinking in a logical way, and because of the way their brains work, they might really believe that what they are telling you is the truth. Confabulation is the term used for when individuals with FASD "fill in the blanks" of stories with whatever makes their experience make sense to them. Sometimes confabulation can be misunderstood as lying, but often this exaggeration makes sense or becomes true in the moment to those who are saying it.

Confronting a person about a story can lead to a blow-up. If they are approached without negativity, accepted, and not confronted or rejected, some individuals with FASD are able to recognize or end a confabulated story.

Example #1

You ask your son if he has brushed his teeth. He says he has but you see that his toothbrush is still dry. You feel mad because he seems to be willfully lying.

What is happening:

- He is telling the truth as he sees it. He HAS brushed, many times in the last month. Because of the way his brain works, his sense of time is different from yours. He doesn't connect your question with something that has happened in the last half hour. His answer shows that he processes information differently.

Example #2

One member of the family has lost \$20 while doing laundry. The rest of the family has been told that the money is missing. The next day your child with FASD finds the money. She insists that this \$20 was not the one that had been lost, even though she found it in the laundry room.

What is happening:

- The child with FASD may believe she is telling the truth. She can't connect the money she has found with the lost cash. After all, in her mind that money is lost – the money she found isn't lost! Even when something seems clear and obvious to you, it might not be to your child. You'll need to make an effort, over and over again, to fill in the gaps of what your child can't understand. For example, when talking to your child, ask questions like, "Do you think it might

TIPS FOR DISTINGUISHING FACT FROM FICTION

- Understand the difference between confabulating and lying. Lying has an intent, confabulation doesn't.
- Avoid asking questions you already know the answer to, like "Are you sure that's what happened?"
- Ask short questions with definite answers. Ask only for the information needed at the moment.
- If the confabulations are not serious or indicative of danger, allow them to engage you with the story.
 - If the confabulation indicates danger, examine the statements further.
- Can your child tell you when she has made a mistake or lied? There are times when you will need to help a child sort out the truth from a lie. It helps to have an open and honest relationship with each other.
- Learn to give very clear instruction like, "Go brush your teeth please." A clear order is less confusing than asking questions.
- Encourage your child to tell you what is true, not what they think you want to hear.
- Practise storytelling with your child. Have your child tell you stories and praise her for having a good imagination. Tell her there are good times to make things up and bad times. Offer real life examples.
- Read stories with your child every day. Many books are based on make believe. Have your child tell you when he thinks the story might be true or when it is made up.
- Be very careful about what you allow your child to see, read and hear. Your child may have a lot of trouble separating reality from fiction in the things he sees. Be aware that a child may believe that what he sees on TV shows, movies and video games are "real". Take the time to sit and watch the TV or a movie with your child. You will be able to help him sort out fact from fiction.
- Know what she has been doing and needs to do next. This way you will know what really happened and be able to guide your child to remember the facts.
- Help family members and school staff understand that your child may not remember things as they really happened. Be positive about it if you can and suggest some of the ideas mentioned here. Do this before there's a problem, if you can.

TIPS FOR CAUSE & EFFECT

FASD significantly impairs information processing. This is one of the most difficult characteristics of FASD, since processing information impacts so many aspects of our daily lives. Cause and effect is the ability to translate information into an appropriate action, or judge the link between action and consequence. An understanding of cause and effect is also impacted by an individual's limited ability to generalize information learned from one situation and apply it to another.

Individuals with FASD often have difficulty predicting long-term consequences, or being able to see how the consequences of one situation are related to the outcomes of another. This is why individuals with FASD may repeatedly make the same mistakes or get in trouble for the same reasons. An inability to conceptualize the link between cause and effect is often misunderstood as having a lack of remorse.

- Use clear and concrete words in short sentences. Use a calm and clear voice. Messages can be lost when given in a highly emotional or excited tone.
- Use positive reinforcements to encourage good behaviour.
- Understanding cause and effect may take teaching over and over again in all situations.
- Create visual reminders of expectations and outcomes.
- Map out decision making so your child has a concrete visual to represent the proper path and consequences of each path.
- Use social stories that are age appropriate to describe the effects of possible actions and inactions.
- Make them accountable for the decisions they make. Remind them of the consequences that they had to experience for past decisions.
- Help your child to problem solve, go through things such as, "What was the effect of your actions? What else could you have done? What else could you do next time?" Try writing it down so they can follow the conversation.

TIPS FOR CONSEQUENCES

When we take a moment to think about classic parenting strategies, we can see how most of them may not work for children with FASD. For approaches such as time-outs, taking things away or grounding to be effective the child must remember what they did to get in trouble, understand the cause and effect of their actions and generalize an understanding that the consequence will happen again if they repeat their behavior. These types of punishments or consequences require a level of executive functioning that may not be possible at the child's developmental level.

These parenting strategies are, of course, not wrong they just may not be a good fit for your child. For some children these consequences will teach them the intended life lessons and skills, for others, you may have to think outside of the box.

- Use one, well-understood consequence for all misbehaviours. Try to make the consequence concrete and easy to understand.
 - If a technique is not working, change what you are doing.
 - Adapt consequences to fit the child's developmental age.
- Make consequences as immediate as possible, if not, the child might not remember or understand why they are being penalized.
- Clearly state expectations and explain the reasons for the consequences.
- Don't debate or negotiate the rules or consequences. Follow through with what you say.
- Try using rewards to teach good behavior instead of punishments (emotional rewards can work well).
- Have a few, firm rules so there's less to remember – rules should state the behavior you want to see rather than “don't do that.”
- Never use physical discipline, children model what they experience.
- Classic techniques that might not work include: time-outs, taking things away, grounding, threats, or loss of privileges. However, every individual is different, try to find a technique that works with your child.
- Instead of time-outs, have a quiet place where child can think about his actions. Try:
 - Green Card - Warning. Return when ready.
 - Blue Card - Write about action and develop plan to prevent it in the future.
 - Yellow Card - Return when given permission.
 - Red Card - Give them a fitting consequence for their actions.

TIPS FOR FRIENDSHIPS

Making & Keeping Friends

It can be hard for children with FASD to get along with others their own age. Children with FASD tend to have the social skills of children much younger than their peers. To cope with daily life, children with FASD need to use a lot of energy focusing on themselves which can sometimes lead them to miss the subtle messages and habits of friendship. For example, they may not wait their turn or they may stand too close to others and get into their personal space.

It can be very lonely and frustrating when other children don't want to play with them. This puts them in danger of being taken advantage of or bullied by others. For a parent it is hard seeing your child not 'fit in'.

Example #1

When your 10 year-old with FASD comes home from school, he wants to play with the 6 year-old down the street and not with his 10-year-old neighbour. He feels more comfortable playing with someone younger. He likes the games played by the 6-year-old more.

What to do:

- Your child just may not be able to play well with children his own age. Avoid situations where his lower maturity level makes it hard for him. Encourage supervised playing when he is around younger children.

Example #2

Your 7 year-old son is at the pool and he's trying to join a group of teenage boys who are jumping off the diving board.

What to do:

- He doesn't understand that the teens don't want him. Help your child become sensitive to body language and facial expressions. Look at pictures of people in books and magazines together and ask him what he thinks the people are thinking or feeling. Explain how humans 'talk' in many ways, not just by using words. Play act together and see if your child can figure out what emotions you are expressing.

TIPS FOR FRIENDSHIPS

- Find games and activities that help your child build social skills. Safe and supervised groups such as Scouts, Girl Guides, Air Cadets, or swimming and skating lessons are great.
- Don't expect that your child will have a large group of friends. One or two close friends who have known her for many years will not only be good friends, but will care enough about her to help her stay safe.
- Keep an eye on your child when he plays with others. This way you can explain why things may have gone wrong and how he might want to act the next time to get along better with his friends.
- Children with FASD usually feel best in a place they know and in situations they can predict. Avoid large sleepovers and parties because they can be too confusing and overwhelming to a child with FASD. A sleepover with one friend in her own home would be best. A birthday party with two friends over for a short time would be more successful than a large party with many children and a lot of chaos.
- Over and over again, teach them the social skills of listening, taking turns, not talking when others are, and taking an interest in other people by asking them questions. Your child will need help and lessons on all these subtle ways of friendship.
- Talk to your child's teachers and ask them to make efforts to include your child in activities and groups. Thank them for their efforts; your child's teachers will be more likely to help if they see you notice their extra care.
- Sometimes children don't notice that they are different. Even though we know they are less mature than their peers, if they are happy the way they are, then that's great.
- If you see that some children are being cruel to your child, you may need to step in and stop them. Try to do this gently, so that your child is not embarrassed. Then, when there's a chance, talk to the children about how great it is that we're all different, and how boring it would be if we were all the same. Ask the other children how they might feel if they were left out or teased.
- From a very young age, children learn a lot from their friends. All parents need to keep an eye on the friends their children make. Like other parents, you may need to forbid your child from being with certain kids.
- Supervise, supervise, and supervise. Keep a close eye on your child and her playmates so you can step in and help her

TIPS FOR SPORTS & CAMPS

Tips for Sports & Activities

- Don't be shy about talking to your child's coaches or teachers about the things that are hard for your child. Coaches and teachers care about children and want your child to have a good season on the team. If you share information about your child with the coach or teacher, they will know more about how to help your child succeed and help her deal with her frustrations.
- If your child has a close friend, try to have them join a group together. It will help your child to go with someone she or he knows.
- Look at opportunities for your child to do an individual activity where there is still opportunity for social interactions such as art class or yoga.
- Help your child to choose activities that she enjoys and has fun doing. This gives her a chance to be successful.
- Supervise. Go to your child's team practices and games. You can also take note of things that may be affecting your child's behavior and make accommodations, such as lighting at indoor soccer.
- Be there and help her by explaining things. Watch for inappropriate behaviour and help her with relationship repair.
- Practise with your child in a safe setting to help him learn the new skills. If there are siblings, have them join in.
- Ask your child to tell you all about his or her activities. Ask many questions about the coach and the other players. Listen for things that are challenging for him and also things that he is doing well.

Tips for Camp

- Pick a camp with as much structure as possible. Call the camps in your area to ask questions about their programs. Ask about what kinds of structures and routines they have.
- Tell the camp director that your child has FASD and explain what this means to your child. Offer to answer all their questions and send them more information about FASD. Let them know they can contact the FASD Network so the camp staff can learn about FASD, make plans, and be prepared.
- Camp staff or counsellors should meet the child and have plans ready to put into place as soon as the child arrives at camp.

TIPS FOR HEALTHY & SAFE SEXUALITY

- Practise things like how to shake hands, hug, and touch others respectfully.
- Teach your child or teen to always ask permission to touch.
- Know where your kids are and who they are with when they go out.
- Ensure that the school reinforces what is being taught at home about sexuality and that as parents you know what is being taught at school.
- Supervision is important. A trusted friend, cousin, or sibling might be willing to double date or even go on practice dates.
- Encourage young couples to attend family events, meet up with friends or get involved in community activities. Let others know to provide extra supervision at events like school dances or camping trips.
- Be aware of the danger of the internet or cell phones. Monitor internet activity, set time limits, and rules that limit or avoid chat rooms. Look into parental controls to block dangerous internet sites.
- Talk about sexuality even if it is uncomfortable. If your son or daughter doesn't get information from you, he or she will get it from someone else. If this is hard for you, find a friend or another parent to help you in this task, you do not need to do this alone.
- When talking about sex, use language that is clear and simple. Use the appropriate name for sexual acts and body parts to avoid confusion and misunderstandings.
- Rules about sexuality need to be simple, consistent, absolute, and concrete. For example, teach that unprotected sex is never safe. Always use a condom.
- Demonstrate the use of birth control methods and show what birth control looks like.

TIPS FOR TEACHING OWNERSHIP

Children and teens with FASD often have trouble understanding what 'ownership' means. There are many reasons for this. First, they might be 'living in the moment,' and if they see something they want, they may take it. Or, if they have problems with short-term memory, they might not remember taking it. Or, they might have thought that it was theirs or that someone had given it to them. They also might lie and deny stealing because they are afraid of being in trouble. Finally, each day is new and different to someone with FASD. The child or teen may not remember that they had stolen before and that this was the wrong thing to do.

It is hard to know what to do when a child or teen with FASD steals something. Are they stealing because they are behaving badly or because they really didn't understand that it is wrong to take things that belong to other people? You will need to use your judgment in each case and you'll need to teach them over and over again about what ownership means.

- Most children will take something that is not theirs at least once while they are young. It is up to the parent or caregiver to teach a child about ownership and right from wrong. Be patient. Ownership is a hard thing to learn for children and teens with FASD.
- If your child takes something that is not theirs, ask her how she would feel if her favourite toy or shoes were stolen. Help her to understand that no one likes to have their things stolen.
- If your child takes something that doesn't belong to her, make sure she returns it with an apology. Practise how she will say sorry. Go with her for support.
- Mark the things your child owns with a sticker. For example, everything with blue stickers are his. If they don't have his sticker on them, he should not take or use them.
- If your child takes something that is not his, do not get caught up in an argument. Simply say, "This...belongs to..." Have him return the item. Stealing needs to be dealt with quickly, firmly, and with appropriate consequences.
- Valuables should not be left around where a child may come across them. Lock up things like cameras, money, and jewelry.
- Stores and malls are not good places for children and teens to "hang out." A good rule is that a parent must always go with the child or teen to the store or mall. Shoplifting can be a big problem with children and teens with FASD.
- Supervise, supervise, supervise. Children and teens with FASD need supervision at home, at school, during free time, and all the time. Be sure to look for opportunities for dynamic supervision such as mentors.

TIPS FOR AVOIDING LEGAL TROUBLE

- Talk about important issues like safety, ownership, right and wrong, and drugs and alcohol. Begin these talks early and repeat often.
- Teach about these ideas in real-life settings. Practice the skills by using role play and demonstration to teach about right and wrong.
 - Teach rules that are understood at home in different settings.
- Help teens and adults find good role models and friends. Help them find activities that are fun and provide opportunities to gain a sense of belonging. A music group, team sport, or other recreational activity is a good choice.
- Minimize negative influences. Look for ways to create structure and build stable routines into everyday life. Provide chances for safe activities that promote success. Look for strengths. Everyone has things that they are good at. When we can use our strengths and are supported we can avoid problems or deal with our legal troubles in better ways.
- Some adults carry a card that states they have FASD. The card has contact information for a support person or parent and explains that due to a brain injury they do not understand their legal rights and do not consent to a search or admit to criminal acts.
- Advocate for police officers, lawyers, and judges involved in the case to use plain language. What they say is very important and needs to be stated clearly to help with understanding. Gather documents and information about diagnosis, assessments, the supports available and the supports needed. Provide information to lawyers, judges, police officers, and others involved.
- Advocate for restorative justice, mediation, or a sentencing circle. Try to make sure that the individual understands what to do and is actually able to do what is instructed or expected. They will need support in carrying out or complying with conditions. You may want to use visuals to simplify the conditions.
- Be specific about which drinks are alcohol and which drugs are illegal. It can be confusing to know the difference.
- Have a plan in place to deal with situations where laws are being broken, or drugs and alcohol are available. Encourage them to phone home or leave immediately.
 - Use role play, practice and rehearse to help teens or adults learn to avoid these situations. Practise over and over how to say no and how to stay safe.
- When problems arise, like sadness, boredom, or feeling alone, deal with these things in positive ways so that drugs or alcohol are not used to self-medicate or dull feelings of emotional pain.

TIPS FOR PHYSICAL DISABILITIES

Prenatal exposure to alcohol can affect how a body grows and develops. People with FASD can have differences in how their bodies are formed and how they move. This can look like poor balance and coordination, lower height or weight, problems with fine and gross motor control or being slow to meet developmental milestones. It can also result in poorer functioning or poorly developed body systems, including skeletal, muscular, renal, circulatory, etc. this can lead to further physical health problems

- Be willing to practice and demonstrate basic life skills like trying shoes or doing up buttons. Often, children with FASD may take longer in life to master these skills.
- Find simple ways to practise in the areas they are affected. For example, tape on the floor as a pretend balance beam to work on the child's balance. There are a lot of resources and ideas for these on the internet.
- Integrating life skills learning into play can help develop some fine motor skills. Tactile toys can be made from basic household items like a zipper or shoe.
- Look for ways to accommodate their needs while they master skills such as thicker crayons or pencils for easier manipulation.
- If possible, arranging sessions with a certified occupational therapist can assist you and your child in identifying and working on the areas they may struggle.
- Individuals with FASD may have a high or low tolerance of pain which is something to be aware of as your child could injure themselves but may not understand the severity of their injuries if they don't feel pain as we do.
- Be aware that prenatal exposure to alcohol can impact the development of internal body systems and may result in health conditions and chronic physical pain. This may be reflected in your child's behaviour and mental health.
 - For example, recent research has found that people living with FASD may experience health problems such as hearing, autoimmune, cardiovascular disease, joint pain, etc.
- The physical implications of FASD can't be seen and are not widely understood in society or the medical field. Remember, you are the expert on your child and how FASD impacts them. Be persistent in advocating when you know certain health concerns are a result of FASD. Do not be intimidated to share this information with professionals.

TIPS FOR SLEEP

Individuals with FASD can often have difficulty falling asleep, staying asleep, and waking up. They are at a high risk for developing sleep problems, and face challenges in getting enough rest. This can lead to daytime fatigue, an inability to pay attention, and hyperactive behaviour.

- Develop a calming sleep routine. This should include a slow transition from evening activities to getting ready for bed and going to sleep. Same bedtime every night. Avoid sleeping in. No television or computer an hour before bed. No sugar after 6 p.m. Warm bath before bed.
- Limit the amount of visual stimulation in the bedroom.
 - Limit furniture and ensure that personal belongings can be stored out of sight.
- The introduction of relaxing music may be helpful for some individuals. Things like fountains or fish tanks in the bedroom can also provide soothing noises to assist with sleep.
- For some individuals, taking a melatonin supplement can help to regulate sleep. Check this option with a doctor or health care professional before using.
- Weighted blankets may be helpful. If finances are an issue, try sleeping bags and/or heavy blankets such as wool fibre.
- Try to be aware of sensory issues – certain sheets, pillows, etc. may bother some people.
- Scents can be helpful. Calming scents such as lavender or eucalyptus can be soothing but some things, like strong detergents can be too much.
- If your loved one has issues with sleep, advocate for them to have later start times for work or meetings as early mornings could be very difficult for them.

TIPS FOR MELTDOWNS

Issues with sensory input and self-regulation can result in frequent or periodic outbursts. As mentioned on the previous page discussing behaviours (page 03), it is important to remember that tantrums, meltdowns, and outburst are not intentional, it is a direct result of the child's disability.

- Having accommodations and strategies in place to create a better fit between the individual and their environment can help alleviate some of the stressors that can cause meltdowns. This can be especially important for your child's sensory needs as they are often the cause of outbursts.
- Try to be aware of what is going on in his head and what his day was like, it can be a good indicator of his stress level.
- Learn their triggers, if you can identify when a meltdown is about to begin you can begin any necessary physical interventions like weighted instruments or bear hugs to help them self-regulate and remain calm.
- If your child seems anxious and unable to cope with an activity, move on to something else for the time being.
- Help your child learn how to identify when their feelings are beginning to escalate. There are several techniques for doing this:
 - After a meltdown, talk to him about how he physically felt. For example, hurting head, hot face, etc.
 - Do 'colour zone' activities with her, teach her that each colour represents a feeling. For example, the green zone is when they are happy, the blue zone is sad, yellow is anxious and red is angry and overwhelmed. It is a concrete way for her to understand the way she is feeling.
- If your child is having a meltdown, it is important that you do not also appear angry or upset.
- Instead of trying to stop the meltdown, you can try letting him get it out of his system. Make sure you tell him that he is safe and wait until he's calmed down to talk through it.
- It's good to stay with the child during the meltdown to ensure no harm comes to them.
- Try having a safe space they can go to where they can control the sensory inputs, it should be comfortable and quiet.
- It is important to not punish her for a meltdown if it's a result of her disability.
 - Remember though, sometimes kids are just kids and will have meltdowns like every other child. Investigating what led up to the meltdown will help you figure out if it was a result of FASD.

TIPS FOR MENTAL HEALTH

Mental health refers to mood disorders such as depression and anxiety, or substance use disorders. These mental health concerns can often become a secondary challenge of FASD, meaning they are not a direct result prenatal alcohol exposure but can occur when there is a poor fit between a person with FASD and his or her environment. Repeated failure and continued high expectations in an environment that is confusing, overwhelming, and frustrating contributes to secondary challenges.

Secondary challenges such as mental health can often be more troubling than the primary disabilities. They often carry a greater risk to the child, youth, adult, and family.

- It is very important to recognize a poor fit and work towards making accommodations to help your child succeed.
 - Identifying strengths is a great starting point. A good fit for an individual with FASD must be based on strengths, abilities, and interests while addressing their struggles.
- If your child exhibits any signs of struggles with mental health such as running away, wanting to drop out of school, self-harming, etc. do not get angry. They need to know it is safe to talk to you about what they are feeling.
- Giving a youth a journal will let her express herself and, if she shares it with you, will help you understand what she is feeling.
- Try to explain to your child how dealing with the disabilities associated with FASD can impact their mental health.
- You may also want to explain how emotions can cause physical responses. For example, anxiety can feel like an upset stomach.
 - Concrete visuals such as a feelings chart or flip book may help your child identify emotions.
- You do not have to deal with mental health issues by yourself. The Saskatchewan government has a searchable database for mental health and addiction services in your community. The Network can help you locate nearby services.
 - Should treatment be required, advocate for a program which recognizes the needs of individuals with FASD or is willing to adjust their programs to increase success.
 - You may need to explain the disability to some mental health professionals as they may not have extensive knowledge on FASD.

TIPS FOR DEALING WITH STIGMA

Stigma can have a significant impact on the experiences of individuals and families living with FASD. Stigma is the process of pointing out differences in a group of people and giving negative meanings to such differences. As a result of stigma, society does not have an accurate perception of the lives and experiences of certain individuals, and the attributes and characteristics they possess.

Stigma may result in individuals being blamed for their behaviour and prevent an awareness and understanding of the root of such behaviours. Stigma, in the lives of individuals living with FASD, contributes to ideas such as FASD being uncontrollable, notions of substance use, and misinformation surrounding criminality. Such inaccurate representations of individuals' experiences hide the fact that many individuals living with FASD face structural and social inequalities and are often at risk of victimization themselves.

For individuals living with FASD such negative feelings and experiences may lessen their ability to seek help and support, may have a negative impact on their self-esteem, add to incorrect beliefs and misinformation, and discourage individuals from disclosing their disability.

- Education is key. By doing our part to provide education and awareness of FASD we can help combat misconceptions and stigmas which often arise simply because people do not know the truth/facts.
- Using person first language distinguishes an individual from the disability and emphasizes that FASD is not that person's defining feature. For example, instead of referring to someone as "an FASD youth," refer to that individual as "a youth living with FASD." Person first language encourages us to get to know the individual first and then explore how the disability impacts his or her everyday life.
- The language we use is also important when discussing an individual's birth family. Mothers to children with FASD face shame and blame. Many people believe that mothers know they could harm their babies by drinking during pregnancy but they still do it because they don't care. Pregnant women do not purposefully harm their babies. The reasons for alcohol use during pregnancy are complex and varied. Some women do not know they are pregnant or are dealing with addictions, trauma, abusive relationships, or mental health issues.
- Sharing your personal experiences can have a significant impact on stopping negative stigma. Sharing success stories and positive personal experiences can help society see the true potential of people living with FASD.
 - Many caregivers share their experiences on social media, or create blogs. The Network is dedicated to sharing people's stories, be sure to contact us if you would like to help spread positive stories about FASD.

TIPS FOR DISCLOSING

It can be difficult deciding when and how much to disclose about your child's disability. You have the right to choose who you tell. Finding the comfort point in speaking about your child's disability and its effects will take time and practice. You may be concerned about 'labelling' your child but, most often, people need to know about the disability to fully understand the individual and their needs.

- When your child becomes old enough, ask for their consent before disclosing their disability to the people in their life, it is of the utmost important that your loved one feels comfortable with this information being shared.
- When you disclose be sure to do the following:
 - Provide education on FASD. Have a support worker accompany your or bring informational resources.
 - Explain your child's strengths and struggles.
 - Provide suggestions for strategies or accommodations to help your child succeed.
- Information may not be shared between the professionals in your loved one's life so make sure you're disclosing to as many people as you have to so everyone is aware of his or her needs.

The professionals in your life aren't the only people you will disclose your child's disability to. You will also tell family members, and one day, you will tell your child that he or she lives with FASD. Telling them about their disability can lead to self-acceptance and allow them to understand themselves.

- Think about it from their perspective and use words that are appropriate to their developmental level.
- Using books or storytelling can help them understand that they have FASD.
- Provide basic information about FASD and how it affects people. Be sure to avoid shaming or blaming birth mothers.
- Try to explain their disability by focusing on their strengths.
- Try to find role models or peers who also live with FASD.
- Be prepared to repeat the conversation. Bringing it up multiple times can help him remember and process the information.
- Emphasize that FASD is just a single part of her life. It is a disability she has, not the sum total of who she is.

TIPS FOR ADVOCATING

Because FASD is an invisible disability and there is a lack of education within the general public, you will have to advocate for your child and his or her needs. Educating others about FASD and teaching them to put the person before their disability is the first step in advocacy. This can include providing resources, involving support workers in meetings, or explaining the specific struggles and strengths that an individual has.

The hard part of advocacy is making your way through complicated systems like the educational, justice and medical systems. Understanding these systems may not come naturally so to do this, you need to develop a set of advocacy skills.

- Focus on being the best advocate you can be for your child. Seek out all the information you can about FASD, take advantage of the services and professionals in your community who can help educate you on the disability.
- Keep records of the meetings and conversations you have about your child.
- Ask other professionals who work with your child to advocate on their behalf, for example your occupational therapist advocating in the school.
- Be prepared before meetings. Develop feasible, concrete suggestions for how to help your child succeed.
- Getting your child a diagnosis can really help with accessing supports and services that may be available to them in the education and social service systems.
- Maintain open and constant communication about your child with the professionals in his life. Keep them in the loop about what's going on at home and some of the behaviours that may result from any stress or upheavals in your child's life.
- Try to bring extra support when you can, whether it be a family member, friend, or support person. Having support can help you keep your strength while advocating.
- Be persistent in the face of adversity. Never stop advocating for your child. Make sure that the people who need to know are always reminded of your child's needs.
 - You will have to advocate to countless people in almost every system your child encounters, this can be daunting, exhausting and overwhelming so be aware of burn-out and take time for self-care.
- You are the EXPERT. You know your child and how they are impacted by FASD so never feel embarrassed or frightened to speak-up when you know something is a result of their disability.

TIPS FOR ADVOCATING

- Check out resources that teach advocacy skills. Learning additional skills is always beneficial.
- Learn from the individual. Always advocate in a way that supports dignity and respect.
- Try to find schools or programs that have education and experience working with children who live with FASD or disabilities in general, this can help alleviate the stress of always having to advocate for your child.
- Create a case management or individual program plan for your child with all of the people who may need to be involved. This allows everyone to be on the same page and to know what direction things are moving in.
- Remember that schools and other systems may have limited resources or are unable to make some accommodations so work with the professionals from these systems to think outside of the box to create new, feasible strategies.
- Teaching self-advocacy to individuals can be a great tool so your child can teach and inform their community about their own needs when you're not there.
- Individuals with FASD can learn their own style of advocating by learning more about their disability and how it affects them.
- Practise advocating where it is safe. See if your support worker can put together a group of parents and professionals to practise with and provide mutual support.
- Some resources are available to help guide the process of self-advocacy, such as booklets that encourage the individuals to describe themselves – what they are good at and what they struggle with.
- You can advocate not only for your child but to achieve large changes as well. Staying informed about issues and connecting with politicians at all levels of government to share your concerns can have a large scale impact.
- Don't be intimidated to go up the chain-of-command to get results for your child.
- Advocating to professionals can have an impact for not only your child. Every time you explain FASD and your child's needs to a professional you make a difference for the next family as well.

TIPS FOR CARING FOR YOURSELF

Being a parent or caregiver can be a great experience, but it is also tiring and challenging. Families with children with FASD are often under a great deal of stress. Others don't always understand the issues you face everyday. This can make one feel alone and overwhelmed. You and your family need to take care of yourselves. If you are stressed and tired, you won't be able to see clearly or give your kids all that they need.

- All parents have dreams for their kids. It may be hard for parents of children with FASD to deal with disappointment or guilt. A counsellor, religious leader, or elder may be able to help you.
- Think about what helps you to relax and make a real effort to do it every day or at least every week. Have coffee with a friend, take a long bath with the bathroom door locked, call a parent you like, go out with your partner, attend a support group, hire a babysitter or share and swap childcare.
- Find someone to talk to who understands what it's like living with children with FASD. This could be a family member who is close to you, or another parent of a child with FASD. If you don't know any other parents, call the FASD Network of Saskatchewan (our number is 1-866-673-3276).
- Sometimes, the only place your children can truly 'shine' is in your own home. Let them be at home a lot and don't feel badly about celebrating holidays and birthdays at home where your children feel safe and comfortable.
- Many children with FASD become very stressed when the family leaves home to go on holidays. It can be hard for them to leave a familiar area and routine or stay in a strange hotel room. It will be good for everyone if your children can stay in their routine. If you do decide to go away, plan ahead and involve your children in discussions about what to expect.
- Give your relatives some information to read about FASD or have them call us at the FASD Network Saskatchewan .
- Arrange for a break for you and/or your partner. Hire a mature babysitter or respite worker who understands your child and train him or her about FASD and the importance of routine.
- Take time to laugh. Watch a funny movie. Think about the funny side of some of the things your kids do.
- Rest, relax, exercise, and try to look at the big picture. You are doing the very best job you can.
- Think about all the things that you love about your children and all the things you admire.
- Educate yourself. Knowledge is empowering.

TIPS FOR BUILDING A SUPPORT TEAM

As a caregiver to a child with FASD, you may feel like the weight of the world is on your shoulders. Building a team of trusted people to help support your child can help you make the important decisions that will impact your child's life. Creating a team of experts can help you and your child succeed.

- As a start your team could include a family doctor, pediatrician, psychologist and an occupational therapist, etc.
 - The individual living with FASD should be an active member of their own support team and involved in decisions.
- Ask other caregivers in your community for advice on which professionals understand FASD.
- It is important that whoever you choose to include on your support team listens to you. The professionals are there to provide advice but they should listen to and consider your input as you are the expert.
- Make sure the professionals you're working with know who your support team is.
 - A good strategy may be to create a list of every service and person you are working with so you can provide the list when you access new supports or if there's a change in workers.
- Sign consent forms that will allow your support team and other professionals to communicate directly with each other.
- When you meet with the team or other professionals you may want to bring someone for emotional support such as a spouse, family member, or friend.

FASD NETWORK OF SASKATCHEWAN

#302-39 23rd Street East
Saskatoon, SK
1-866-673-3276
www.saskfasdnetwork.ca