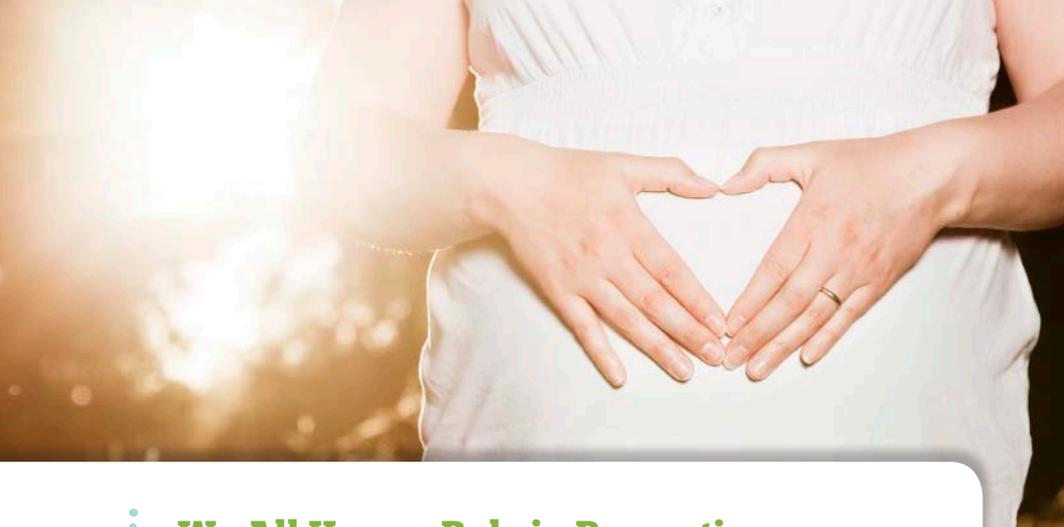


# The Hidden Disability

FETAL ALCOHOL SPECTRUM DISORDER



FASD Family Support, Education and Counselling



**We All Have a Role in Preventing FASD and Understanding the Effects of Alcohol Use During Pregnancy.**

## Did You Know?

Family members, partners, friends, community and society all have a responsibility to become aware and understand the impact alcohol plays in the lives of women who use alcohol during pregnancy. Alcohol is the single most widely accepted and used substance in society.

- In 2010, 77% of Canadian's reported drinking (alcohol) in the past year. <sup>(1)</sup>
- Statistics show that 76% of women surveyed in the Canadian Addictions survey reported drinking (alcohol) in the past year. <sup>(2)</sup>
- Research shows that approximately 50% of pregnancies are unplanned.
- All women of child bearing age, who are sexually active and consuming alcohol, are at risk of having a child with FASD. <sup>(3)</sup>
- Most women don't realize they are pregnant until six weeks or more into their pregnancy.
- No woman intentionally seeks to harm her unborn child.
- Lack of information, peer pressure, poverty, homelessness, violence and childhood abuse, isolation, poor mental health, addiction and lack of access to resources are contributing factors to alcohol use during pregnancy.
- While men cannot cause FASD, they have a role in prevention by helping the women in their lives remain alcohol free.

<sup>(1)</sup> Health Concerns: Canadian Alcohol and Drug use Monitoring Survey, retrieved From Health Canada, [www.hc-sc.gc.ca](http://www.hc-sc.gc.ca)

<sup>(2)</sup> Women and Alcohol: A Women's Health Resource, retrieved from [www.hcip-bc.org](http://www.hcip-bc.org)

<sup>(3)</sup> Alcohol and Pregnancy/Prevention of Fetal Alcohol Spectrum Disorder (FASD), retrieved from [www.niagararegion.ca](http://www.niagararegion.ca)



## About Fetal Alcohol Spectrum Disorder

FASD is a medical diagnosis which describes the effects caused by alcohol use during pregnancy. Most often there are no outward signs to show a person has FASD, but the brain can still be affected. Prenatal alcohol exposure may affect multiple areas (“domains”) of brain functioning. The new guidelines require significant impairment (major differences) in at least 3 different areas, resulting from prenatal alcohol exposure.

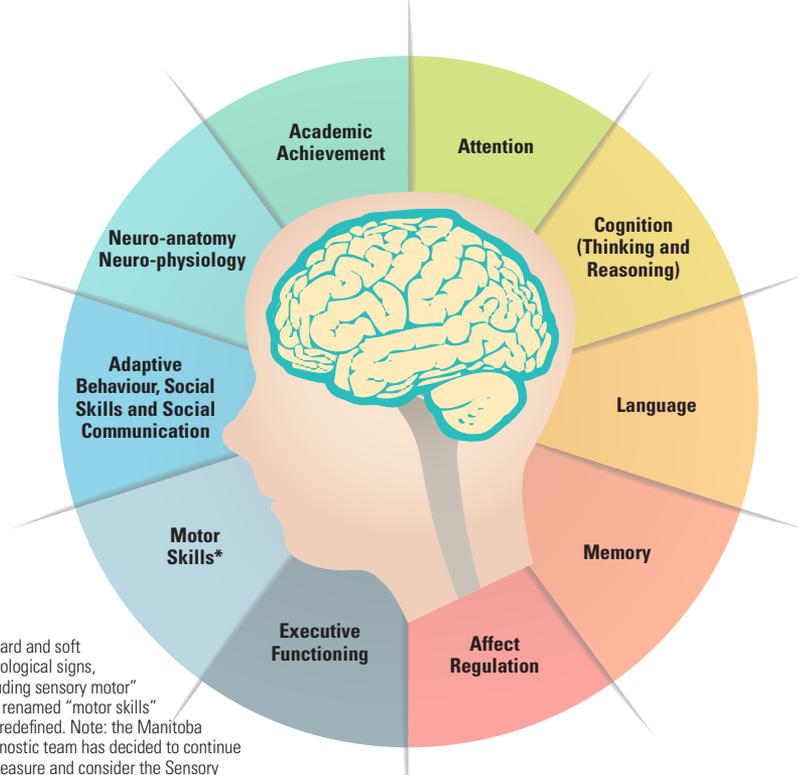
Individuals who meet these criteria may be diagnosed with:

- **FASD** with sentinel facial features: short palpebral fissures (small eyes), smooth philtrum (smooth skin between nose and upper lip) and thin upper lip

OR

- **FASD** without sentinel facial features

**There are Ten Brain Domains (Functions) that can be affected by alcohol use during pregnancy, which may lead to a diagnosis of FASD, they are:**



\* “Hard and soft neurological signs, including sensory motor” was renamed “motor skills” and redefined. Note: the Manitoba diagnostic team has decided to continue to measure and consider the Sensory Domain as important to understanding the individual’s functioning – Manitoba FASD Centre.

The new Canadian Guidelines for FASD diagnosis (Cook et al “Fetal Alcohol Spectrum Disorder: A guideline for diagnosis across the lifespan,” CMAJ 2015. This illustration has been adapted from a diagram contained in the “Every Day is an Adventure: What Parents and Caregivers Need to Know About FASD”, Healthy Child Manitoba.



# Ten Brain Domains (Functions) Affected by FASD

Alcohol affects the growth and formation of the brain, and this is often seen in an individual's behaviour and development. The following brain functions or domains are evaluated by a diagnostic team during an FASD assessment:

## Academic Achievement

- May have difficulty in school: reading, math, comprehension (understanding), organization and abstract concepts

## Attention

- Can be easily distracted, difficulty paying attention and sitting still

## Cognition

### (Thinking and Reasoning)

- Difficulty reasoning, planning, solving problems and comprehending complex ideas
- A wide range of IQ scores are found

## Language

### (Expressive and Receptive)

- Delay in language development
- Difficulty understanding lengthy conversation and instructions
- May speak well, but not fully grasp the meaning
- Can repeat instructions or rules, but may not follow through

## Memory

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

## Neuroanatomy/Neurophysiology (Brain Structure and Function)

- Could have a smaller head, brain size, and/or a seizure disorder, and/or abnormal findings on a scan (e.g. MRI or EEG) consistent with prenatal alcohol exposure

## Executive Functioning

- May have trouble with planning, sequencing, problem solving and organizing

- May be impulsive and/or hyperactive
- Difficulty understanding cause and effect and controlling behaviour
- Challenges with transitions and change
- Often repeats mistakes
- Difficulty with concepts, abstract ideas, consequences and managing time

## Adaptive Behaviour, Social Skills and Social Communication

- May not understand personal boundaries and have difficulty reading social cues
- May be socially vulnerable and easily taken advantage of
- Difficulty seeing things from another's perspective
- Socially and emotionally immature and may behave younger than actual age
- May have trouble with hygiene, money and coping skills

## Motor Skills

- Difficulty with balance, strength, endurance, coordination, reflexes and muscles tone
- Difficulty with printing, using pencil and scissors

## Affect Regulation (Ability to Control and Adjust Emotions)

- Includes anxiety, depression, and mood imbalance in the severe range (meets DSM-V criteria)\*

Note: The most significant change has been the removal of the Sensory Domain, which the Manitoba team has decided to continue to measure and consider as important to understanding the individual's functioning –Manitoba FASD Centre

\*DSM-V: Diagnostic and Statistical Manual criteria



## Strategies for Success

This is a brief review of some strategies that are helpful for individuals with FASD. Each individual is affected differently and will have a unique set of strengths and challenges. Assistance from a professional with knowledge about FASD may be helpful.

### Routine and Structure

- Regular routines provide a sense of control and predictability
- Use words, picture cues or timers to prepare individual when changing activities
- Structure routines for mornings, bedtimes and after school (*e.g., home from school, have a snack, do homework, help with dinner, and eat together*)
- Picture symbols, calendars and day books can be helpful for planning routines

### Relationship

- Meaningful and trusting connections are important
- An understanding, caring and consistent approach works best
- Work as a team (*e.g., "let's work together" and "I am here to help"*)

- Become familiar with "warning signs" indicating individual is becoming overwhelmed and respond supportively
- Have fun together, and accept the individual as they are
- Plan for successful experiences by building on individual's strengths and interests

### Environment

- Understand the abilities and challenges of the individual
- Change the environment rather than the individual
- Decrease noise, number of people and things in the environment
- Organize toys, clothing, cupboards, etc.
- Provide a quiet retreat with books and blankets

Continued...



## Strategies (Cont'd)

### ✓ Calming Activity

- Movement may help with calming and to address high energy levels (*e.g., go to the playground, ride a bike, stretch, use a rocking chair, roll on a ball or walk to water fountain.*)<sup>\*</sup>
- Try a warm bath, firm massage, chores or have a break
- Engage in structured exercise, like running, jumping jacks, bouncing on cushions or a floor mattress<sup>†</sup>
- Use a settling routine before bed (*e.g., snack, bath, rocking chair and read, brush teeth, to bed, hugs and kisses*)

\* Activities to be used with supervision

### ✓ Sensory

- Decrease stimulation in the surroundings (*e.g., natural light, tidy desk surface, one toy at a time, TV off when eating or before bedtime, use ear plugs, remove labels in clothing etc.*)<sup>†</sup>
- Engage in movement involving pushing, pulling, squeezing (*e.g., pushing a vacuum, pulling a sled, squeezing Play-Doh*)<sup>†</sup>

† Consult with an Occupational Therapist for other sensory strategies

### ✓ Communication

- Keep communication clear, simple and short
- State the behaviour expected (*e.g., "walk" vs. "don't run"*)
- Use demonstration, reminders and repetition
- Provide praise, encouragement, and cues to learn expectations. Be aware that some individual's behaviour may be linked to their inability to understand what is being asked of them. It's not that they won't listen, it's that they can't

### ✓ Thinking and Reasoning

- Assist with steps to solve a problem, make a plan, and to get organized
- Use step by step instructions and visual cues
- Support and guidance may be needed for making decisions and dealing with money
- Use supervision to address safety concerns (*e.g., crossing street, talking to strangers, out late at night, answering the door*)

This booklet was written by the FASD Family Support, Education and Counselling Program of New Directions for Children, Youth, Adults and Families and in consultation with Dr. Anna Hanlon-Deerman and Dorothy Schwab of the Manitoba FASD Centre.

**This booklet is meant to be a quick reference guide and is not an exhaustive presentation of the material.**

**Any information in this booklet may be reproduced without alteration.**

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## FASD Resources

### **Manitoba FASD Centre**

[www.fasdmanitoba.com](http://www.fasdmanitoba.com)

Phone: 204-258-6600

### **Manitoba FASD Coalition**

[www.fasdcoalition.ca](http://www.fasdcoalition.ca)

### **Healthy Child Manitoba FASD Resources**

[www.gov.mb.ca/healthychild/fasd/resources.html](http://www.gov.mb.ca/healthychild/fasd/resources.html)

Phone. (204) 945-2266 or

1-888-848-0140

### **Public Health Agency of Canada**

[www.phac-aspc.gc.ca/hp-ps/dca-dea/prog-ini/fasd-etcaf/index-eng.php](http://www.phac-aspc.gc.ca/hp-ps/dca-dea/prog-ini/fasd-etcaf/index-eng.php)

### **Alcohol & Pregnancy: Be with Child, Be without Alcohol**

[www.withchildwithoutalcohol.com](http://www.withchildwithoutalcohol.com)

*(Available in English, French, Cree and Ojibway)*

### **FASD Family Support, Education and Counselling Program of New Directions**

<http://newdirections.mb.ca/counselling-assessment-support-prevention/fasd-family-support-education-and-counselling-program/>  
Phone: 204-582-8658

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## References

- Public Health Agency of Canada. Fetal Alcohol Spectrum Disorder (FASD), (2005), [www.phac-aspc.gc.ca/hp-ps/dca-dea/prog-ini/fasd-etcaf/index-eng.php](http://www.phac-aspc.gc.ca/hp-ps/dca-dea/prog-ini/fasd-etcaf/index-eng.php) (visited January 4, 2012)
- Manitoba Fetal Alcohol Spectrum Disorder Centre, Assessment, Education, Training, Research. [www.fasdmanitoba.com](http://www.fasdmanitoba.com) (visited January 19, 2012).
- Berg, Sandi, et al. *A Layman's Guide to Fetal Alcohol Syndrome and Possible Fetal Alcohol Effects*. FAS Support Network of BC., 1995
- Appendix to: Cook JL, Green CR, Lilley CM, et al.; Canada Fetal Alcohol Spectrum Disorder Research Network. Fetal alcohol spectrum disorder: a guideline for diagnosis across the lifespan. CMAJ 2015. DOI:10.1503/cmaj.141593. Copyright © 2015 8872147 Canada Inc
- Manitoba FASD Centre

# A Story of Hope

**W**ell... I had a really hard time in school when I was younger. My mom tells me she was always getting phone calls from the school to come pick me up, because they "couldn't manage" my behaviour. I don't remember much from that time. But, as I started getting a little older, I do remember getting into a lot of trouble. I wasn't trying to make problems for anybody, I just couldn't sit still and I was a bit of a daredevil too. I was sent to the office a lot, and fighting with just about everyone; students and even teachers.

I just had a real hard time and didn't feel anyone understood me. I got suspended a lot. I was finally moved from my school to a school with a classroom for students with FASD. This really changed my life! The teacher there really made a difference; she was strict, but cared about me (I could tell). She let me move around a lot, I guess she knew that I could still listen, even if my body couldn't stop moving. This was the first time I felt like I could succeed!

Today I am in grade 10, in high school and going to classes like everyone else, but I have support from a great teacher. Even though I attend regular

classes, I sometimes just need to connect with her for some reassurance and support. That's what she is there for. She is kind of like my old teacher, strict (some would say, "consistent") but believes in me and likes me.

I have always been interested in cooking, but while attending high school, I came to realize how much I love it! Culinary Arts is my favorite subject; I'm good at it and it helped me find a volunteer job over the summer at a special summer camp.

This camp program helps kids with FASD; they get to come out and have fun with each other and with adults who understand them. I was the guy in charge of their "nutrition breaks", by planning and making their snacks. I had a lot of fun doing this, it was a great experience and I am told I can do it again next year. People even believe I can get a job in this area when I get older. My goal in life is to be the first person in my family to graduate high school, and I know I can do it too!

Oh, by the way, I have FASD.



*A first hand account of a person with FASD*

## Contact Us For More Information:

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