



FASD *Tip* ***Sheets***

***Information* for Health and Human Services Professionals**

These Tip Sheets have been designed to provide information about Fetal Alcohol Spectrum Disorder or FASD. They have been prepared by Alberta Children's Services for the Alberta Partnership on Fetal Alcohol Syndrome.

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What is Fetal Alcohol Spectrum Disorder (FASD)?

Fetal Alcohol Spectrum Disorder (FASD) is a medical condition that refers to the range and severity of disorders from brain injury caused by prenatal exposure to alcohol. Other terms used to describe the spectrum of disorders associated with FASD include Fetal Alcohol Syndrome (FAS), Fetal Alcohol Effects (FAE), Alcohol-Related Neurodevelopmental Disorder (ARND), Alcohol Related Neurological Defects (ARND), Alcohol-Related Birth Defects (ARBD), Alcohol-Related Birth Injury (ARBI), and Partial Fetal Alcohol Syndrome (pFAS).

Our current understanding about FASD is that it represents a “spectrum” of disorders dependent upon a number of factors including the dose, timing and amount of prenatal exposure to alcohol, the manner in which the mother metabolizes alcohol and by characteristics of both the child and mother. Each person with FASD is unique and exhibits distinctive strengths, weaknesses and issues.

FASD commonly results in abnormalities of cognition, language and behaviour. These abnormalities may lead to health, speech and language problems, learning disabilities and behavioral problems. However, individuals suffering from FASD are differentially affected. Some may have greater levels of abnormality in areas of cognition and others may be challenged by behavioral issues.

FASD is a lifelong condition that presents different challenges at different stages in a person’s life.

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What are the physical and neurological features of FASD?

Each individual with FASD is unique and differs in the manner in which they present with the disorder. The following are features associated with FASD; however, it is noteworthy that no one feature alone can be used to diagnose FASD.

Growth failure: Prenatal exposure to alcohol is often associated with growth failure, or deficits, that may include low birth weight, decelerating weight over time not caused by other factors, or disproportional low weight to height. Some failure to thrive children may, in fact, have FASD.

Facial features: Children with FASD may display unique facial features that are most notable between the ages of 3 to 12 years but may continue into adulthood. Facial features include short eye slits, thin lips and flattened facial bone structure.

Neurodevelopmental and behavioral characteristics: In infancy and early childhood (0 to 5 years), abnormalities may include delayed developmental milestones, sleeping problems, impulsivity, attention deficits, and difficulty adapting to change.

From ages 6 to 11 years, youngsters with FASD may experience the following: significant learning disabilities, cognitive delay, poor understanding of social expectations and an inability to appreciate cause and effect.

In childhood through to adolescence and adulthood, difficulties may lead to problems with independent living, competitive employment, addictions, sexual inappropriateness and involvement with the legal system.

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How is FASD diagnosed?

FASD is a medical condition. It is diagnosed by a multidisciplinary team that includes a physician, and other health and education professionals such as a neuropsychologist, neurophysiologist, occupational therapist, physical therapist, speech and language pathologist, psychologist, teacher and others. Members of the multidisciplinary team have defined roles, and the composition may vary based on local requirements and if the diagnosis/assessment/intervention plan is for a child or an adult.

Within Alberta, diagnosis is based on the Guideline for the Diagnosis of Fetal Alcohol Syndrome (FAS) published by the Alberta Clinical Practice Guidelines (CPG) Program of the Alberta Medical Association prepared in association with the Alberta Partnership on Fetal Alcohol Syndrome (www.albertadoctors.org/resources/cpg/fas-diag-guideline.pdf).

Diagnostic criteria for FASD includes confirmed maternal alcohol exposure, evidence of characteristic patterns of facial anomalies, growth retardation, and selected central nervous system (CNS) abnormalities. In the absence of confirmed maternal alcohol consumption, a diagnosis can be made based on the final three criteria. A diagnosis of FASD can be made with confirmed maternal alcohol exposure in the instance of facial anomalies, and evidence of growth retardation, CNS abnormalities or a complex pattern of behaviour or cognitive abnormalities, that are inconsistent with developmental level and cannot be explained by familial background or environment alone.

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What is a functional assessment? How does it relate to the diagnosis of FASD?

A functional assessment is the middle component of a three part process that includes: 1) Diagnosis of FASD; 2) Assessment of the strengths, weakness and issues of an affected individual (functional assessment); and 3) Intervention - provision of supports to foster independence, maximize quality of life and prevent secondary disabilities.

Functional assessment seeks to answer questions about the functional abilities of a person affected by FASD. A neuropsychologist generally conducts functional assessments. The functional assessment will ultimately define the range of supports and services (intervention) that a person requires to maximize their quality of life, foster independent living and protect them from secondary disabilities. Three methods are utilized to conduct a functional assessment: 1) Information gathering including the use of interviews, rating scales, and related tools; 2) Direct observation that does not interfere with normal daily activities; and 3) Functional analysis manipulations in which variables are changed to observe the effect on a person's behaviour.

Critical questions include: What can this person do? Can this person learn? Are they capable of independent living? What are their prospects for competitive employability? What are the potential risks for the person and the public? What types of supports are required to maximize independence, foster a good quality of life, and prevent secondary disabilities?

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What are secondary disabilities in a person with FASD?

Secondary disabilities refer to disabilities or problems that emerge as a result of the disorders experienced by a person with FASD. Most often, they relate to a person's inability to adapt or address challenges that are common in the lives of all individuals.

Secondary disabilities include but are not limited to:

- Mental health problems
- Disruptive school experience
- Trouble with the law
- Inappropriate sexual behaviour
- Drug and alcohol problems
- Employment difficulties

Protective factors may prevent or mediate the severity of secondary disabilities. They include:

- Early diagnosis before age 6
- Stable and understanding caregiver in a non-abusive environment
- Access to resources for persons with disabilities, specifically effective intervention and supports to foster independence and maximize quality of life.

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What is the most appropriate intervention for a person with FASD?

The most appropriate type of intervention depends upon strengths, weaknesses and issues exhibited by the person affected with FASD. Optimal intervention is customized to address the needs of the person diagnosed with FASD, *and* those of the person caring for or living with a person with FASD.

Good intervention strategies draw upon the outcome of effective, well-conducted functional assessments. Interventions should include a range of supports and services that are suggested by the response to key questions:

- What can this person do?
- How does this person learn?
- Are they capable of independent living?
- What are their prospects for competitive employability?
- What are the potential risks for the person and the public?
- What types of supports are required to maximize independence, foster a good quality of life, and prevent secondary disabilities?

Because of their close interdependencies, current best practice suggests that diagnosis, assessment, and an intervention plan should be integrated, connected and not conducted on a “piecemeal” basis. Best practices also include reliance upon a multidisciplinary team to conduct the diagnosis, assessment and define the range of required interventions.

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How can FASD be prevented?

FASD is caused by prenatal exposure to alcohol. No amount of alcohol has been established as being safe for a fetus. FASD is prevented by abstaining from alcohol

during pregnancy. Prevention strategies may be primary, secondary or tertiary in their focus.

Primary prevention: The focus of primary prevention is on education. It involves social and public marketing about FASD and how it can be prevented. Primary care providers have an important role in the prevention of FASD. This role includes discussing FASD with women and their partners, contraception options, and in distributing promotional materials about FASD. Information provided by physicians and other health providers, in a clinical setting, is seen as credible and effective in relaying the message about the prevention of FASD.

Secondary prevention seeks to reduce the risk, duration and harm of maternal drinking by identifying women at risk. Major prevention activities include discussion with the woman about the effects of alcohol on her baby. Support also includes referral for alcohol and addictions treatment and information about contraceptive counselling.

Tertiary prevention involves identifying women who may be at risk for drinking during future pregnancies and having a child with FASD. Strategies include referring and supporting the woman in obtaining treatment for alcohol and addictions counselling, and in supporting contraceptive options.

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What is the incidence of FASD?

It is difficult to accurately determine the incidence and prevalence of FASD. No woman or population is exempt; FASD is an equal opportunity disability. Studies indicate that the worldwide incidence of Fetal Alcohol Syndrome ranges from 10 per thousand births in high risk populations to 0.5 to 3 per thousand births in the general population. However, investigations into the prevalence of FASD vary widely in their methodology and scope. All have limitations and consequently there is difficulty in interpreting and comparing results.

FASD is consistently ranked among the top three known causes of mental disability in the western world, and is the leading cause of preventable birth defects.

While the actual incidence of FASD is not fully understood, current research on alcohol consumption patterns lends some insight into the possible use of alcohol during pregnancy.

- Alcohol consumption among women aged 18 to 34 years ranges from 60% to 75% with 4% considered to be alcohol dependent or alcohol abusers.
- An Alberta Health and Wellness study on live births indicates that 3.9% of women reported drinking during their pregnancy. The Canadian Community Health Survey (2000/01) indicates a rate of alcohol consumption during pregnancy of 9.1% for Alberta compared to 13.7% nation wide.

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Who is at risk for FASD?

Alcohol is the common denominator in all high risk populations. In populations with a high proportion of women who drink, the risk of FASD is higher.

There is wide variation among studies that attempt to define high risk groups for FASD.

- Some studies indicate that women of low economic status and lower education levels are at risk for abusive drinking and having a child with FASD. Others studies indicate that women at highest risk are those with a college education, or live in households of over \$50,000 per year. These studies contradict each other and lead to the conclusion that women, in any population, who drink are at risk of having a child with FASD.
- The risk of reoccurrence of FASD appears higher for families who already have affected children. The estimated risk is 77% for families where a child is already affected by FASD.

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Where can I refer people who I think have FASD for diagnosis or support?

Resources and supports vary across the province. To identify the resources in your area, please go to the FASD section of the Alberta Children's Services Web Site at www.child.gov.ab.ca and follow the links. You may also contact FASD Programs and Services, Alberta Children's Services, for information on resources and supports in your community.

FASD Programs and Services
Alberta Children's Services
6th Floor, Sterling Place
9940-106 Street
Edmonton, Alberta T5K 2N2
Tel: (780) 415-8150
Fax: (780) 415-5841
fasd@gov.ab.ca

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References:

These tip sheets draw upon reference material contained in the following documents:

- Alberta Clinical Practice Guidelines Program: *Guideline for the Diagnosis of Fetal Alcohol Syndrome (FAS)*. Alberta Medical Association in association with the Alberta Partnership on Fetal Alcohol Syndrome. 1999
- Alberta Clinical Practice Guidelines Program: *Recommendations for the Prevention of Fetal Alcohol Syndrome (FAS)* Alberta Medical Association in association with the Alberta Partnership on Fetal Alcohol Syndrome. 1999
- Alberta Clinical Practice Guidelines Program: *Preface to the Prevention and Diagnosis of Fetal Alcohol Syndrome (FAS)*. Alberta Medical Association in association with the Alberta Partnership on Fetal Alcohol Syndrome. 1999
- *Alberta Learning. Teaching for the Prevention of Fetal Alcohol Spectrum Disorder (FASD) Grades 1-12: A Resource for Teachers of Health and Life Skills and Career and Life Management* Alberta Partnership on Fetal Alcohol Syndrome, 2002.
- *FASWorld Website, www.fasworld.com. Fetal Alcohol Spectrum Disorder Support Services)*
- *1509 Danforth Avenue, Toronto, Ontario, M4E 5C3, Tel: (416) 465-7766; fax (416) 465-8890*
- Beach Centre of Families with Disability. "Functional Assessment of Behavior: A Fact Sheet" as adapted from O'Neil, R.H., Albin, R.W., Sprague, J.R., Storey, K & Newton, N.S., (1977) *Functional Assessment and program development for problem behavior: A Practical Handbook*. Pacific Grove, CA.: Brooks/Cole