

Test Your Knowledge of FASD 101 (Revised)
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ALL professionals working with FASD must understand IT VERY WELL to be successful. Ideally ALL staff with ANY connection to a program must understand FASD 101 well and be *on the same page* as their colleagues. People with FASD can often appear to be incredibly sensitive to negative feedback of any kind, especially, it seems, if it is unintended. Think before you speak.

- 1-What is FASD?
- 2-How common is FASD in North America?
- 3-Name two kinds of damage caused by alcohol in pregnancy?
- 4-What is a neurotoxin? What is a teratogen? What does each one do?
- 5-What factors may affect the amount of damage caused by alcohol?
- 6-FASD is usually an “invisible disability.” What does this mean?
- 7-How does FASD usually show up in an individual with FASD?
- 8-When was FAS/FASD formally recognized as a problem?
- 9-Is alcohol use in pregnancy common in Canada?
- 10-List some reasons for drinking during a pregnancy.
- 11-What role do fathers play in the development of FASD?
- 12-List some of the signs of a successful FASD intervention program

1-What is FASD?

Fetal Alcohol Spectrum Disorder (FASD) refers to the many disabilities caused only by drinking alcohol during a pregnancy.

2-How common is FASD in North America?

FASD is the most common birth defect in North America and is now estimated to occur in 4% of all live births. (CANFASD, 2018) Hundreds of thousands of Canadians live with FASD. An incidence rate of 4% indicates that at least 1.5 million Canadians have FASD. Most are not diagnosed or recognized.

3-Name two kinds of damage caused by alcohol in pregnancy?

Alcohol consumption can cause a variety of physical birth defects and varying levels of permanent brain damage if consumed during pregnancy.

4-What is a neurotoxin? What is a teratogen?

A **neurotoxin** causes toxic effects to neurons (nerve cells). Sometimes they die. In FASD alcohol is a neurotoxin that appears to change the number and structure of brain cells, brain size and brain structures, cell organization and neurochemistry. This is permanent brain damage. There is no medical way to “fix” this damage.

A **teratogen** is an agent that causes physical birth defects. Many physical birth defects are common with but not limited to FASD. Mid-line defects involving the ear, heart and skeleton are common with FASD. However, the 3 visible facial birth defects of FAS are ONLY caused by using alcohol in a pregnancy. (See also Q #6)

5-What factors may affect the amount of damage caused by alcohol?

The amount of damage caused by alcohol consumption in pregnancy varies with factors such as the timing and dose of alcohol consumed, age and genetics of the mother and/or baby plus maternal stress and nutrition. It is possible for two fetuses to be exposed to the same amount of alcohol and show completely different results.

6 -FASD is usually an “invisible disability.” What does this mean?

Only people with the three facial features of FASD (The Face of FASD) have visible FASD. These are 1-short horizontal eye openings, 2-a smooth philtrum (valley from the nose to lips) and 3- a thin upper lip (no “cupid’s bow). Very few, about 10% of people with FASD have these very visible, signature features which form early in a pregnancy if alcohol is being consumed. So, most North Americans show no identifiable physical signs of FASD and have an invisible disability as a result. These people are the part of the FASD” iceberg below the waterline”. They are invisible and frequently stigmatized and marginalized for behaviours they cannot control without on-going help and support from others.

7-How does FASD usually show up in an individual with FASD?

Approximately 95% of people with FASD show only dysfunctional and unusual “primary behaviours” because of exposure to alcohol during pregnancy. The permanent brain damage of FASD is usually not recognized as the source of this behaviour and interventions and support may fail as a result.

8-When was FAS (first name for FASD) formally recognized as a problem?

FAS (not FASD) was officially first recognized in 1973 in an article by Jones *et al* in the medical journal, *The Lancet*. But FASD is not a new condition and humans have “recognized” the effects of alcohol on a fetus for centuries. Eg. Judges 13:3-4 is thought to warn ancient women of the dangers of alcohol usage in pregnancy.

9-Is alcohol use in pregnancy common in Canada?

Even though FASD prevention education has been widely available in Canada for a long time many Canadian women still consume alcohol during pregnancy and before realizing they might be pregnant. Exact numbers are difficult to determine reliably. In 2020 PHAC notes 11% of Canadian women drink during pregnancy.

10-List some reasons for drinking during a pregnancy.

There are a variety of reasons why women drink in pregnancy. Alcohol use is pervasive in our culture and many people think of it as a “food group.” The dangers of alcohol are not recognized and/or the FASD story just seems “too bad to be true.” Alcohol advertisers and the general public tend to avoid dealing with this story. (Continued on page 3.)

Many women do not realize they are pregnant (and may stop when the pregnancy is confirmed). Others do not realize that any alcohol in pregnancy could cause damage and/or think that responsible or light drinking is harmless to the fetus. A medical professional or a trusted relative or friend may also say that is alright to drink carefully in pregnancy E.g. *they drank in pregnancy and their kids are OK!* We hope that most of the above reasons for drinking in pregnancy will eventually succumb to aggressive FASD prevention education and liquor bottle labelling. But there are other, more “difficult” reasons for drinking in a pregnancy. Binge drinking (4 or more drinks at a time) and partying are a more common North American custom now than they used to be. Binge drinking appears to be especially dangerous for the development of FASD during pregnancy.

The cause of drinking in pregnancy that is proving to be the hardest to deal with (depending on your perspective) is that of women who are drinking because of addiction, abuse, poverty, severe stress and mental health issues. **Society at large tends to ignore the fact that addiction is a disease not a moral failure.** When we are able establish this truth more firmly in our social consciousness it may be easier to deal with these difficult and interrelated causes of drinking in pregnancy.

11-What role do fathers play in the development of FASD?

Men do not cause FASD directly. However, studies indicate that men who abuse alcohol and drugs prior to conception can produce damaged sperm that can create other serious, but yet unnamed, conditions. Some look similar to FASD. And Importantly, fathers can play a valuable positive role in the prevention of FASD if they actively support and encourage their partner not to drink in a pregnancy.

12- List some of the signs of a successful FASD program?

- Front-line workers & ALL other staff have an excellent understanding of FASD
- Invisible people with FASD are recognized and acknowledged
- Staff “think FASD first” and provide environmental adaptations immediately
- “Difficult Behaviours” are understood as brain-based or caused by brain damage
- Clients with FASD are not sanctioned or ejected for these “primary behaviours”
- “Person First” language is always used. A person with FASD, not a FASD person
- Interdependence is always expected and fostered in place of independence
- The paradigm is shifted from “won’t to can’t” (E.g. can’t behave, can’t remember)
- The environment is modified to accommodate Sensory Processing Disorders
- Support persons /coaches/a supportive circle or network are supplied as needed
- Abilities are recognized and supported by using a strength- based approach
- Meaningful, “permanent” roles in the community are sought for people with FASD
- FASD diagnoses are made by trained multi-disciplinary teams