



WHAT TO KNOW ABOUT FASD

What is FASD?

Fetal Alcohol Spectrum Disorder (FASD) is a diagnostic term describing a spectrum of effects to an individual who was prenatally exposed to alcohol. As a result, the alcohol altered brain development and these individuals grow up with physical, mental, social and emotional disabilities that will last their lifetime. It is a brain disorder where there is no cure, but is the most preventable of all mental disorders in the industrialized world.



CURRENT STUDIES SUGGEST APPROXIMATELY

1,108,500

PEOPLE IN CANADA HAVE FASD

(CAMH STUDY ESTIMATE 2018)

FASD – THE WORLDWIDE PANDEMIC

- FASD is the most common and most expensive of all neurodevelopmental disorders in the industrialized world;
- Prenatal Alcohol Exposure causing FASD affects at least 2.9% of Canada's population – that's over 1,108,500 Canadians struggling with this disability;
- FASD is the most preventable of all neurodevelopmental disorders when alcohol is avoided in pregnancy;
- Women who drink during pregnancy often do so to self-treat significant (but often undiagnosed and untreated) mental health problems, so lowering the barriers for effective recognition and treatment of mental health problems in at-risk families is essential.
- Alcohol is a known teratogen, that is a neurotoxin that causes damage to a developing fetus. If food must be labeled for its ingredients, why not a known poison?
- Alcohol disrupts the neuropathways of developing brains in the embryo and fetus stages;



How Does It Happen?

PREGNANCY

- Pregnancy is a 12-15 month process when counting planning time (i.e. sexual activity without contraception);
- 40 years of FASD research have shown that there is no low threshold for fetal damage in pregnancy; this means that measurable harm to the fetus can result from very low amounts of prenatal alcohol exposure;
- Doctors estimate that 50% of pregnancies are unplanned, and pregnant women are often unaware during the first trimester while still drinking
- Exposure to alcohol at 19-21 days of gestation (weeks before most women realize they are pregnant) can cause brain and other organ damage to the developing fetus;

WHY SOME WOMEN CONTINUE TO DRINK IN PREGNANCY

- Addiction to alcohol;
- Social acceptance of alcohol misuse;
- Some men often encourage or insist their partners drink with them;
- There are numerous cases of low self-esteem;
- Poverty and intergenerational trauma make a devastating combination;
- Some women will self-medicate with alcohol for mental health problems such as depression;
- Too many women are getting misinformation from doctors and other healthcare professionals who provide inconsistent or ambiguous information regarding alcohol use in pregnancy;

EFFECTS OF FASD

- A wide range of neurodevelopmental impairments;
- Poor impulse control, attention and executive functioning among other traits;
- Poor recognition of social cues, problem solving and adapting to new situations;
- Inability to predict consequences or inability to learn from experience;
- FASD is frequently missed by healthcare professions and may be masked by other frequently co-occurring diagnoses, such as Attention Deficit Disorder, Attention Deficit Hyperactive Disorder, Oppositional Defiant Disorder, Radical Attachment Disorder or learning disabilities;
- Impaired the ability to accurately remember the past clearly resulting in charges of lying;
- Difficulty following complex instructions, often losing jobs as a result;
- Alcohol and drug addictions (often used as a coping mechanism)
- Poor insight into their disability and/or may be resistant to being viewed as “different”, which can get in the way of them accessing appropriate supports;
- Low adaptive or day-to-day functioning due to neurodevelopmental deficits;
- Most people with FASD do not display recognizable physical features which may lead to their disabilities being missed; lack of support puts those with FASD in danger;
- The spirit of people with FASD is not affected by this disability except through the response of others. Shaming and misunderstanding leads to disconnection and reduced self-esteem;
- FASD can be associated with debilitating health issues in later adult life - increasing demands on our health system;



How is the Brain Effected by FASD?

PRIMARY CHARACTERISTICS

Individuals with FASD are born with effects to multiple brain functions. These effects are referred to as primary characteristics and commonly include:

Motor Skills

- poor eye-hand coordination executing small or large body movements
- diminished muscle tone poor reflexes
- difficulty balancing
- lack of co-ordination

Neuroanatomy/Neurophysiology

[Brain Structure]

- smaller brain and head circumference

Cognition

[Thinking and Reasoning]

- difficulty reasoning, planning, solving problems and comprehending complex ideas
- difficulty with concepts, abstract ideas, consequences and managing time
- a wide range of IQ scores are found

Language

- may speak well, but not fully grasp the meaning
- delay in language development
- difficulty understanding lengthy conversation and instructions
- can repeat instructions or rules accurately, but may not follow through

Academic Achievement

- difficulty in school: reading, math, comprehension, organization and abstract concepts
- learn best with visual and hands-on approach

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

Attention

- can be easily distracted, over-stimulated, inattentive, hyperactive, and can't sit still

Executive Functioning

[including impulse control and hyperactivity]

- may have trouble with planning, sequencing, problem solving and organizing
- may be impulsive, have difficulty understanding cause and effect and controlling emotions
- challenges with transitions and change
- often repeats mistakes
- may under or over respond to stimulation
- inability to accurately sense what is going on in the environment
- struggle with sensory integration and sensitivity to light, noise, touch, smell and/or taste
- difficulty with self-regulation

Affect Regulation

- predisposition to certain mental health concerns (eg. anxiety, depression and mood dysregulation disorders)

Adaptive Behaviour, Social Skills or 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

Of individuals with FASD between the ages of 12 and 51*:

95%

will have mental health problems

55%

will be confined in prison, drug or alcohol treatment centre

68%

will have "disrupted school experience"

68%

will experience trouble with the law

52%

will exhibit inappropriate sexual behaviour

* *Understanding the Occurance of Secondary Disabilities in Clients with FAS&FAE – now FASD*, 1996; Streissguth, Barr, Kogan, Bookstein

What are the Challenges and Impacts?

LACK OF EDUCATION ABOUT FASD

- Most doctors, nurses, midwives and social workers are not receiving FASD training before graduation;
- Primary and secondary school children do not receive any information about FASD in their family life or sex education programs;
- Lawyers, judges, crown prosecutors and police do not receive training in FASD, despite this disability affecting a large proportion of the individuals they encounter in our criminal justice system;
- The lack of trained diagnostic clinical staff throughout the country, especially in rural and remote areas, means most affected individuals are going undiagnosed.

COSTS TO SOCIETY AND FAMILIES

- FASD causes tremendous personal suffering and emotional pain for those with this disability and those close to them. Government services per patient can cost as much as \$2 million per affected individual's lifetime (roughly equivalent to the Canadian national debt);
- FASD for individuals from birth to 53 years of age is estimated to cost Canada 5.3 billion dollars per year (Public Health Agency Canada and CanFASD);
- FASD creates a great, ongoing need for social services to cope with the secondary disabilities that impact health, welfare, education and the justice systems;
- Lack of information and training for adopting and fostering families can cause placement failures and increased, long-term negative impacts on the children with FASD;
- Provincial and federal governments must acknowledge FASD officially and make the fact of FASD official or this endemic situation will continue at great cost to society and to individual families in particular;

CHALLENGES IN DIAGNOSTIC SERVICES

- The lack of trained professionals capable of staffing diagnostic clinics throughout the country, especially in rural and remote areas plus the lack of support for diagnostic clinics means most affected individuals are undiagnosed and live in a limbo of misunderstanding;
- FASD is an invisible and under diagnosed disability because of the difficulty to diagnose when maternal drinking information is unavailable;
- Most health practitioners have no formal training in FASD diagnosis or support interventions so patients with this brain trauma are often misunderstood at "noncompliant" or "resistant to treatment" when treatment modalities such as behaviour modification techniques fail to improve the clinical situation;

JUSTICE SYSTEM IMPACT

- Due to neurodevelopmental deficits, youth and adults with FASD are susceptible to inappropriate activities resulting in interaction with the justice system;
- Individuals with FASD may be prone to falsely confessing to criminal activities that they didn't commit;
- Individuals with FASD, with the intent of sounding cooperative, may say they understand what they are told when, in fact, they do not;
- Memory difficulties make accurate recollection and sequencing problematic; obtaining corroborative evidence from their witnesses is often necessary;
- Prenatal alcohol exposure can damage the sense of judgment to the extent that those affected have difficulty determining right from wrong;

Of individuals with FASD between the ages of 21 and 51*:

82%

will not be able to live independently

70%

will have problems with employment

50% males
and

70% females

will have alcohol and drug problems

* *Understanding the Occurrence of Secondary Disabilities in Clients with FAS&FAE – now FASD*, 1996; Streissguth, Barr, Kogan, Bookstein



What Does Success Look Like?

SOME HOPEFUL OUTCOMES:

- Early diagnosis can help individuals receive the supports and accommodations they require to reach their potential
- Individuals with FASD can have a more successful education experience if Individual Education Plans (IEPs) address their challenges and schools are equipped with the resources needed to carry them out
- When individuals are supported and accommodated they will experience fewer meltdowns or violent episodes reducing the use of extreme measures such as restraints in schools or medical facilities
- Many individuals with FASD show strength in such “hands-on” fields as hospitality, animal services, landscaping, carpentry, computers, and so on;
- These same individuals can excel doing jobs that involve hands-on activities especially when training does not require a lot of academic skills like note-taking and remembering information from lectures;



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This information piece was developed by FASWorld and is meant to be a quick reference guide and not an exhaustive report of the affects of FASD.