

A CAREGIVER'S GUIDE TO

FASD DIAGNOSIS

This guide will help you to understand Fetal Alcohol Spectrum Disorder (FASD) and provides information on where to find support for your child or a child in your care.

CONTENTS

*	3	IS THIS GUIDE FOR ME? WHAT IS FASD?
*	4	SIGNS AND SYMPTOMS OF FASD
*	6	WHY IS A DIAGNOSIS IMPORTANT?
*	7	BRAIN ASSESSMENT AREAS
*	8	GETTING A REFERRAL
*	9	WHO WORKS AT AN FASD DIAGNOSTIC CLINIC?
*	10	WHY DOES AN ASSESSMENT TAKE SO LONG?/CLINIC DAY
*	11	WHAT CAN I EXPECT THROUGHOUT THIS PROCESS?
*	12	WHAT WILL THE DIAGNOSIS AND FINAL REPORT TELL ME ABOUT MY CHILD?
*	13	WHO DO I NEED TO TELL ABOUT THE RESULTS OF THE ASSESSMENT?
*	14	WHERE CAN I FIND SUPPORT?
*	15	ONLINE RESOURCES

IS THIS GUIDE FOR ME?

This guide is intended for caregivers (birth parents, kinship caregivers, foster parents, or adoptive parents) of children who were prenatally exposed to alcohol, and who are soon-to-be assessed for Fetal Alcohol Spectrum Disorder (FASD), or have recently been diagnosed with FASD.

If you or a health care professional believe that your child may have FASD due to atypical behaviour and development or confirmed alcohol exposure during pregnancy, and your child has begun their journey towards a diagnosis or has recently received a diagnosis, it is important to know what to expect moving forward.

This guide will inform you of potential signs and symptoms of FASD, how to seek out a diagnosis, what the diagnostic process looks like and what it will tell you, who is involved in the diagnostic process, and what to do after a diagnosis.

WHAT IS FASD?

Fetal Alcohol Spectrum Disorder (FASD) is a diagnostic term used to describe impacts on the brain and body of individuals prenatally exposed to alcohol.

FASD is a lifelong disability. To reach their full potential, individuals with FASD will experience some degree of challenges in their daily living, and need support with motor skills, physical health, learning, memory, attention, communication, emotional regulation, and social skills.

Each individual with FASD is unique and has areas of both strengths and challenges.

SIGNS AND SYMPTOMS OF FASD

There may be several reasons why you are concerned about your child. They may include:

AS BABIES

THEY MAY:

- Cry often
- Sleep poorly or sleep often
- Be difficult to comfort
- Have poor feeding or weight gain
- Shake and tremble uncontrollably

AS TODDLERS

THEY MAY:

- Have delays in development (ex. talking, crawling, walking)
- Have many temper tantrums
 - Be increasingly active
- Dislike certain food or be a picky eater
- Cover their ears when there is a loud noise

IN ELEMENTARY SCHOOL

THEY MAY:

- Have difficulty keeping attention and focus
 - Act impulsively
- Demonstrate risky behaviours
- Have trouble making friends, or keeping friends
- Develop issues with anger and self-control

EACH CHILD IS UNIQUE

It is important to remember that these are general signs and symptoms, so a child with FASD may experience any number of these challenges. Prenatal alcohol exposure affects everyone differently.

IN MIDDLE SCHOOL

THEY MAY:

- Have trouble learning
- Have difficulty remembering important dates, leading to problems completing assignments
- Have difficulty staying organized and planning ahead
- Have a hard time following instructions, therefore requiring close supervision and one step instructions
- Take other peoples' belongings

IN HIGH SCHOOL

THEY MAY:

- Develop mental health issues such as anxiety and depression
 - Stop going to school
- Get in trouble with the law
- Use drugs and alcohol

Head to [this link](#) to find more information about signs and symptoms that might indicate FASD.

WHY IS A DIAGNOSIS IMPORTANT?

Head to [this link](#) to find more information about the importance of getting a diagnosis.

Head to [this link](#) to learn about FASD throughout a person's life, and to learn about interventions.

01

The assessment will show your child's strengths and challenges, so you can find the best ways to help them.

02

A diagnosis can make it easier for caregivers, because you will better understand your child's developmental delays, challenging behaviours, and learning difficulties, and can get help for your child.

03

The diagnostic team will help develop recommendations that will address your child's unique challenges and may provide community support organizations with strategies to build on your child's strengths.

Getting your child assessed for FASD is an important step to understanding them.

BRAIN ASSESSMENT AREAS

Your child will be tested by a pediatrician, psychologist, speech language pathologist, and occupational therapist for the following:

- 1. Academic Achievement:** reading, math, comprehension
- 2. Attention:** ability to stay focused, for example, in a classroom setting
- 3. Cognition:** reasoning, problem solving, planning, and IQ (intelligence quotient)
- 4. Language:** receptive language (ability to understand what is said to them) and expressive language (ability to clearly communicate to others)
- 5. Memory:** short and long-term memory, working memory
- 6. Neuroanatomy/Neurophysiology:** head size, and other disorders related to the nervous system (i.e. seizures)
- 7. Executive Functioning:** problem solving, planning, organizing, understanding of consequences, impulsive behavior and hyperactivity, abstract concepts such as time and money
- 8. Adaptive Behaviours, Social Skills and Social Communication:** understanding of personal boundaries, social vulnerability, behaving younger than actual age
- 9. Motor Skills:** balance, strength, coordination, reflexes and muscle tone; will ask whether your child has reached developmental milestones on time (i.e. crawling, walking, grasping objects)
- 10. Affect Regulation:** ability to control emotions and display appropriate emotional responses
- 11. Trauma History:** history of any traumas experienced, for example physical or emotional abuse
- 12. Sensory Issues:** ability to process information that comes in through the senses

GETTING A REFERRAL

A referral for potential FASD diagnosis may be made in the following situations:

- Discussions about prenatal alcohol exposure with parents and caregivers;
- Behavior in your child that cannot be easily explained;
- Any of the common signs and symptoms of FASD.

Most clinics have a website where you can learn about the diagnostic process as it happens in your local area.

Head to [this link](#) to find a clinic in your area.

WHO WORKS AT A FASD DIAGNOSTIC CLINIC

AND WHAT ARE THEIR ROLES?

You likely have met or are soon to meet with a FASD diagnostic team.

The diagnostic team consists of several professionals who have specific roles in the assessment process. They all help to make recommendations that can improve life for your child.

PEDIATRICIAN

Collects medical history, measures head size and other possible physical conditions; participates in or leads the caregiver interview; signs the medical report

PSYCHOLOGIST

Measures the strengths and challenges of brain function such as IQ and memory, attention, social skills, and life skills; retrieves information on how your child is doing in school

SPEECH LANGUAGE PATHOLOGIST

Measures language development, vocabulary, and language skills

SOCIAL WORKER

Assists with collecting information before the assessment; determines the social and environmental history of the child, and assesses trauma history

OCCUPATIONAL THERAPIST

Measures motor ability (balance, strength, reflexes); assesses sensory issues

CLINIC COORDINATOR

Oversees the activities of your child's diagnostic process, coordinating pre-assessment information including questionnaires from people who interact with your child on a daily basis, as well as tell you about timelines and appointments throughout the process

WHY DOES AN ASSESSMENT TAKE SO LONG?

The assessment process is very thorough, and involves several professionals.

Each clinic is unique in how it operates.

The assessment process may be many appointments over a period of days, weeks, or months, or all in one day.

The waitlist can range from a few months to a few years.

CLINIC DAY

The clinic day happens after all of the assessment are complete. On this day, you will meet with the team to discuss the diagnosis.

The diagnostic team will meet to review all the information and previous assessment results.

An interview will be completed with you, the caregiver, and some team members.

If some of the assessments were not completed yet, your child will be seen by some of the team members to complete all of the assessments.

The team will then meet together to determine the diagnosis and recommendations.

The team will review the results of the assessments and diagnosis with the caregivers and support team.

The caregiver will then debrief one on one with a team member before leaving for the day.

Some clinics provide follow up supports to assist with addressing the clinical recommendations.

Note: All clinics operate slightly differently, and you should ask what the process is prior to clinic.

WHAT CAN I EXPECT THROUGHOUT THIS PROCESS?

- You will be asked to provide details about your knowledge of prenatal alcohol exposure. Confirmed prenatal alcohol exposure will be needed in most cases prior to beginning the assessment process. Most clinics will assist you in finding this information, and whatever you can provide to help locate this information is useful.
- You will be asked about your social and medical history, or your knowledge of the birth mother's history. For example: What kind of housing and environment does the child live in? What school programming or other services do they have? Do you or any members of your family (or the birth mother's family) have a history of mental illness or addictions? Have other siblings been diagnosed with FASD?
- You will be asked about your child's development, behaviour, strengths/weaknesses and education history. For example, did your child achieve their "developmental milestones" on time? How are they doing in school? Socially? Physically?
 - Your child will be given a physical examination that will include an assessment of the following facial features: length of the eyes, size of the upper lip, and the smoothness of the area above the lip (called the philtrum). These features can be associated with prenatal alcohol exposure, however, not everyone with FASD will have these features.
- The team will consider other causes for your child's behaviours and development and may ask questions about family history, including the existence of genetic disorders or other medical conditions.

WHAT WILL THE DIAGNOSIS AND FINAL REPORT TELL ME ABOUT MY CHILD?

The diagnosis and final report will help you understand your child's strengths and challenges, in order to provide the best supports and strategies to help them.

01

A report outlining recommendations to caregivers and others who will work with your child on a daily basis will be written. This report is usually made available within 6 weeks after the assessment.

02

The report will provide a summary of other diagnoses that were found, such as learning disabilities, memory impairments, attentional difficulties, etc.

WHO DO I NEED TO TELL ABOUT THE RESULTS OF THE ASSESSMENT?

- 1) It is important to tell your child about the results of their assessment.

The team can help you decide when and how to talk about FASD with your child because it is important that they understand their diagnosis.

- 2) It is important to share the results of the assessment with your child's school, so that accommodations can be made and their learning environment can be personalized.
-

- 3) It will be helpful to share the results with your family so that they have a better understanding of your child's situation.

FASD is not something to be ashamed about. It is recommended to share the diagnosis with trusted people in your life, to ensure your child received the best support possible.

You have full control over who you confide in and reach out to during this process.

It is important for your child that you seek support from those around you, such as friends and family, teachers, doctors, or social workers. This will provide further supports and resources to you and your child.

WHERE CAN I FIND SUPPORT?

The diagnostic team may help direct you to community supports that can help you as you navigate your child's challenges.

After a diagnosis, the FASD clinic coordinator can be very helpful in assisting with sharing this information with needed support systems, such as the school your child attends. This is something that you should bring up with the coordinator.

Finding out that your child has been diagnosed with FASD can be very overwhelming for you, as well as for your child. If formal FASD supports are not available for you, it can be helpful to join a parent support group or an online support group.



ONLINE RESOURCES

Head to the links below to find valuable courses and guides to help you through this journey.

[Fetal Alcohol Spectrum Disorder: a guideline for diagnosis across the lifespan](#)

[Foundations of FASD](#)

(free online course)

[Caregiver course](#)

(free online course)

[Caregiver resource guide](#)

[How to Explain a FASD Diagnosis to your Child](#)

