

Fetal Alcohol Spectrum Disorder (FASD) – Overview

FASD is a neuro-developmental disability that occurs in individuals who were exposed prenatally to alcohol. It is a lifelong disability for which there is no cure. However, it can be prevented by avoiding alcohol during pregnancy.

Every year 3,000 babies in Canada are born with Fetal Alcohol Spectrum Disorder (FASD). It is estimated that more than 130,000 children and adults in Ontario are currently living with this lifelong disability.ⁱ

FASD is a term used to describe a range of physical, mental, behavioural, and learning effects in children who were exposed to alcohol as a fetus. It is now a known fact that alcohol use in any amount is unsafe and causes birth defects in varying degrees. Alcohol consumption during pregnancy, whether a large quantity in a short timeframe or frequent consumption ex. more than seven drinks per week, poses significant risk to the fetus.ⁱⁱ

When a woman drinks alcohol while pregnant, her fetus is exposed directly to alcohol through her bloodstream. Alcohol can interfere with the growth and development of all fetal body systems; however, the developing central nervous system (the brain and spinal cord) is especially vulnerable to the damaging effects of alcohol. These effects, which can vary from mild to severe, may include physical, mental, behavioural, and/or learning disabilities with possible lifelong implications.ⁱⁱⁱ FASD affects individuals from all socioeconomic and ethnic backgrounds.

FASD is one of the leading causes of preventable birth defects and developmental delays among Canadian Children. Although this disorder is preventable, the statistics for prevalence in Canada are not decreasing. In fact, according to the first population-based study in Canada, conducted by the Centre for Addiction and Mental Health (CAMH), an estimated 2 to 3% of elementary-aged children (7-9 years) in the Greater Toronto Area (GTA) likely have FASD.^{iv}

Although some children with FASD possess certain characteristic facial features, the majority of people with FASD are not visibly different. As such, FASD is primarily an invisible disability. People with FASD may have average to above-average intelligence; however, they can experience executive functioning and communication challenges along with neuromotor deficits.^v

“People living with FASD, particularly those who have not received effective early and ongoing interventions, are at increased risk for a range of issues including:

disrupted school experiences and early school failure; depression, anxiety, and other mental health conditions; substance use issues; involvement with the law; and, family disruption. The majority of people with FASD are unable to live independently and are at risk for homelessness.”^{vi} The fact that FASD is preventable, yet the rates of prevalence remain high signals the need for enhanced public awareness, particularly awareness among educators of school-aged children.

Bill 172: Education Statute Law Amendment Act (Fetal Alcohol Spectrum Disorder) and Bill 43: Sandy’s Law:

The prevention of FASD is supported by Bill 172 (Education Statute Law Amendment Act (Fetal Alcohol Spectrum Disorder) and Sandy’s Law: (Liquor Licence Amendment), 2004, S.O. 2004, c.12 – Bill 43, a provincial requirement for establishments selling or serving alcohol to post signs warning women of the risks of consuming alcohol during pregnancy. (See **Appendix B**)

Bill 172 requires school boards to develop policies and guidelines regarding FASD. Teacher education programs (colleges) and early childhood education programs shall now be required to provide training regarding FASD. All of the following: Early Childhood Educators Act, 2007, Ontario College of Teachers Act, 1996, and the Education Act have been amended to include minimally:

- a) awareness of the signs and symptoms of FASD; and
- b) strategies to accommodate the needs of children who have diagnosed or suspected FASD.
- c) however, the Education Act amendments go into more detail to include also that every board shall establish policies and guidelines respecting FASD.

The policies and guidelines must:

- a) promote awareness and understanding of FASD;
- b) include established and emerging best practices to support pupils who have diagnosed or suspected FASD; and
- c) identify strategies for the identification of pupils who have diagnosed or suspected FASD and for providing accommodation for those pupils.

Furthermore:

- d) Every board shall facilitate collaboration with parents and FASD Support Groups in undertaking the promotion of awareness and understanding of FASD.

Causes, Risk Factors, and Prevention of FASD:

FASD is preventable. There is no safe amount or type of alcoholic beverage, and no safe time to drink alcohol during pregnancy. Pregnant women are advised not to drink any alcohol during pregnancy.

Signs and Symptoms:

The Centre for Addiction and Mental Health (CAMH) provides the following detailed information regarding FASD^{vii}. Individuals with FASD do not all present with the same visible and non-visible physical features, or strengths and weaknesses. However, individuals with a diagnosis anywhere on the FASD spectrum will have some degree of brain dysfunction. The signs and symptoms of FASD are categorized into primary and secondary disabilities such as the following:

Primary, brain-based disabilities of FASD are those that most directly reflect the underlying central nervous system damage caused by prenatal exposure to alcohol. This damage is made manifest in a range of difficulties with adaptive behaviour, attention, cognition, executive functioning and memory. As a result, individuals with FASD may have trouble with abstract reasoning, organization, planning, understanding or recalling a sequence of events, connecting cause and effect relationships, and/or regulating their own behaviours and emotions. They include:

- a) inconsistent memory and recall;
- b) inability to filter out environmental or emotional distractions and sensory stimuli;
- c) slow and inconsistent cognitive and auditory processing;
- d) decreased mental stamina;
- e) difficulty interpreting and applying abstract concepts (for example, managing money and time);
- f) impulsivity and poor judgment;
- g) inability to predict outcomes (of their own or others' actions);
- h) difficulty shifting from one context to another;
- i) resistant to change;
- j) inability to see another person's perspective;
- k) inability to recognize indirect social cues.

Another common characteristic of individuals diagnosed with FASD is 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.

Individuals with FASD do not have the ability to meet many of society's age-based social and academic expectations. Since FASD is not usually outwardly visible, the effects of dysmaturity can be confusing and frustrating to people who have FASD as well as to those around them.

Individuals with FASD can also have permanent vision and hearing problems; poorly developed bones, limbs and fingers; and damage to the heart, kidney, liver and other organs.

Secondary disabilities are those not present at birth, but occur later in life as a result of the primary disabilities associated with FASD. They include:

- a) mental health problems;
- b) disrupted school experience (suspension, expulsion, and/or drop-out);
- c) involvement with the law (trouble with authorities, charged and/or convicted of a crime);
- d) confinement (inpatient treatment for mental health and/or alcohol/drug problems, or incarceration for crime);
- e) alcohol and/or drug problems;
- f) poor academic achievement and school failure
- g) sexually deviant behaviour;
- h) problems with employment; and
- i) dependent living.

When combined with individuals' primary disabilities, these secondary disabilities increase the complexity of care for individuals both while school-aged and later on in life.

Diagnosis and Treatment - Strategies for Home and School:

According to CAMH, if FASD is diagnosed early, interventions may be able to lessen its impact and prevent secondary disabilities. Many types of treatment are available for individuals with FASD such as:

- a) medical care/specialists (for example, speech-language pathology, occupational therapy, physical therapy, mental health care, etc.);
- b) medication to help lessen some of the symptoms of FASD;
- c) behavioural and educational therapy;
- d) parent training; and
- e) alternative approaches (auditory training, creative art therapy, meditation.

An individual with FASD can be assisted by special school programs with their learning and behaviour. Such assistance can enable a person with FASD to maximize their independence and achievements. Other factors can help reduce the effects of FASD and help individuals with these conditions to reach their full potential such as:

- a) early diagnosis;
- b) involvement in special education and social services; and
- c) loving, nurturing and stable home and school environments.

Strategies for Home and School:

When dealing with a child with FASD, it may become evident that s/he presents with difficulty learning a pattern of acceptable behaviour or that s/he responds inconsistently in a favourable manner to learning situations.^{viii}

When situations such as this emerge, the challenge for educators becomes the determination about which teaching method to utilize in order to maximize the FASD child's ability to learn.

While many children without FASD tend to learn in sequential stages of difficulty of task completion, the child with FASD requires repetitive teaching of a task until it becomes automatic. All children learn best in a way that resonates with their strengths.

The Importance of Routine:

High importance is placed on the creation of routines for individuals with FASD as they do not adapt well to change. Therefore, daily routines are a source of comfort and stability.^{ix} The use of visuals/signs can be helpful for children's memory for the order of tasks in daily routines such as: dressing, personal hygiene, and the organization of one's personal space.

Behaviour and Discipline:

The consistency of one's approach to discipline is critical when considering the effects of FASD. Changing or make exceptions to the rule can become confusing for the child. Problems with memory and making the link between actions and consequences mean that strategies such as reflecting on one's past mistakes might not be effective.^x

Adapting the Environment:

Both at home and at school, the learning environment has a significant impact. The manifestations of FASD highlight the importance of creating a safe, stable, and

nurturing environment. Since sensory integration can be a challenge for children with FASD, it is important for educators and parents to have a good understanding of potential impacts of the environment on the five senses. Caregivers are encouraged to seek out an assessment with an Occupational Therapist if there are concerns.^{xi}

If a child presents with hypersensitivity (feels too much), consider taking the following steps to mitigate the effects of it:

- a) use soft bedding and avoid new linen;
- b) remove labels from clothing and wash it several times before wearing;
- c) avoid wool sweaters, turtlenecks, jeans, or other close-fitting clothing that has a distinct texture;
- d) avoid crowds or other high-traffic areas;
- e) turn off strong lights and use softer, indirect lighting; and
- f) keep spaces clutter free.

If a child presents with hyposensitivity (feels too little), supervise him/her carefully as s/he might not feel pain, hot, or cold. Consider taking the following steps:

- a) help ensure that s/he is not over/underdressed for the season;
- b) provide opportunities for oral stimulation using various foods that are: crunchy, chewy, or slurpy;
- c) provide opportunities to engage in physical/kinaesthetic activities such as: running, jumping, lifting, or shovelling snow;
- d) offer the use of a fiddle toy, stress ball, or bean bag when required to sit still for long periods of time in order to improve focus and sustain attention.^{xii}

It is essential that educators and other providers avail themselves of opportunities to engage with specialized trainers who can provide the skills and strategies that are useful for children and youth with FASD. A number of resources and links can be found through the Best Start Resource Centre (Health Nexus) (see **Appendix A**), CAMH, Catholic/Children's Aid Societies of Toronto, Toronto FASD Coordinating Network, and Toronto Public Health.

Building Better Brains:^{xiii}

“To build better futures, we need to build better brains.” As parents, educators, and community members, we have the capacity and responsibility to help build healthy

brains. Brain builders are who we are. Brains are not just born, but they are built over time.

The experiences of our lives help to build the architecture of the brain: positive experiences help to build a more solid foundation; negative experiences prevent the building up of solid supports for healthy brain function. Just as a house needs a solid foundation on which to be built, a brain needs a solid foundation on which to grow. A solid foundation and the earliest years build a good foundation in the earliest years of life. A good foundation helps to promote a lifetime of success

A solid brain foundation is built and maintained in a developing child through what are known as “Serve and Return” interactions that function similarly to a tennis match. In ‘serve and return’ relationships, the child acts, the parent responds and notices the child.

Stress and Executive Functions: Stress helps to shape childhood development, for better or for worse. However, toxic stress can damage sturdy brain architecture. Executive function and self-regulation are like the air traffic control centre of the brain. These centres of the brain help children to self-regulate.

Brain Hero:^{xiv}

The Harvard Centre on the Developing child, 2011, provides some critical facts about the developing brain and the impact of communities on the shaping of childhood experiences and the quality of life within communities.

The brain is built and shaped over time. Parents, extended family, and care givers of all kinds have a part to play in a child’s life. Formative events and family and community events can shape child development. What happens early matters for a lifetime. Formative events, family, and community environment affect child development.

Lower levels of stress and more opportunities for learning improve brain architecture. Serious adversity early in life can disrupt brain development. Brain architecture and behaviour are increasingly difficult to change over time.

A child raised in a healthy environment, who is exposed to lower levels of stress, and who is provided with more opportunities for learning, has the foundation that creates a sturdier brain architecture. Good early brain development can improve health, behaviour, and learning and have an impact throughout life.

Resiliency and (community) protective factors can help to inform the translation of a strategy into action. A community/organization needs to create opportunities for “stress inoculation” in children. However, it is important to note that not all stress is toxic; in fact, some is instrumental towards positive change and growth in a child’s life. The emerging biology of parenting and adults who are working towards reducing adversity in the lives of children is a goal towards healthy social and emotional (childhood) development.

ENDNOTES

- ⁱ City of Toronto, Fetal Alcohol Spectrum Disorder, <https://www.toronto.ca/community-people/children-parenting/pregnancy-and-parenting/pregnancy/during-pregnancy/staying-healthy/fetal-alcohol-spectrum-disorder/>
- ⁱⁱ Toronto Public Health (TPH) Report: Fetal Alcohol Spectrum Disorder (FASD) - Activities to Address Key Priorities, May 30, 2019, p.2.
- ⁱⁱⁱ Centre for Addiction and Mental Health (CAMH), Mental Illness and Addiction Index, FASD, <https://www.camh.ca/en/health-info/mental-illness-and-addiction-index/fetal-alcohol-spectrum-disorder>.
- ^{iv} TPH FASD Report, 2019, p. 3.
- ^v TPH, p.3.
- ^{vi} TPH, p.3.
- ^{vii} CAMH, Mental Illness and Addiction Index, FASD.
- ^{viii} Toronto FASD Coordinating Network, 2008, p.13.
- ^{ix} Ibid, p.14
- ^x Ibid, p. 15.
- ^{xi} Ibid, p. 16.
- ^{xii} Ibid, p. 17.
- ^{xiii} How Brains are Built: <https://www.youtube.com/watch?v=LmVWOe1ky8s&list=PL8trYXJ3BbwMO-ORVmeLtBSa6J9sfT6v5&index=2&t=0s>
- ^{xiv} Brain Hero: Harvard Center on the Developing Child, October 2011, <https://www.albertafamilywellness.org/resources/video/brain-hero>.