



Adoptive Families  
Association of BC



# All about FASD

A guide for adoptive and permanency families

## All about FASD: A guide for adoptive and permanency families

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The Adoptive Families Association of BC is a charitable, accredited, non-profit organization offering adoption and permanency support, information, and education.

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# FASD 101: An introduction

**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.** Individuals with FASD will experience some degree of challenges in their daily living, and need support with motor skills, physical health, learning, memory, attention, communication, emotional regulation, and social skills to reach their full potential. **Each individual with FASD is unique and has areas of both strengths and challenges.**<sup>1</sup>

While not everyone who is exposed to alcohol in utero will be diagnosed with FASD, they can still experience effects. Read more about this in [Seeking an FASD Diagnosis](#) on page 8.

Even if a child cannot be, or has not yet been diagnosed, caregivers may find the information in this guide helpful in parenting their child.

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<sup>1</sup> [Policy Action Paper: Toward a Standard Definition of Fetal Alcohol Spectrum Disorder in Canada](#)



# FASD by the numbers

**4%**

*of the Canadian population has FASD (estimated).*

*This is greater than the rates of Autism, Down Syndrome, Cystic Fibrosis, Cerebral Palsy, and Spina Bifida combined.<sup>1</sup>*

**27%**

*of children in care had qualitative evidence of diagnosed or suspected FASD.<sup>2</sup>*

**90%**

*of individuals with FASD also experience mental health issues.<sup>3</sup>*

**10%**

*of people with prenatal alcohol exposure have visible facial differences.*

*FASD is often an invisible disability.<sup>4</sup>*

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1 [The Prevalence of Fetal Alcohol Spectrum Disorder](#)

2 [Excluded: Increasing Understanding, Support and Inclusion for Children with FASD and their Families](#)

3 [CanFASD: FASD Stats](#)

4 [CanFASD: FAQ](#)



# Important terms

## **Adaptive functioning**

Adaptive functioning is defined as the practical, everyday skills needed to function and meet the demands of one's environment, including the skills necessary to effectively and independently take care of oneself and to interact with other people.<sup>1</sup>

<sup>1</sup> [FASD Ontario](#)

## **Central Nervous System (CNS)**

The central nervous system consists of the brain and spinal cord. It is referred to as "central" because it combines information from the entire body and coordinates activity across the whole organism.<sup>2</sup>

<sup>2</sup> [Medical News Today](#)

## **Dysmaturity**

Dysmaturity is a term used to refer to widely varying levels of maturity in different areas of development,

such as expressive language and language comprehension, social and self-care skills, and awareness and regulation of emotions.<sup>3</sup>

<sup>3</sup> [The Centre for Addiction and Mental Health \(CAMH\)](#)

## **Executive functioning**

A set of mental skills that help you complete tasks. Examples include: time management, paying attention, etc.<sup>4</sup>

<sup>4</sup> [The Asante Centre](#)

## **Invisible disability**

A disability that lacks obvious physical characteristics—you cannot outwardly tell the person has a disability.

## **Neurodevelopmental disorder**

Neurodevelopmental disorders are disabilities associated primarily with the brain and nervous system.

They may involve dysfunction in attention, memory, perception, language, problem-solving, or social interaction.<sup>5</sup>

<sup>5</sup> [Merck Manual: Definition of Developmental Disorders](#)

## **Sentinel facial features or facial characteristics of FASD**

Sentinel facial features are physical characteristics that are associated with prenatal alcohol exposure. The three sentinel facial features are: Small palpebral fissures (short horizontal length of the eye opening); smooth philtrum (diminished or absent ridges between the upper lip and nose); and thin upper lip. Most people with FASD do **not** have sentinel facial features.<sup>6</sup>

<sup>6</sup> [FASD HUB Australia: Assessing sentinel facial features and growth](#)



# The symptoms of FASD

FASD often presents as an invisible disability, and it is always a brain-based disability. While a child with FASD may outwardly look like other children do, their brain works much differently, FASD causes symptoms that they cannot control.

Suppose a child with FASD is struggling in school or socially. Telling them to behave or remember their manners probably won't work. It's a symptom of their disability and needs to be treated as such.

These are just some of the common symptoms that your child *may* have.

## Primary symptoms of FASD

- Regulatory problems
- Sleeping
- Eating
- Activity levels
- Impulse control

- Transitions
- Sensory issues
- Over- or under-sensitive to noise, lights, textures, food, touch, temperature.

## Social

- Dysmaturity
- Poor boundaries
- Vulnerability
- Poor judgment
- Delayed emotional development

## Communication

- Slow information processing
- Difficulty understanding directions
- Delayed language (expressive vs receptive)

## Mental health

- Trauma
- Anxiety

- Depression
- ADHD

## Physical health

- Infections (lower immune system)
- Ligament/joint pain
- Vision/hearing

## Learning and behavioural challenges

- Attention span
- Memory issues
- Abstract reasoning
- No cause and effect
- Learning disabilities
- Executive functioning issues: impulse control, working memory, planning/problem solving, shifting/cognitive flexibility.
- People with FASD often have average IQs but extremely low executive functioning.





# Strategies for successful parenting

Use these strategies as ideas to help you parent your child with FASD. Remember that what works for one child may not work for another child—or even the same child the next day. Keep trying, and find strategies that work.

## Predicting and preventing

Successfully parenting a child with FASD is mostly about predicting and preventing problems before they happen. A key characteristic of FASD is impaired executive functioning. This means that, many people with FASD struggle to understand and remember that actions have consequences. Rewards and punishments don't work for them.

### What is a time-in?

A time-in is a form of discipline similar to a time-out, but instead of sending your child to their room alone, you have your child sit quietly in the same room with you. Time-ins help kids feel supported instead of isolated.

Managing behaviour is about predicting and preventing an unwanted behaviour before it happens.

### TIPS

- Use firm limits.
- Be clear and consistent about rules and limit.
- Children with FASD may not respond to behaviour modification.
- No time-outs. They can often escalate the situation. Use time-ins instead.
- State the behaviour you want to see. For example, say "Keep your hands in your pockets" instead of "Don't touch that."

### What, why, how

Parents need to be detectives. Try to figure out:

- Why the behaviour occurs;
- What strategy is best, and;
- How well it's working.

Consistency is important, but parents also need to be flexible. Try different strategies to find what works. Don't give up.

Sometimes you need to be creative. Always remember their brain works differently, and they need you to help.

### Can't vs. won't

They are not misbehaving to make you mad, even though sometimes it sure feels like it.

Remember their developmental age, not their chronological age. Just because they are 10 and *should* be able to cut up their waffles, doesn't mean they're actually able



to do it. Developmentally they may be much younger. Learn more developmental vs. chronological age in “Teaching children with FASD” on pg. 20.

### **Routines**

Routines are helpful to their success each day.

The routines need to be predictable. Repetition helps them remember, but you will still need to be their “external brain” and remind them.

If you need to go off your daily routine, give your child lots of warning that their day will look different. And then get back on your routine as soon as possible.

### **Visual charts**

Use charts and pictures to help them remember their chores, kids like to feel successful.

You can also use magnets or pictures to describe their feelings, or try using fun or colourful sticky notes for reminders.

### **Break down tasks**

Break down tasks into small tasks and tell them to come back to you after they’ve finished each one. For example:

Clean your room:

- ✓ put dirty clothes in the hamper
- ✓ make your bed
- ✓ put toys in the toy box
- ✓ put books on the bookshelf

Remember to keep your instructions short and to the point. Use six words or less.

Remember repetition. Teach the same concepts over and over in a different situations.

### **Celebrate their successes**

Reward accomplishments, recognize and nurture strengths, and set realistic, attainable goals.

### **Calming techniques**

Teach them self-soothing and calming techniques. They need your help. Sit with them through meltdowns.

### **Sleep**

Kids with FASD require a lot of sleep. Their brains get very tired from trying to manage and learn.

Have a good sleep routine such as a putting away electronics, having a bedtime snack, and taking a warm bath.

### **Expectations**

Know your strengths and build your expectations on those. But also know your child’s limits. Remember: can’t vs won’t.

Pay attention to their cues and learn to understand their body language. Their brains get tired very quickly, so don’t overload them with lots of extracurricular activities. Be sure to make room for downtime.

### **Ignore behaviours**

Pick your battles carefully. Ask yourself: is it worth it or should you just let it go? Be prepared for a big meltdown.

### **Electronics**

Encourage a mix of activities that include physical movement as well as electronic devices.

It is especially important to try to limit electronics before bedtime—they can be overstimulating and the light from screens can interfere with sleep.

Monitor and regulate what they are watching.

### **Play**

Enjoy your child. Kids with FASD need you to play with them and spend quality time with them, just like other kids do.

### **Choices**

Give them choices, but not too many.

Keep it simple and concrete.

For example, “Would you like a sandwich or mac and cheese for lunch?”

### **Patience**

Parenting is hard! Try to develop strategies for managing impatience and frustration.

Do something you find calming, or try to leave the room and take a break, if you can.



# Seeking an FASD diagnosis

The Canadian diagnostic guidelines for FASD were revised in 2015<sup>1</sup>. The guidelines introduced several significant changes. They are specific to Canada; other countries such as the UK and the USA use different guidelines and terminology.

Here, we further breakdown the route to getting an official diagnosis.

## Why get an official diagnosis?

An official diagnosis can be a gateway for understanding your child. It can open doors to understanding challenging behaviours or developmental and learning difficulties, as well as your child's strengths. Some resources, funding, and supports may only be

available once you have an official diagnosis.

## How to get a referral for testing

Your family doctor or pediatrician can refer you to an assessment and diagnostic clinic in your area. There are eight across the province.

If you suspect your child may have FASD or have been prenatally exposed to alcohol, talk to your family doctor or pediatrician about your concerns. Tell them about any behavioural or developmental issues you have noticed. Share anything you know about their history of prenatal alcohol exposure.

A referral is needed for you to claim the costs for an FASD assessment. Let them know your concerns for

your child, and they can refer you to the assessment and diagnostic clinic in your area. There are eight throughout the province.

## Can you still get a diagnosis if you don't know if the child's mother consumed alcohol while pregnant?

Unfortunately, due to the stigma around FASD, it can be tough to get official confirmation that a mother consumed alcohol while pregnant. Confirmation can also come from other birth family members, birth records, FASD facial characteristics (also known as sentinel facial features), etc.

If you do not have confirmation and your child does not have any FASD facial characteristics, the

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**1 [Fetal alcohol spectrum disorder: a guideline for diagnosis across the lifespan, Canadian Medical Association Journal, Vol 188 Issue 3, 16 February 2016](#)**

assessment team cannot make an alcohol-related diagnosis. They may still be able to make recommendations for specialized care and interventions, though.

If your child does have facial characteristics of FASD, an official diagnosis is still possible. Further testing will be done to determine how much their central nervous system (CNS) is impaired.

### Who does the diagnosis?

#### For infants (under 18 months of age):

- A pediatrician/physician, and;
- A child development specialist who has the skill set to conduct physical and functional assessments. This could be a speech-language pathologist, physiotherapist, occupational therapist, or clinical psychologist.

#### For preschoolers aged 18 months to 5 years:

- Pediatrician/physician,
- Occupational therapist,
- Speech-language pathologist, and;
- Psychologist.

#### For school-aged children, 6 to 18:

- Pediatrician/physician with expertise in FASD and differential diagnosis,

- Occupational therapist,
- Speech-language pathologist, and;
- Psychologist.

#### For adults:

- Physician,
- Psychologist,
- Speech-language pathologist/psychologist with expertise in language assessment.

### Where is the testing?

There are eight Assessment and Diagnostic Clinics across the province:

[Complex Developmental Behavioural Conditions \(CDBC\) Team Sunny Hill Health Centre for Children](#), Vancouver

[CDBC Clinic Nanaimo Child Development Centre](#), Nanaimo

[Beacon Community Services FASD Circle Adult Diagnostic Clinic](#), Victoria

[Diagnostic and Assessment Services Fetal Alcohol Spectrum Disorder \(FASD\) Society for British Columbia \(The Asante Centre\)](#), Maple Ridge

[Northern Health Assessment Network \(NHAN\) Provincial Health Services Authority](#), Prince George



[Interior Health Children's Assessment Network \(IHCAN\)](#), Kelowna

*Note: Various places throughout the BC Interior do testing through IHCAN*

[Fraser Developmental Clinic](#), New Westminster

[CDBC, Clinic Queen Alexander Centre for Children's Health Vancouver Island Health Authority](#), Victoria

### What do they test for? What kinds of questions and procedures do they do?

The assessment team will conduct several assessments:

Medical assessment:

- A complete social and medical history will be compiled based on documents and interviews with the family and child
- A physical exam will happen
- Determine the confirmation of prenatal alcohol exposure
- Check for sentinel facial features

Neurodevelopmental assessment:

- Motor skills
- Neuroanatomy/neurophysiology (head size,





and other disorders related to the nervous system, such as seizures)

- Cognition
- Language
- Academic achievement
- Memory
- Attention
- Execution function (including impulse control and hyperactivity)
- Affect regulation
- Adaptive behaviour, social skills, and/or social communication

### How long does it take to get an assessment?

After referral, an assessment can take months or even years to start (the 2020/21 average wait time in BC was approximately 18 months<sup>2</sup>). There are private options, which some people choose to pay for out of pocket, that expedite the process.

Once your referral goes through, each clinic is unique in its testing process. Some complete their assessment in one day, but others

can take weeks or months over several appointments.

### You have a diagnosis, now what?

#### Talk to your child:

- It's essential to explain a child's diagnosis to them. They need to understand that they will have different challenges and strengths from other kids. Even from a young age, you can bring up FASD as just part of their identity.
- More resources for talking to your child:

Read: [CanFASD: How to explain an FASD diagnosis to your child](#)

Watch: [Keira Knowlton: Living with FASD](#)

Watch: [FASD Resources for individuals with FASD](#)

Book, younger children: [Forgetful Frankie, The World's Greatest Rock Skipper, Fetal Alcohol Spectrum Disorder](#)

Book, younger children: [The Way I am is Different: A Children's Book](#)

### [about a boy with Fetal Alcohol Spectrum Disorder](#)

Book, teens: [The Best I Can Be: Living with Fetal Alcohol Syndrome or Effects](#)

#### Educate yourself:

- AFABC has an educational FASD webinar, available for free on our website:

[Parenting a child with FASD](#)

#### Talk to your child's school:

- Ensure that your child's school and teachers are aware of the diagnosis and have the tools to help your child succeed in the classroom.

Read and share: [Let's learn together: A guide for parents and teachers](#)

*Note: this is UK-based but has valuable information that can be shared with your child's teachers*

Sources: [Fetal alcohol spectrum disorder guidelines](#), [CanFASD](#), [Asante Centre](#). A special thank you to the Asante Centre for reviewing this article.

## Some disabilities look like this:



## Some look like this:



*Invisible disabilities are real disabilities.*



# Interview with an FASD Key Worker

Children with FASD do best when their strengths are recognized. It's the job of a Key Worker to work with children and their parents to identify these strengths, find resources and services, and much more.

Key Workers are free, and you don't need a referral from your doctor. They are located all over the province and can be a great resource to help your child on the way to success. Learn more about how a Key Worker can help you and your family here.

**Can you please tell us a bit about yourself and your role as a Key Worker? What kind of other support do you offer families?**

My Name is Stacey Robertson; I have been in the Cowichan Valley Key Worker role for 6 ½ years. My

background is in early childhood education; I got my Child and Youth Care (CYC) degree and started working in the Aboriginal Infant Development Program (AIDP) field, and then into FASD. I was born and raised in the Cowichan Valley.

Key Workers provide family support on daily living skills for those living with a Complex Neurodevelopmental Diagnosis, primarily FASD. However, for many, there are adjacent diagnoses, or they have other diagnoses, and they don't tick all the boxes for Children and Youth with Support Needs (CYSN).

A big part of our role is helping change the narrative associated with a child or youth with this diagnosis and making sure all parties know that everyone has a

chance to live a successful life with individual strategies and planning.

**Can you tell us the process to get a Key Worker?**

The process is straightforward; parents and youth can do referrals for themselves or their child. Professionals may also make referrals, with parental consent. Delegated agencies can refer a child or youth in their care. Most of the time, it starts with a phone call or an email to my office, and then I send out a referral form to get the process started.

**Can you tell us the importance of working with a Key Worker for kids with FASD?**

The role of the Key Worker offers kids, and their families a non-judgmental person to connect



with who understands the neuro-complexity that comes with an FASD diagnosis. We can build on the strengths and resiliencies of the children, youth, and their families to support them to be successful in their day-to-day lives and build for the future.

### What kind of things/activities do you do with kids who have FASD?

Most of our work is done on the family level. Often, the children we are supporting have a lot of day-to-day support—at school, in their community, and at the professional level. But for those that don't, we work to find them the right supports, such as speech and language pathologists, therapeutic riding, youth workers, and the list goes on. We work with the family, including the child or youth, to make sure we make the right connections.

### What kind of other support do you offer families?

We offer medical, legal, educational,



and advocacy support for the needs of children to help make life as successful as possible.

Whether applying for funding, finding programs, or attending meetings with them, we use a family-focused lens and make our support unique to each family.

### What are your top tips or strategies for helping parents?

A few of my top tips and strategies for parents are:

- Routine and repetition are crucial to success for daily living skills;
- Creating supports of visual schedules;
- Technology such as smart watches and planning tools such as calendars can set youth up to be successful at navigating young adulthood;
- And lastly, when we as parents and professionals can re-frame our thinking from our child won't do this, to our child can't do this.

This allows us to have a whole new perspective on situations and come up with outside the box strategies for success.

### Anything else you'd like to add?

Parents should also try to do community training and FASD advocacy to help break the stigma



and reach new clients and families who may not know about the Key Worker program.

*Stacey is an FASD Key Worker based out of the [Hiiye'yu Lelum Society](#) in Duncan, BC.*

### Finding your Key Worker

The Key Worker program is offered in most regions across the province.

These links can help you find resources in your community:

[Find your Key Worker](#)

[Learn more about the Key Worker program](#)

You can also contact the Children & Youth with Support Needs Branch of MCFD if you would like more information.

**Local (Victoria):** 250.952.6044

**Toll free:** 1.877 387-7027

**Email:**

[mcf.childrenyouthspecialneeds@gov.bc.ca](mailto:mcf.childrenyouthspecialneeds@gov.bc.ca)



## Q&A: FASD and adoption

*Allison Wong is the Special Projects Consultant at The Asante Centre (learn more about Asante on page 22 of this guide). She assists individuals, family members, and service providers in understanding the diagnostic process and the implications for providing integrated post-assessment supports and services. Allison has been involved in FASD prevention and intervention efforts for numerous years in Northern BC and the Lower Mainland, including work in early childhood education, the public school system, the criminal justice system, and adult support settings.*

*Here she answers your questions about FASD.*

### **Is it true that children from international adoptions don't have FASD?**

Whenever a woman of child-bearing age consumes alcohol, there is a risk of her having a child with FASD. The same is true of children worldwide, though awareness of FASD and the broader cultural and environmental patterns associated with alcohol consumption in

pregnancy can vary considerably in different countries. The concern for children adopted internationally (and locally) is that an accurate prenatal history isn't always provided. Without accurate prenatal information, it's challenging to make an alcohol-related diagnosis. A comprehensive developmental assessment will likely help the adoptive family understand the child's needs and any potential concerns, such as the impact of trauma, neglect, or other medical conditions.

### **I keep hearing that it's safe to have an occasional glass of wine during pregnancy. Have researchers been able to determine if there is such a thing as a safe amount of alcohol consumption during pregnancy?**

The Governor General recommends no alcohol use in pregnancy, and emerging research supports that assertion. In discussing light or moderate drinking in pregnancy, it's essential to recognize the difference between FASD and the broader spectrum of people who have

been prenatally exposed to alcohol.

Not every person who's exposed will be diagnosed with FASD. The diagnosis only identifies individuals who have a specific level of disability that can be attributed to alcohol exposure. Alcohol exposure may more subtly impact other people. Sometimes they aren't diagnosable as a disability but still represent a real loss of potential (the term for this is "blunting").

The most accurate recommendation is that no amount of alcohol is safe during pregnancy or breastfeeding.

### **Can you tell us about the updated FASD guidelines?**

The current diagnostic guidelines for FASD were published in 2015 through the Canadian Medical Association Journal. [Ed. note: See [page 10](#) for more information]

The updated guidelines include expanded factors on how to diagnose young children and adults. Instead of an "umbrella"

term, FASD is now a diagnostic term with or without sentinel facial findings previously associated with fetal alcohol syndrome. The new guidelines added a tenth brain domain for affect regulation and redistribution of the measures for all brain domains to evaluate areas of impact best.

### **How can a doctor tell whether a child has FASD or ADHD, and what are the differences?**

Approximately 60% of individuals with FASD also present with attention difficulties and may be diagnosed with ADHD as part of their FASD (though ADHD has other causes). Individuals with FASD experience global delays; they must demonstrate disabilities in multiple areas to be diagnosed. A child with ADHD may be high functioning in all other areas.

### **My child with FASD is 10, but she functions more at the level of a four-year-old. It can be hard to remember that. Sometimes her behaviour frustrates me. Any suggestions?**

No matter how well we understand FASD and its associated special needs, it can be difficult to maintain patience. FASD is challenging! Children work very hard to do well and get as overwhelmed as you do. First, remember that you're human, and frustration is usual. Many strategies can be helpful. Some

families join support groups, and others memorize a crucial phrase from their child's assessment report that struck them. Try to make this your mantra: "We all do the best we can with the internal and external resources that we have." Every time you have an "aha" moment, consider writing it down so you can keep track of what you've learned.

### **My daughter's assessment showed that she has some challenges consistent with her prenatal alcohol exposure, but her scores didn't meet criteria for a diagnosis. How can we help her?**

My first response is to consider the age of your daughter. Many younger children do not meet the brain criteria, but they may be diagnosed later when the discrepancy between their chronological and developmental ages widens. She may need another assessment in a few years. Without a diagnosis, you may not be able to access disability services but can still work with the people in her life, such as her teacher, soccer coach, social worker, or family doctor, to meet her needs.

You can use her assessment findings as a starting point to brainstorm accommodations for her. Some possibilities include adaptations to communication approaches, additional tutoring for school, or support around calm-down techniques if she has

emotional regulation or sensory concerns.

### **Are there any medications that can help with the symptoms of FASD? When and how are they used?**

There are no medications that treat FASD in general, but there are medications that may help alleviate particular symptoms such as attention difficulties. Supplements that promote brain health may also be beneficial for people with FASD and anyone in the general public who wants to ensure optimal nutrition for their central nervous system. Please consult with your healthcare practitioner to find an approach that works best for your child.

Learn more about the Asante Centre at [asantecentre.org](https://asantecentre.org).

*Note: This article, originally published in 2015, was updated in February 2022 for this guide.*







# My life with FASD

*People with FASD struggle with lifelong behaviour and learning problems. In this article, one young adoptee shares her story of life with FASD. All names have been changed.*

What assumptions do you make when you see someone in a wheelchair? Or with a hearing aid or really thick glasses? What if they have a red and white cane or are wearing a cast? A lot of people could be identified as having a disability or needing extra support. But what if your disability is brain-based? It's then an invisible disability, which can lead to people to judge you or make assumptions that you are dumb, bad, undesirable and much more.

My name is Tianna Jones. To you, I may look like a typical, happy and fun, 15-year-old teenage girl. What you may not know by looking at me is that I have an invisible

disability. I have ARND (Alcohol-related neurodevelopmental disorder), I'd tell you what that means but I can't spell it. And I want you to know how important it is not to do drugs or alcohol when you're pregnant.

**“Her drug of choice was crystal meth, and it is suspected she also drank alcohol. It is hard to know why she didn't stop while she was pregnant with me.”**

When my birth mom was pregnant, she made a choice to do drugs for six months out of the nine months she was pregnant.

Her drug of choice was crystal meth, and it is suspected she also drank alcohol. It is hard to know why she didn't stop while she was pregnant with me. I do know it's not my fault but it doesn't make living with the consequences

of her actions easy. I am going to refer to my disability as FASD, not ARND, because that is a more recognized term.

There still needs to be more education around FASD. I am misunderstood a lot because people do not understand I have FASD. Some people think it's not a big deal to drink or use drugs while you're pregnant. But it is a big deal, a really big deal. I know because I live with it every day.

## **A new way of learning**

I find it very hard living with FASD. I have brain damage, sensory problems, learning disabilities and short term memory problems. It's not easy to live like this and my adoptive parents live with it too. They are with me every step of the way. They are my external brain and they help me be successful.

My parents have taught me along the way that my brain simply works differently. I have felt stupid many times, especially at school. I need adaptations that the other kids don't need and sometimes it makes me stand out differently. My brain can work really hard for a couple of days but then I forget what I have learned and I have to be taught it again. Sometimes people say I'm lazy or trying to get out of my work but that's not true, my brain just has to work extra hard to store information. I also get so tired that I sometimes need breaks. And sometimes that means I even need to miss school just to rest my brain and body.

I like to think of it like a filing cabinet. Filing cabinets are supposed to be organized with all the information easy to find when you need it. Well, imagine how my brain works: the information goes in but it's never filed in the right folder. You can't find the things you need. I can't remember them.

People like to make assumptions about me because I look like everyone else. I try to act like everyone else too. I have really great coping skills and can trick people. I know when to raise my hand in class at the right time so I'm not called upon but I look like I know the answer. I can move my mouth so I look like I'm reading, even if I'm not. I can even look like I know what I'm doing by

pretending to help my friends. This is all very exhausting because it takes a lot of energy to be something you aren't.

### Dealing with bullies

I have been bullied and made fun of. Back in elementary school, I had help from an EA. Focusing was really hard for me because I just didn't understand the work. I was loud and impulsive so my EA had to be my external brain. She calmed me down when I got hyper and she would help me when I didn't understand the questions. You see when I get overwhelmed I get very hyper and loud or I get a migraine. Peers would get frustrated with how loud and hyper I can get. Part of my disability is not being able to regulate my own body. Kids noticed that and started picking on me in grade 6 and 7 just because I was different.

In grade eight, boy did it get really bad. Kids from elementary school who didn't like me or understand me started teasing me in class about my disabilities. One girl even tried to schedule a day to jump me outside and beat me up but we reported her before that happened. That same girl and her friend attacked me in the gym during lunch a couple of weeks later but luckily an adult caught them. Then there was a boy in my foods class who thought it would be okay to

say something real hurtful to me. He said my mom didn't love me and I should have been aborted. That made me angry and then sad. First of all, she was not my mom she was my birth mom and second of all I am worthy and valuable and wanted, so I should have been born.

### Lifelong problems

Exposure to drugs and alcohol result in lifelong problems. These problems do not go away. You just learn to do things differently. No two people with FASD will be the same. What works for me may not work for someone else. It's a spectrum.

How would my life be without the support I have now? Where would I be today? I have learned and still am learning that it's okay to get support. It is okay to be me. I am one of the lucky ones because my family is always there for me. They have my back and they are my number one supporters.

No amount of alcohol or drugs are safe during pregnancy. We need to think about what's important: a few moments of fun or the life of another person not yet born. Is one hit of speed worth hurting a child like me?

*Tianna Jones is a teen adoptee who hopes her story will inspire others.*

**Note: This article was originally published in 2019.**





# Teaching children with FASD

By David Gerry

What your life would be like if it took three painful falls from the same tree branch for you to learn not to climb on that branch 12 feet from the ground?

We take for granted our ability to learn from mistakes, to create better outcomes tomorrow. Psychologists call this ability Adaptive Functioning (AF). When my wife and I became foster parents, we knew nothing about prenatal alcohol exposure, nor its effects. Our child falling repeatedly from the tree was an early indicator that despite normal appearance, she was different. We subsequently learned that the inability to apply the lessons of today to leverage better outcomes tomorrow is symptomatic of FASD.

If we won the lottery and didn't

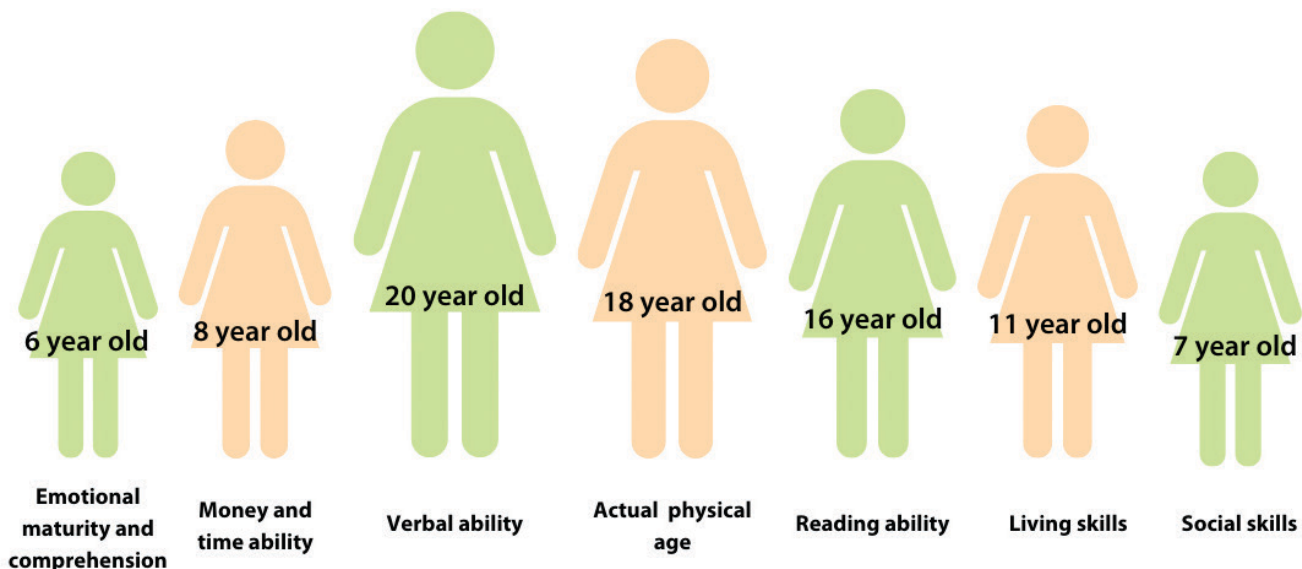
pay the rent or mortgage consistently, we would be evicted—having lots of money but not knowing how to use it effectively does not improve the quality of life. Having normal IQ but low AF is like having lots of money, but frequently facing homelessness.

Many people with FASD have IQs in the normal range but struggle to organize and achieve things that would be expected of people with their IQs. Within the general population, the difference between an individual's IQ score and their AF score is two points. The average for those with FASD is twenty-five points. This huge discrepancy has major significance in school and across the life span. An AF assessment can make distinctions between the various

aspects of a child's development (e.g. social and living skills, comprehension of abstractions like time and money). When the results of the AF assessment are used to inform the pictograph shown below, we see a very powerful demonstration of the complex and contradictory range of abilities and challenges typical of someone with FASD.

Increasingly, schools are finding they have to deal with children who seem unable to learn normally and who display challenging behaviour. Being aware of how prenatal alcohol exposure affects children can help a teacher understand their difficulties and look for relevant support. The pictograph makes it easier to see those discrepancies in development.





90% of students with FASD will often have a bewildering array of sensory sensitivities:

- For many, their sensory inputs are scrambled and they become overwhelmed with sights, sounds or smells;
- Ordinary ambient noises, (computers, heating systems etc.) can prove extremely distracting;
- Visually cluttered teaching environments can be overwhelming—the student does not know what they should pay attention to.

The discrepancy between calendar age and emotional capacity is likely to cause significant problems for the child with FASD:

- Such children may be unable to self-regulate;
- To cope with travel on school transport and a field trip may well be impossible without alternative, supported transport;
- Unstructured times like lunch break or play break can be

overstimulating and result in unacceptable behaviour.

Identifying, then eliminating or managing environmental triggers is a simple way of making your school environment more FASD inclusive/supportive. An Occupational Therapist (OT) or Physical Therapist (PT) can provide guidance and practical tips. They can suggest different types of seating options, personal space modifiers, weighted vests etc.

If it proves difficult to access the services of an OT or PT, then try to identify and avoid some of the common or hidden triggers that cause agitation or shut-down in these environmentally-sensitive students.

Once you have identified a problem, it becomes possible to look for help in resolving it. The key to success with this population is trying differently rather than harder.

*David Gerry began his applied learning in FASD as a direct result*

*of becoming a foster parent to two children with FASD. In 2000, he co-founded The FASD Community Circle – Victoria, a charity that develops programs and services for those with FASD.*

*The Circle set up the first children's multidisciplinary FASD clinic on Vancouver Island, Canada and also the first multidisciplinary FASD clinic for at-risk women.*

*He was co-chair of a comprehensive support program for pregnant and early parenting women who struggle with substance use and co-founded the international Living with FASD Summit.*



# Adaptive Functioning assessments



By David Gerry

## Why is it useful to have an Adaptive Functioning assessment of your child? What is Adaptive Functioning?

Briefly put, Adaptive Functioning (AF) is our ability to consistently remember and apply the lessons learned yesterday to improve outcomes and life tomorrow. We use these skills in order to find our way effectively through the complex demands that daily living places on us. In most people there is a close correspondence between their AF and their IQ (which is sometimes described as “general intelligence”).

However, this is not the case for people with FASD. They can have a normal IQ and low AF scores.

The age range pictogram page 21 shows clearly how a young person with good verbal abilities scores at a much lower age-equivalence in other key areas. It explains how a child who seems “normal” can often behave in ways totally at odds with expectations. For instance, my

child of 13 talks like a 15-year-old but sometimes behaves socially and emotionally like a 7-year-old. This is because her emotional and social skills are affected by her compromised receptive language and understanding.

## Preparing for an assessment

A variety of AF assessment tools are available.

Whether your assessor is government funded or is being paid by you, remember that you are the expert on your child—you see the 24/7 version. Schools get the edited version of them.

Make sure to have a preliminary meeting with your assessor. At this you should make clear that you require three things from the assessment report:

- A viable, agreed timeline;
- All raw data—you will need this in the future for consultations with other professionals;
- Usable outcomes and recommendations, not just

percentiles and statistics.

## How has getting an AF assessment helped me?

It has improved the quality of our home life. When I remember the pictograph on the previous page and how it applies to my child, it helps make my reactions more appropriate.

I can then try to acknowledge that what is frustrating me at the moment is the fact this is a 13-year-old whose ability to appreciate dangerous consequences is operating at their personal 7-year-old level in this area of their abilities. They are actually doing their best. This is not poor behaviour or willfulness, and I am not a bad parent.

I can also introduce the concept of AF to other adults my child is in contact with—knowledge which will hopefully then inform their interactions. The child’s self respect and self awareness will also benefit from their gaining a better understanding of how their AF influences their experience of the world.



# The importance of advocacy

## Advocating at school

Your child spends most of their week at school, so it can be challenging when teachers and other school staff don't understand their challenges. Advocating for your child's right to an education is one of the most important things.

### TIPS

- Most teachers don't learn about FASD; we need to educate them. Bring them resources to help.
- Set meetings as often as you need to ensure your child gets the best education possible.
- Build relationships with teachers, the principal, and admin staff.
- Check-in with the school to see how your child is progressing.
- Write notes for your child's teachers in their agendas or send them emails if you have

any questions, concerns, or comments.

## Advocating to medical professionals

FASD often gets misdiagnosed or ignored. You know your child best. Be sure to share exactly what is going on.

### TIPS

- Don't take no for an answer. Push for assessments. Ask for referrals to specialists. And don't forget to follow up on the requests.
- Get a pediatrician (which requires a referral from your family doctor).
- Educate them about your child—FASD is different for every child. Tell them your child's specific strengths and challenges.

## Advocating to family and friends

While friends and family often have the best intentions, they usually can't understand what you and your child are going through. Remember to advocate for your child, even to the people who are closest to you.

### TIPS

- Educate as much as you can.
- Share information to help keep them informed.
- Be prepared for inappropriate comments.
- Be prepared to lose friendships with those that just don't get it.
- Be prepared to receive lots of parenting advice.
- Be confident in your parenting strategies, you know your child better than they do.





# Inside an FASD assessment centre: The Asante Centre

The Asante Centre serves the entire province of BC with offices in Maple Ridge and Surrey. It was started in 2000 by a team of family members and community stakeholders who identified a need for FASD assessments, advocacy, and support.

The Centre was named for Dr. Kojo Asante who worked in Northern BC for many years and became a pioneer researcher in FASD through his pediatric work. The Asante Centre provides assessment and diagnostic services for FASD and other neurodevelopmental disorders, as well as family and community support, education and training, research projects, resource development, and more.

Staff at the Centre provide pre-adoption assessments, assessment of school-age children and youth,

youth involved in the criminal justice system, and adults. In their pre-adoption assessments, they have worked with families who have adopted from a variety of countries including Vietnam, Romania, Russia, the Ukraine, India, and Canada.

It is difficult to do a thorough assessment based on the often-incomplete medical information given to families. However, the multidisciplinary team provides parents with as complete a picture as possible of the developmental risk factors the child may experience from prenatal alcohol exposure. They also take into account postnatal concerns such as abuse and neglect.

The Centre provides a comfortable home-like environment for families attending a multi-day assessment

for their child. Families, social workers, care workers, foster families, and other professionals who work closely with the child are invited to be present at the assessment, to support and learn from the child and participate in developing the plan for the child's care.

Staff work hard to provide emotional support to families who are often overwhelmed when their child is first diagnosed with FASD.

During a diagnosis, the Centre helps families and care providers to fully understand the individual's strengths and weaknesses. They are then better prepared to support the child with his/her disabilities and to advocate for their child.

After diagnosis, the Centre is

available to help families access services and interventions available.

Asante also helps families and care providers become more knowledgeable about the disability and the appropriate methods for assisting their child.

The Centre provides consultation services and training to teachers, lawyers and other professionals who work with people with FASD.

### Why have a pre-adoption assessment for FASD?

- Helps paint a realistic picture of how the family must accommodate the child's special needs.
- Provides direction and guidance for intervention.
- Provides opportunities for assistance such as disability services.
- Allows for earlier diagnosis and intervention, which increases the likelihood for positive outcomes for the child.
- Makes the caregivers and child more knowledgeable about the disability and how to assist the child more effectively in their development.
- Creates realistic expectations about the child.
- Helps the caregiver know their child better in some of

the following areas: memory, language, social skills, attention or activity level, gross and fine motor skills, academics, affect regulation, executive function, and daily living skills.

To contact the Asante Centre and find out more about their services, call (604) 467-7101 or check out their website at [asantecentre.org](https://asantecentre.org).

*Note: This article, originally published in 2003, was updated in February 2022 for this guide.*

### We provide free, confidential support and connection

to the entire adoption and permanency community at every stage of the journey.

Whether you're considering adoption and have some questions, are struggling with a parenting challenge, or just want to know you're not alone, we'd love to connect with you.

[bcadoption.com/support](https://bcadoption.com/support)







## Many doors, no master key

*Julie Gelo is mother to 16 children, ages 16 to 55. She and her husband were licensed foster parents for 24 years. They are also in the process of adopting two of their prenatally exposed granddaughters ages 32 months and almost 1 year old.*

*Julie has been the Family Advocate for the FASD Diagnostic Team at the University of Washington (UW) for 25+ years. She is the Executive Director for the National Organization on Fetal Alcohol Syndrome Washington State. She also provides trainings on variety of topics an independent contractor. Here, she shares the story of her son Brandon.*

### **Brandon's story—and mine**

As the adoptive parent of 10 children with Fetal Alcohol Spectrum Disorders, I know how

difficult it can be to access services and develop a support network for people with FASDs. I regularly give presentations about FASD to groups, using the story of my son Brandon's life (with his full permission) to illustrate these difficulties. I'll share a condensed version of his story in this article.

When the foster care placement desk called my husband and me in June of 1995 and asked us to take placement of an eight-day-old infant who was in the NICU at the University of Washington hospital, we were better prepared than many families for a child with special needs. I have a medical background, we had been fostering for three years, and I had already brought eight foster children to the FAS Diagnostic Clinic at the University of Washington. This new placement would require me to draw on all

those skills and experiences. Baby Brandon was exposed to alcohol on a daily basis during his birth mother's pregnancy. He was growth deficient, and was experiencing respiratory distress, seizures, and feeding problems when we brought him home two days later.

### **Amazing joys and profound challenges**

Brandon was diagnosed with full FASD at three months of age. At that time, he was given a very poor prognosis. He only weighed 11 pounds by one year of age, he had a feeding tube for over a year, and he didn't crawl until he was 14 months old. He walked with an orthopedic walker at 24 months old and finally walked independently at three years old.

Over the years, he qualified for



speech and language therapy, occupational and physical therapy, and feeding therapy. He suffered multiple respiratory, sinus, and ear infections, had many surgeries on his ears, and suffered hearing loss for a period of time. For the first three years of his life, he attended at least one specialist or therapy appointment on almost every day of the week.

Brandan qualified for special education and received services in a birth to three program, a developmental preschool, and a special education program throughout elementary school, middle school, and now in high school. His cognitive and academic challenges are very profound. He also shares his unique and amazing sense of joy with the world. He often says, "This has just been the most beautiful day."

When Brandan was younger, he had enormous difficulty with sensory processing. He couldn't handle being in the cafeteria at school, he couldn't attend assemblies in the gym, and he wasn't able to attend the graduation ceremony of one of his older brothers because of the echoing in the auditorium. Four years ago, we went to the Everett Event Center to see the Harlem Globetrotters. Brandan was so overwhelmed and overstimulated that he dropped to the floor in a fetal position and dry heaved. He

continues to work with community providers and has made tremendous gains.

### **Elvis impressions and swimming lessons**

Today, Brandan's self-confidence and self-esteem is astonishing. He loves music, including rhythm and blues, country and western, big band swing, bluegrass, and old-time rock and roll. He has always loved singing and playing instruments. He was thrilled when he transitioned to high school and was given the opportunity to join the concert band and then to be in the percussion ensemble and drum line. He takes drumming, guitar, and banjo lessons. He even performed his Elvis impersonation at a National Conference on Fetal Alcohol Syndrome in Nashville, Tennessee in 2010 in front of over 300 attendees.

Brandan's successes haven't come easily. Washington State, where we live, has been at the forefront in FASD diagnosis and research for years, but we often lacked specific intervention services.

For example, Brandan has very low muscle strength in his hands and his core. We had to be creative and persistent in order to locate swimming and guitar instructors who recognized his talents and accommodated his challenges. These were just two interventions



that required extensive research and exploration.

A diagnosis of FASD may assist with securing eligibility for a program or service. In my experience, though, we often get further if we specifically discuss the affected person's unique needs and strengths, such as math disability, low processing speed, poor working memory, social immaturity, kindness, motivation, and being musically gifted. We then go on to cultivate relationships with interested and caring people who are willing to listen and learn.

### **Supportive relationships make the difference**

More than anything else, these kinds of supportive relationships are the key to Brandan's success. In 2003, one of my friends and I wrote a grant proposal asking for funding to hold a three-day FASD Family Summer Camp. The proposal was successful, and the camp was a wonderfully encouraging and positive experience for our family and for 12 other families as well.

Out of that camp grew a support





## Brandan and his sister Cayenne

network that eventually became the Washington State affiliate to the National Organization for Fetal Alcohol Syndrome. As the Executive Director for NOFAS Washington State, along with a powerful volunteer board of directors and passionate families, I created an online support group, a face-to-face support group for parents/caregivers/community providers, a teen social skills group, a friendship group for elementary aged youngsters, conferences, and summer camps. These programs

and networks have been our family's lifeline over the years. Unfortunately, due to state budget cuts, NOFAS Washington no longer receives any state funding.

Brandan's support team now consists of devoted parents, encouraging siblings, a phenomenal pediatrician, the Special Olympics, drum and banjo instructors, a special education teacher who is always open to learning, a band teacher who makes sure that Brandan is able to

shine and is included in all events, and a group of amazing friends at school that include cheerleaders and band members. He has been selected by his band classmates as the most inspirational student for three out of four years. This support network is truly the most important intervention and support in Brandan's life.

*Note: This article was originally published in 2015, but the bio and update on the following page have been updated for this guide.*





## Brandan's life today

Since graduating high school, Brandan (now 26 years old) has stayed connected with his school and band friends. He frequently has jam sessions with his former principal. And before COVID-19, he volunteered at an assisted living facility playing music with a few of his bandmates from school. This summer, Brandan plans to take a road trip with one of his friends from high school.

Julie continues to advocate for her son. Brandan is passionate about music. Julie has been pressuring the Division of Vocational Rehabilitation (DVR—the association in Seattle that assists people with disabilities to prepare for, secure, maintain, advance in, or regain employment) to provide jobs outside of the basic custodial positions they usually offer. While Brandan could easily do one of these roles, Julie is striving to find a position for Brandan where his passions and talents can be

pursued and grow. She acknowledges they are lucky to be in a place where waiting for employment is possible. “One gift that I can give my son is that no matter what he’s got dinner tonight, he’s got groceries. So, he doesn’t need just any job. I want him to have a job that fulfills him—a job that meets his passion.”

Julie envisions a life for Brandan filled with music, maybe a job at a recording studio or becoming self-employed in the music business. Brandan has written and recorded both his own music and cover songs. She would love an opportunity for him to record his music and put out albums on Bandcamp or Spotify. It’s been an uphill battle getting any response or support for these goals, but Julie will continue to fight for her son to be able to pursue his passions.

Health-wise, Brandan is improving from his youth. Although he

still has asthma, his chronic ear infections have subsided, and his growth consistency is stable. His balance and coordination aren’t the best, but that doesn’t stop him from going for walks, bike riding, and swimming. He even wants to learn to drive and has had a few practice sessions with his father.

Brandan continues to be a friendly, engaging, social, and empathic young man. He is kind to his friends, family, and animals. He is very conscious of his surroundings and is always polite. “He’s just, all in all, a pretty doggone good kid— young man—I shouldn’t call him a kid anymore,” Julie laughs as she corrects herself.

What’s next for Brandan? Driving, recording a music album, road trips—Brandan has big plans for the future, and things are looking bright.

[Click here to watch Brandan perform.](#)





## More resources

**AFABC Family Support**  
[bcadoption.com/support](https://bcadoption.com/support) |  
[adoptbckids@bcadoption.com](mailto:adoptbckids@bcadoption.com)

We provide free, confidential support and connection to the entire adoption and permanency community at every stage of the journey.

Whether you're considering adoption and have some questions, are struggling with a parenting challenge, or just want to know you're not alone, we'd love to connect with you.

**AFABC On-demand webinar: Parenting a child with FASD**  
[bcadoption.com/civcrm/event/info?reset=1&id=1772](https://bcadoption.com/civcrm/event/info?reset=1&id=1772)

This on-demand webinar offers information and practical strategies for parents of prenatally exposed children.

**AFABC Online support group: Caring for Children with Complex Needs**  
[facebook.com/groups/AFABC.AdoptiveFASD](https://facebook.com/groups/AFABC.AdoptiveFASD)

This group supports anyone parenting through adoption or other forms of permanency where the child has FASD, ASD, and/or other complex needs.

**Asante Centre**  
[asantecentre.org](https://asantecentre.org) | 1.877.327.7101

Creating compassionate communities for individuals and families with FASD, Autism

Spectrum Disorder (ASD,) and other complex developmental disabilities.

**BC Government FASD information**  
[gov.bc.ca/gov/content/health/managing-your-health/child-behaviour-development/support-needs/fetal-alcohol-spectrum-disorder-fasd](https://gov.bc.ca/gov/content/health/managing-your-health/child-behaviour-development/support-needs/fetal-alcohol-spectrum-disorder-fasd)

Information on support and information from the BC Government, including the Key Worker program, HealthLink BC, and more.

**CanFASD**  
[canfasd.ca](https://canfasd.ca)

The Canada Fetal Alcohol Spectrum Disorder Research Network (CanFASD) is a collaborative, interdisciplinary research network, with collaborators, researchers and partners across the nation. It is





Canada's first comprehensive national Fetal Alcohol Spectrum Disorder (FASD) research network.

**CanFASD: I am a caregiver PDF**  
[canfasd.ca/wp-content/uploads/2019/03/Caregiver\\_ENG\\_2019-Final.pdf](https://canfasd.ca/wp-content/uploads/2019/03/Caregiver_ENG_2019-Final.pdf)

PDF download with challenges, supports, and other information for caregivers.

**FASD & Me: Strengthening My Community worksheet**  
[bit.ly/3IB94FK](https://bit.ly/3IB94FK)

A worksheet from Adopt 4 Life to help families update and share information about their child's strengths and needs as they change over time.

**FASD HUB: Australia | Brain impairment in FASD**  
[fasdhub.org.au/fasd-information/understanding-fasd/what-is-fasd/brain-impairment-in-fasd/](https://fasdhub.org.au/fasd-information/understanding-fasd/what-is-fasd/brain-impairment-in-fasd/)

An interactive website which shows 10 neurodevelopmental domains involved in the diagnosis of FASD.

**FASD Okanagan Valley Assessment and Support Society**  
[fasdokanagan.ca](https://fasdokanagan.ca) | 250.938.5022

Provides adults and youth suspected of having FASD with a

confirmed diagnosis and provides support, education, and training.

**FASD Network**  
[saskfasdnetwork.ca/resources](https://saskfasdnetwork.ca/resources)

Based in Saskatchewan, the Network has created several resources to help people learn about FASD and create strategies to support individuals with this disability.

**FASD United**  
[fasdunited.org](https://fasdunited.org)

Based in the United States, FASD United works to prevent prenatal exposure by raising awareness and supporting women before and during their pregnancy, and supports individuals, families, and communities living with FASDs and other preventable intellectual/developmental disabilities.

**Key Worker program**  
[Find your Key Worker](#)

[Learn more about the Key Worker program](#)

Information about the Key Worker program in BC.

**Know FASD: alcohol in utero knowledge base**  
[knowfasd.ca](https://knowfasd.ca)

An interactive website that introduces the neurobehavioural

difficulties that may appear throughout the lifespan of individuals with FASD.

**Manitoba FASD Coalition | Videos about FASD**  
[fasdcoalition.ca/looking-after-each-other-project/mini-documentaries/](https://fasdcoalition.ca/looking-after-each-other-project/mini-documentaries/)

A series of mini documentaries to showcase how communities, services, systems, and other initiatives can creatively support the success of those impacted by FASD and the women who have used alcohol during pregnancy.

**Me and my FASD**  
[fasd.me](https://fasd.me)

An interactive website created for young people with FASD. UK-based.

**Provincial Outreach Program for Fetal Alcohol Spectrum Disorder (POPFASD)**  
[fasdoutreach.ca](https://fasdoutreach.ca)

A collection of FASD resources from around the web.

**YWCA | Learn the basics of FASD and the FASD Dictionary**  
[ywcavan.org/blog/2021/09/learn-basics-fasd](https://ywcavan.org/blog/2021/09/learn-basics-fasd)

[fasddictionary.ywcavan.org](https://fasddictionary.ywcavan.org)

Learn the basics of FASD and check out their dictionary to learn common FASD terms and phrases.



# adopt

**Adoptive Families Association of BC**

#200-7342 Winston Street  
Burnaby, British Columbia V5A 2H1  
Canada

[info@bcadoption.com](mailto:info@bcadoption.com)  
1-604-320-7330  
1-877-ADOPT-07