UNDERSTANDING FETAL ALCOHOL SPECTRUM DISORDER – BRINGING SCHOOLS AND TEACHERS ON BOARD

Gideon Koren, MD

The Motherisk Program, Division of Clinical Pharmacology/Toxicology, Hospital for Sick Children, Toronto, Ontario, Canada

ABSTRACT

A new approach to the educational aspects of FASD will help educational experts to be better prepared for students affected by this challenging condition.

ASD adversely impacts all aspects of life of affected individuals and one of the highest impacts reveals itself in school, where most FASD-affected children are challenged beyond their abilities. Critically, it appears that in 2011 most school boards and educational practitioners have very little to none preparation, strategies, or resources to deal with the number one cause of developmental disability in North America. With 1% of North American children afflicted with FASD, the lack of preparedness of the educational system to deal with their needs is nothing short of a calamity. Failure of these children in the educational system is a sure recipe for future failure in all aspects of their lives.

With that reality in mind, the paucity of resources to prepare teachers for approaching and supporting children with FASD is very obvious.

To close this gap, the Motherisk Program has just published a Guide entitled "Understanding Fetal Alcohol Spectrum Disorder – A Resource for Education Practitioners in Ontario". This Guide is based on a previous draft published by Healthy Child Manitoba, with additions and updates.

This 100 page document is arranged in 3 parts, commencing with Introduction to FASD, and continuing with the Impact of FASD on Learning, followed by Planning for Success. An interesting assortment of Appendices includes: common misinterpretation of FASD-related behaviors, common misconceptions about FASD, questions to ask parents, summary of program planning, options and tools and FASD services

and programs. We quote here the "Common Misconceptions about FASD".²

The Guide has been supported by FAS World, Healthy Child Manitoba and Alliance Youth Services Inc., and since its publication, the Toronto District School Board and The Public Health Agency of Canada have committed to its distribution and inclusion in Ontario schools.

Common Misconceptions about Fetal Alcohol Spectrum Disorder

1. MYTH: Children with FASD will outgrow it. There is no known cure for FASD and this disorder does not go away over time. However, the characteristic facial and physical features that some children display may become less noticeable as they age and mature. While the specific characteristics and challenges of FASD may change as the individual ages, those with FASD will likely require a lifetime of support.

2. MYTH: There is no benefit in receiving a diagnosis. This diagnosis will brand them for life.

Rather than labeling, a diagnosis provides an understanding of how to best support the child. A large part of the diagnostic process is the development of individualized strategies and recommendations that are aimed at promoting the child's well-being and helping the child learn and succeed in everyday life. A diagnosis may provide access to additional community supports and services. Research has also shown that receiving a

diagnosis may mitigate the development of subsequent secondary disabilities such as unemployment, mental health problems, trouble with the law, inappropriate sexual behavior, and disrupted school experience (Streissguth, Kanter et al. 1997). Many individuals who have received a diagnosis express relief in discovering that there is a medical reason why they often struggle more than their peers, and that it isn't their fault. This has helped many to develop a more positive self-image.

3. MYTH: Diagnoses of pFAS and ARND aren't as serious as FAS.

The only difference between ARND, FAS, and pFAS is the presence of physical characteristics, not the severity of brain dysfunction. Individuals diagnosed with FAS, pFAS and ARND all may display eaually poor neurodevelopmental outcomes (Rasmussen, Andrew, Zwaigenbaum & Tough, 2008). Although individuals with pFAS and ARND do not display some of the physical or facial features that are present in individuals with FAS, in all three cases, brain damage has occurred. Although the cognitive, learning and behavioural impacts will vary between individuals because each person is uniquely affected by alcohol use, any diagnosis means that the brain has been negatively affected by alcohol use during pregnancy.

4. MYTH: People with FASD have low IQ's.

This is sometimes true, but not always. FASD affects every individual differently, and experience individuals will strengths and challenges in different areas. Some individuals may have an average IQ, but experience difficulties with impulsivity, attention, judgment, problem solving, relationships, sensory integration or time management. Many students with FASD will function in a classroom setting or in everyday life at a lower level than what is expected based solely on their IQ.

5. MYTH: Children usually plateau at Grade 4 in their ability to learn.

Around Grade 4, there is a change in the way that all children learn in the classroom. The curriculum lessons become more abstract, children are expected to work more independently, and the method of teaching becomes less interactive and

more lecture style. These new materials, expectations and teaching approaches may be challenging for students with FASD, and thus, they may appear to stop progressing or learning. If teaching can remain interactive, visual, concrete, and support is provided, students with FASD can learn in all grades.

6. MYTH: Behavioural problems associated with FASD are a result of poor parenting.

No. While every individual's development is impacted and shaped by their environment, brain damage caused by prenatal alcohol exposure leads to information being processed differently. Memory difficulties, poor problem-solving abilities, sensory stimulation issues and a poor understanding of reality often lead to behavioural problems. While a child's home environment may influence their behavior, poor parenting is not usually the cause of misbehavior. Behavioural problems often occur when a child responds inappropriately to a particular situation due to feelings of frustration, embarrassment or anger (or because they simply don't have the tools necessary to respond appropriately).

7. MYTH: The mothers of these children must be alcoholics; social drinking wouldn't cause FASD.

There is no known threshold for "safe" alcohol consumption during pregnancy. However, we do know that the more alcohol a pregnant woman consumes, the greater the risk to the developing fetus. Drinking regularly, even less than one drink per day, can negatively impact fetal development. According to Health Canada, drinking five or more alcohol beverages on one occasion, or seven drinks spread over the course of one week is considered high risk binge drinking, which may put the fetus at a higher risk for developing alcohol-related disorders. An average of one drink per day may be considered social drinking by many Canadians however; it is by definition highrisk drinking during any stage of pregnancy. Many women who aren't addicted consume these amounts of alcohol, often before they even know they are pregnant (during many critical periods for fetal development). There is no known safe amount of alcohol intake during pregnancy. If you are pregnant or planning on becoming pregnant, please do not drink.

8. MYTH: FASD is only an issue for certain populations.

Women of all different backgrounds, ethnicities and income levels use alcohol. The 2004 Canadian Addiction Survey found that 76.8% of all Canadian women use alcohol. A 1998 survey of Canadian university students found that 87.5% of female students used alcohol in the past 12 months, 41.1% of students reported harmful drinking, and 29.3% reported dependent drinking. A 2005 report by the Public Health Agency of Canada found that roughly 14% of mothers reported drinking alcohol during pregnancy (Public Health Agency of Canada, 2005). Another study found that women in the highest income brackets were most likely to have used alcohol during their last pregnancy. Among those who used alcohol heavily (12 or more times per week) there were no age or income differences (Alberta Alcohol and Drug Abuse Commission, 2004). Unfortunately, some women are treated differently by social service providers and researchers which have led to the untrue assumption that certain groups have higher rates of FASD. For example, poor women and women of color are more frequently screened for substance use when accessing prenatal care than are middle-class and Caucasian women (Poole & Dell, 2005).

9. MYTH: The mothers of children with FASD could have easily chosen not to drink during pregnancy. They damaged their children through callousness or indifference.

Alcohol addiction is difficult to overcome and is often related to complex and long-term issues involving abuse, various exposures to violence, and mental health problems. When a man or woman is addicted to drugs (and is not pregnant) most people assume that quitting will be a challenge for them, and that relapse is likely for most. Being pregnant does not mean someone can suddenly overcome a long-term addiction overnight. Pregnancy is a critical time for women to stop or reduce their use of alcohol. In order to do so, they need respect, understanding and caring support. Furthermore, many pregnancies are unplanned, and often women are unaware they are pregnant until they are well into their first trimester. Since most women in Ontario drink

alcohol, the developing fetus may have already been exposed to alcohol. Discontinuing the use of alcohol, providing adequate nutrition and the reduction of stress will help to ensure the best possible outcomes.

10. MYTH: A woman who has FASD will have children with FASD.

The only cause of FASD is alcohol use during pregnancy. There is no genetic link for this disability. If a woman with FASD abstains from alcohol during her pregnancy, her baby will not have FASD.

Have more questions? Call the Motherisk FASD Line: 1-877-FAS-INFO

Corresponding Author: gkoren@sickkids.ca

REFERENCES

- 1. Understanding FASD A Resource for Educational Practitioners in Ontario (Koren GI, Todorow M, eds.). The Motherisk Program, Toronto, 2010.
- Common misconceptions about FASD. In: Understanding FASD – A Resource for Educational Practitioners in Ontario (Koren GI, Todorow M, eds.). The Motherisk Program, Toronto, 2010, pp76-78.