Fetal Alcohol Spectrum Disorder (FASD):

Frequently Asked Questions (FAQ) List

1) What is FASD?

Fetal: related to an unborn baby
Alcohol: the drug found in beer, wine and hard liquor
Spectrum Disorder: a combination of birth defects ranging from the least severe to the most severe

Fetal Alcohol Spectrum Disorder is the non-medical, umbrella term that describes the combination of birth defects caused by prenatal exposure to alcohol.

The following chart shows the Institute of Medicine (IOM) diagnostic terms and criteria:

Diagnosis	FAS Facial Features	Confirmed Prenatal Alcohol Exposure	Additional Criteria
Fetal Alcohol Syndrome (FAS) with confirmed maternal alcohol exposure	Yes	Yes	Growth retardation; central nervous system (CNS) abnormality; or evidence of a behavioral or cognitive disorder inconsistent with the expected developmental level, with hereditary factors, or with the environment
FAS without confirmed maternal alcohol exposure	Yes	No	
Partial FAS (pFAS) with confirmed maternal alcohol exposure	Some	Yes	
Alcohol Related Birth Defects (ARBD)	No	Yes	Any of a number of anomalies (such as heart or kidney defects) present at birth that are associated with maternal alcohol consumption during pregnancy
Alcohol-related Neurodevelopmental Disorder (ARND)	No	Yes	Evidence of CNS abnormality (such as abnormally small head, abnormal brain structures, and neurological signs); evidence of a behavioral or cognitive disorder inconsistent with the expected developmental level, with hereditary factors, or with the environment; or both

[Stratton et al. (1996) Reprinted with permission from Fetal Alcohol Syndrome: Diagnosis, Epidemiology, Prevention, and Treatment, National Academy of Sciences, Washington, DC.] in the 10th Special Report to the U.S. Congress on Alcohol and Health, National Institute on Alcohol Abuse and Alcoholism (NIAAA).

1) What is FASD? continued…

The University of Washington 4-Digit Diagnostic Code uses a different set of criteria and terms to assess prenatal exposure to alcohol. The 4-digit diagnostic codes rates the following criteria on a 4-point scale:

- Growth deficiency (1=none, 2=mild, 3=moderate, 4=severe)
- FAS Facial Features (1=absent, 2=mild, 3=moderate, 4=severe)
- Brain Dysfunction (1=unlikely, 2=possible, 3=probable, 4=definite)
- Gestational Alcohol (1=no risk, 2=unknown, 3=some risk, 4=high) risk)

Based on the above scores, the following diagnostic terms would be applied:

- Growth deficiency score of 3 or 4 = Sentinel physical findings
- FAS Facial features score of 3 or 4 = Sentinel physical findings
- Brain dysfunction score of 2 = Neurobehavioural disorder
- Brain dysfunction score of 3 or 4 = Static encephalopathy
- Gestational alcohol score of 2 = Alcohol exposure unknown
- Gestational alcohol score of 3 or 4 = Alcohol exposed

The resulting diagnosis will be expressed in a 4-digit code which can also be described in words (e.g. 3443 = Sentinel physical findings/Static encephalopathy/Alcohol exposed).

(Diagnostic Guide for Fetal Alcohol Syndrome and Related Conditions: The 4-Digit Diagnostic Code, Second Edition. FAS Diagnostic and Prevention Network. University of Washington. January, 1999.)

2) What is the difference between FAS and FAE?

The term FAE (Fetal Alcohol Effects) was previously used to describe a child who shows some of the characteristics of FAS with known significant prenatal alcohol exposure. The term FAE has been replaced with the term Partial FAS (pFAS) and Alcohol-related Neurodevelopmental Disorder (ARND). Cognitive and behavioural problems associated with pFAS/ARND can be very debilitating and lead to life long disabilities. Partial FAS/ARND therefore, is not necessarily a milder form of FAS because the signs, though fewer in number, may be just as severe as FAS.

FASD (Fetal Alcohol Spectrum Disorder) is a non-diagnostic umbrella term used to encompass the entire continuum of the effects of prenatal exposure to alcohol, from the least severe effects to the most severe effects. FASD is the term to be used throughout this paper**.**

[Adapted from Institute of Medicine (1996) Diagnostic Criteria for Fetal Alcohol Syndrome (FAS) and Alcohol Related Effects]

3) How does Fetal Alcohol Spectrum Disorder occur?

Following consumption, alcohol is absorbed into the blood, from the stomach and intestines and transferred to the liver. The alcohol is metabolized or broken down in the liver by two enzyme systems. It takes about one hour for the liver of a person weighing 70 kg (154 lbs) to process and eliminate 8-10 grams of alcohol, or about two thirds of the alcohol contained in a standard drink. This rate is constant, no matter how much alcohol has been consumed, or what food or non-alcoholic beverages are taken*. [Alcohol: Centre for Addictions and Mental Health, 2002]* With additional drinks the blood alcohol concentration rises. In the pregnant woman, alcohol easily crosses the placenta to the circulatory system of the fetus. Due to the baby's small and underdeveloped liver and enzyme system, it cannot rid itself of the alcohol at the same rate the mother can. Alcohol can damage a growing baby's brain, organs and body. This can affect how a

baby thinks, acts, looks and learns as a child and as an adult. Alcohol also passes easily into breastmilk.

[Health Canada (1997) It Takes a Community – A Resource Manual for Community-based Prevention of FAS and FAE]

4) What is the cure for FASD?

Unfortunately alcohol causes brain damage that is irreversible. There is no cure for FASD. One does not outgrow FASD, although the manifestations may change with age. A bad environment (one of abuse, neglect, poverty) cannot cause FASD, just as a good environment (one of love) cannot fix it *[Streissguth A. (1997) FAS – A Guide for Families and Communities].* Strategies to help students affected by FASD are brought to parents/classroom teachers. They are helped to create learning environments that fit the way the student learns (i.e. multi-sensory teaching, self-regulating). These strategies merely help the child with FASD learn within his environment, but by no means act as a cure to brain injury.

[The Story of CHIP (1998) BC Ministry of Health: Aboriginal Health Policy Branch]

5) Can a good diet help treat FASD?

A good diet will not treat FASD, as FASD is a brain injury, however it may help decrease some inappropriate behaviours. Because a poor diet can lead to behavioural challenges in any child, a proper diet is always encouraged. Avoiding food additives (MSG, artificial food colouring, Nutrisweet) may help decrease hyperactivity. Avoiding dehydration may help to decrease irritable behaviour. Ensuring adequate vitamin and mineral intake (multivitamin) may help to decrease some aggressiveness. However, hyperactivity, irritable behaviour and aggressiveness may occur regardless due to the initial effects of alcohol on the developing brain.

[Sumner, Dubovsky (1997) Iceberg Newsletter 7(4),Kieran O'Malley Centre for Science in the Public Interest]

6) How do you prevent FASD?

The only way to prevent FASD is to avoid alcohol while pregnant. No one knows how much alcohol a pregnant woman can safely drink without affecting the baby. We do know,
however, that all types of drinking including daily alcohol use, a mealtime glass of wine, binge drinking (5 or more drinks in one sitting), casual social drinking, or "partying" will put the developing baby at risk. Therefore all children are at risk if mother drinks during pregnancy. There is also no time during pregnancy when it is safe to drink alcohol. If you are thinking about getting pregnant, are already pregnant, or are breastfeeding, it is best to avoid alcohol altogether.

[AADAC (1998) Making a Difference]

7) How much alcohol causes harm?

Not all women who drink while pregnant will have a child with FASD. Factors that affect the amount of damage depend on:

- the amount of alcohol consumed
- the stage of the pregnancy
- how the pregnancy itself is going
- how long the mother has been drinking before the pregnancy
- her age
- her body weight
- her drinking style – either daily or binge
- the quality of the mother's nutrition
- whether or not she smokes
- additional drug use *[AADAC (1998) Making a Difference]*

According to research done by Drs. J. Gusella and P. Fried, even light drinking (average one-quarter ounce of absolute alcohol daily) can have adverse effects on the child's verbal language and comprehension skills. Ultimately, the safest decision is to avoid alcohol during pregnancy and breastfeeding altogether.

[Neurobehavioural, Toxicology and Teratology, Vol. 6:13-17, 1984]

8) Is alcohol as dangerous to a fetus as hard drugs?

Alcohol is a teratogen meaning that it can damage a developing fetus. In fact, of all the substances of abuse, including heroin, cocaine, and marijuana, alcohol produces by far the most serious neurobehavioural effects in the fetus, resulting in life-long permanent disorders of memory function, impulse control and judgement.

[National Institute of Health]

9) How common is FASD?

It is estimated that one to three children in every 1000 in industrialized countries will be born with full FAS. This rate increases to 3.3 per 1000 as older children are identified and the rate for pFAS/ARND may be five times as high. Based on 42,909 births a year *[BC Vital Statistics Annual Report (1998)]* this suggests that we have a minimum of 142 infants born with FAS and 710 infants born with pFAS every year in BC.

[Adapted from MacDonald et al (1991) A Report to Communications and Education Branch BC Ministry of Health]

10) Is FASD more common among First Nations communities?

FASD is related to use of alcohol during pregnancy, not to race or ethnicity. The levels and cultural values related to drinking vary across First Nations communities and thus the prevalence of FAS varies as well *[BC FAS Community Action Guide].* Stereotyping certain population groups as being more at risk for giving birth to children with FASD (ie: the poor, the uneducated, particular ethnic groups) can be dangerous and misleading. Contrary to these types of stereotypes, one study reported that women who were college educated, unmarried, employed, students, smokers, or had annual household incomes of more than $50,000/yr were at higher risk for having a baby with FASD.

[Ebrahim et al (1998) Obstet Gynecol]

11) How well known is FASD among women of childbearing age?

Over 60% of women of childbearing age drink alcohol and only 39% of women of childbearing age even know what FAS is [National Institute of Health, USA]. About 20% of women who are known to be pregnant continue to drink during their pregnancy. The incidence of drinking during pregnancy has increased substantially in the past several years, possibly due to the misleading media message that a drink a day is healthy.

[Centre for Disease Control and Prevention, USA]

12) Is FASD inherited?

FASD is not inherited. It is directly linked to maternal drinking habits. A baby will only be born with FASD if his mother drank while pregnant. If a woman abstains from drinking throughout her pregnancy she will not have a baby with FASD, even if she is an alcoholic herself or has a past history of alcohol use. If a woman with FASD does not drink throughout her pregnancy, her baby will not be affected.

[FASAT (2002) Fun and Free Resources for Families with Special Needs]

13) Does drinking among men cause FASD?

FASD is considered to be directly linked to maternal drinking, not paternal drinking or alteration in sperm. Alcohol, however, can result in a lower sperm count and abnormal sperm, decreasing the likelihood of pregnancy, and increasing the risk of miscarriage. Some research suggests that we have overlooked the impact of paternal alcohol consumption on offspring. The view that a mother is solely responsible for a child who is born with FASD is controversial *[Cicero, (1994) Effects of Paternal Exposure to Alcohol on Offspring, Alcohol, Health and Research World]*. Experimentation among mice and rats suggests that alcohol seems to have a damaging effect on the DNA in sperm [*Abel, E. (1992) Paternal Exposure to Alcohol, Perinatal Substance Abuse].* Clearly, results are still in the early stage of development and more work needs to be done in this field. In the meantime, men are advised to stop using alcohol and drugs at least three months before attempting to have children, and to continue to abstain from alcohol and drugs throughout the pregnancy in order to support the mother.

[Health Canada (1997) It Takes a Community – A Resource Manual for Community-based Prevention of FAS and FAE]

14) Can paternal drinking cause any other problems for the baby?

Children of alcoholic fathers have been shown to have defects in intellectual function (learning, memory) and hyperactivity. This raises the question of whether these effects are the result of genetics or a direct effect of alcohol on the father's sperm prior to conception. There is no conclusive evidence that paternal drinking before conception causes direct adverse effects on the fetus. The social effects of the father's drinking, however, are enormous, as women most often drink with their partners. A father's drinking after the baby is born could also adversely affect the nurturing environment needed to raise a child.

A study reported in the June, 1996 Journal of American Academy of Child and Adolescent Psychiatry suggested that alcoholism in fathers increased their offspring's risk of both alcoholism and mood disorders – in particular major depression and bipolar depression.

[Health Canada (1997) It Takes a Community – A Resource Manual for Community-based Prevention of FAS and FAE]

15) Does paternal use of other substances (ie: tobacco, cocaine) cause any problems for the baby?

Besides alcohol, there are a number of other substances that can affect fertility and the infant's outcome ~

- **Tobacco**: Smoking can depress sperm motility which can contribute to infertility. Smoking half a pack or more a day has been shown to reduce sperm count by as much as twenty percent. Cigarettes smoked by a male can cause decreased circulation of blood in the testicular area due to the enlargement of the spermatic veins that drain the testicles (varicocele). This affects fertility. Paternal smoking has also been connected with lower birth weight and increased risk of disease in babies. Other studies found that the children of men who had smoked at any point in their lives were thirty percent more likely to have cancer than children of fathers who didn't smoke.
- **Chemical Exposure**: It is possible for a male's job to affect his ability to reproduce. Exposure to lead has been associated with his partner's miscarriage. Other substances (pesticides, radiation) may adversely affect the male reproductive system and sperm count, leading to infertility, miscarriage, or still birth.
- **Cocaine**: Cocaine has been found to bind to sperm cells, thus exposing future offspring to the drug upon fertilization.
- **Marijuana**: Marijuana enters the testicles through the bloodstream and lowers sperm count**.** It also diminishes the sperm's motility or ability to swim.

Since sperm cells are made continuously throughout a man's life, they are at more risk of mutation, thus increasing the chance that the baby may have problems. A male should plan ahead for a healthy family. Good steps would be to quit smoking, drinking, and using drugs, and also do as much to protect oneself from exposure to harmful chemicals at work. Such actions will not only lengthen a person's life span, but will also increase the possibility of having healthy children in the future.

[Jeffery, C (2000) Dads and Birth Defects: The Inside Story, Fasalaska]

16) What happens to babies born with FASD?

The consumption of alcohol during pregnancy can lead to a variety of alcohol-related birth disorders. These defects can be mild to severe. Children with FASD have a higher frequency of birth disorders than the general population. The disorder may involve the craniofacial area, the mouth (ie: cleft palate, crooked teeth, speech problems), the skeleton, skin, heart, brain, spinal cord and kidneys. Because their brain is damaged, children may have trouble following simple instructions, remembering things, seeing, hearing or speaking. When they get older they may have trouble controlling how they act, paying attention and learning. They may struggle with depression and may have drug and alcohol problems. They may have trouble holding jobs and may get into trouble with the law *[Addiction Foundation of Manitoba (2000)].* It is important to remember that children with FASD often have many strengths that must be nurtured. Some strengths include a good sense of humour, politeness, good with younger children, hard working, artistic, athletic, and skilled in the outdoors. Children with FASD need support, love, and understanding. They need guidance and supervision. Above all they need acceptance in everyday living.

[The Story of CHIP (1998) BC Ministry of Health: Aboriginal Health Policy Branch]

17) What do IQ tests tell us about children with FASD?

Although the accuracy of IQ testing has been challenged, studies show that IQ levels for FASD children vary widely. Although many individuals with FASD may have intellectual disabilities, others can have an IQ in the normal range. For example in one study of clients with FAS, the IQ ranged from 29 to 120, with the mean IQ being 79. This study highlighted the point that although these people with FAS could score reasonably high in their IQ level, they scored much lower in the communication, living and adaptive behaviour skills *[Streissguth, A. (1996) Secondary Disabilities in FAS and FAS: Centre for Disease Control and Prevention].*

Unlike children with typical cognitive delays, children with FAS tend to show the greatest difficulty in areas requiring the use of abstract thought and written performance. Many children with FASD show difficulties in social/family relationships, memory and attention. An assessment called the Vineland Adaptive Behaviour Scale (VABS) can be more helpful than IQ tests when working with individuals with FASD. IQ tests look at verbal skills, reading and math skills, vocabulary and comprehension. The VABS looks at three areas of functional ability: communication, daily living, and socialization. Research suggests that social deficits in children with FASD are beyond what can be explained by low IQ scores, and indicate that there may be arrested, and not simply delayed, development of social abilities. Deficits such as the inability to control impulses or use good judgement may not show up on an IQ test, but they can show up using the VABS *[Thomas et al, (1998) Alcoholism: Clinical and Experimental Research in www.come-over.to/FAS disk].* It is important to note that although many alcohol affected children show delays in the classroom, many have the capacity to learn and grow if provided with the opportunities and environment to learn using their best skills.

[FASAT (2002) Fun and Free Resources for Families with Special Needs]

18) What is the connection between FASD and ADHD (attention deficit/hyperactivity disorder)?

Many children with FASD also show signs of hyperactivity and impulsivity. Recent research is showing that FASD and ADHD are definitely two different disabling conditions. Although children with ADHD have difficulty focusing on activities, they are able to respond to behaviour modification approaches, sort through and encode information, and go on to change their behaviour using their new skills. Children with FASD however, have great difficulty encoding information and often do not have the capacity to sort through information. Instead they tend to continue to make the same impulsive and poor choice.

[FASAT (2002) Fun and Free Resources for Families with Special Needs]

19) I know someone with cleft lip. Does that mean he was exposed to alcohol prenatally?

Cleft lip and palate can be caused by prenatal exposure to alcohol but also can be caused by genetic factors, maternal/paternal age, cigarette smoking, exposure to German Measles, certain medications, and vitamin deficiencies *[Borowitz, K. (1998) Cleft Lip and Palate Tutorial, HSC].* Diagnosis of FASD includes a history of maternal alcohol consumption during pregnancy, prenatal and/or postnatal growth retardation, neurodevelopmental and behavioural characteristics, and characteristic facial features. No single feature alone can be used to diagnose FASD.

[Guideline for the Diagnosis of Fetal Alcohol Syndrome (1999) Alberta Medical Association]

20) Why do women drink during pregnancy when they know it could harm their baby?

A drinking problem is never easy to stop. It is an addiction. Pregnancy is an excellent time for women with drinking problems to stop or reduce their use of alcohol but unfortunately not all women are able to do so. They need respect, understanding and caring assistance throughout their pregnancy and beyond.

[BC FAS Community Action Guide (1998)]

21) Shouldn't pregnant women be court ordered to go to detox, for the safety of the baby?

Alcohol and drugs are available everywhere in our society, even in supposed protective environments. Instead of imposing solutions on a woman, it is important to support her as she works toward a chosen and sustainable change for herself and her children *[BC FAS Community Action Guide (1998)].* Not all communities feel this way, however. In July 1998, South Dakota became the first state to enforce treatment of pregnant moms who drink by:

- Allowing relatives or friends to commit a pregnant woman to emergency detoxification centres for up to two days
- Allow judges to confine them to treatment centres for as long as nine months
- Make drinking while pregnant a form of child abuse

Critics feel that this law violates maternal rights and say it could alienate women from friends and relatives. It is being challenged under Civil Rights Laws. The Manitoba government is taking alternate steps to address FASD by assisting the high risk woman. Once identified at being at risk of giving birth to another FASD child, the woman is assigned a community advocate who will work with her on a one-to-one basis for three years.

[ARBI & The Law (2000) In and Around the Courthouse]

22) What if I drank before I knew I was pregnant?

The majority of pregnancies are not diagnosed until after the woman misses her period. Although fertilization occurs upon ovulation (usually around 14 days before the next menstrual period) the first two weeks before ovulation are included in the dates of pregnancy. This means that the first four weeks of pregnancy are actually the first two weeks of fetal life. Implantation occurs between day 7 and 10 of fetal life, 21-24 days into the pregnancy *[Simkin, P (1991) Pregnancy, Childbirth and the Newborn].* If alcohol exposure has occurred within the first 21-24 days after the last menstrual period, the embryo has not implanted into the uterus yet, and therefore there is no connection between what is in the mother's bloodstream (alcohol) and the developing embryo.

[Smith, S. (2000) Mental Retardation/Developmental Disabilities Research Centre]

23) What if I am pregnant and have been drinking?

If you are already pregnant, the best thing to do is to stop drinking alcohol completely. The risk of FASD is reduced as soon as the alcohol consumption is reduced or ceases. If you find it too hard to stop, try to drink less often or have fewer drinks at a time. Every time you choose not to drink, you're helping your baby. If you can't stop drinking by yourself, ask someone for help, for example, your doctor, public health nurse, CHIP, EK alcohol and drug counselling service. The Motherisk Helpline (1-877-FAS-INFO) is a toll-free, bilingual telephone service that provides information and counselling on alcohol/substance use during pregnancy. You may find different programs helpful (i.e. hospital detox, residential services, outpatient counselling, and support groups). If a fetus has been exposed to alcohol, stopping at any time will have benefits for both mom and baby.

[Pediatric and Child Health, March 2002]

24)Is it alright to drink alcohol while breastfeeding?

Because an infant's brain continues to develop until around two years of age, it is not recommended to consume alcohol while breastfeeding as it can be passed into breastmilk. Just 1 ½ ounces of alcohol has been associated with disrupted infant sleep. In the event of a specific occasion where alcohol might be consumed, research has been done to determine how many hours after drinking a woman should wait before safely breastfeeding, depending on maternal weight and number of standard drinks:

A 120 lb woman who drinks 1 drink should **wait 2 hours and 30 minutes**
A 120 lb woman who drinks 2 drinks should **wait 5 hours**

A 140 lb woman who drinks 1 drink should **wait 2 hours and 19 minutes**
A 140 lb woman who drinks 2 drinks should **wait 4 hours and 38 minutes**

A 160 lb woman who drinks 1 drink should **wait 2 hours and 10 minutes**
A 160 lb woman who drinks 2 drinks should **wait 4 hours and 20 minutes**

[Motherisk – 1-877-FAS-INFO, 2002]

25) How does someone find out if they have a child with FASD?

Early diagnosis is important as it may result in more support for the child (i.e. at daycare and school). Early diagnosis can help to make the most of the brain's early development, and it can give parent's/caregivers the tools they need to help their child. Although the assessment process is lengthy, having a diagnosis from a diagnostic centre will ultimately open doors for the child now and through his lifetime. A complete assessment will test hearing, vision, speech & language, movement & coordination, thinking & reasoning, physical development and general health. Your family doctor or pediatrician can make the initial referral. Once the referral has been made, the diagnostic centre will send an extensive information form to be filled out by parents/caregivers. When the form is returned to the centre, the child is placed on a waiting list.

When an individual is over 19 years of age, diagnosis of FASD becomes much more challenging. The assessment process is no longer covered by the health care system and can cost thousands of dollars. In addition, very few facilities assess adults for FASD. If prenatal exposure to alcohol is suspected, assessment before 19 years of age is crucial.

The centres to refer to are: Sunny Hill (Vancouver), Alberta Children's Hospital (Calgary), The Asante Centre for Fetal Alcohol Syndrome (Maple Ridge), and Shodair Children's Hospital (Helena, Montana). To access support for travel, contact your Community Health Advocate. For further support and information, contact CHIP (Community Healing and Intervention Program).

[Assessing and Diagnosing Fetal Alcohol Related Conditions for East Kootenay Residents- CHIP Pamphlet]]

26) When should a child be told that they have FASD?

There is no set time to tell a child about their prenatal exposure to alcohol. Each situation is different. A diagnosis may help a child learn about her/his own strengths and weaknesses. Some children may feel less frustrated as their learning challenges are finally validated. Alterations in the classroom after diagnosis may also create a sense of acceptance. There is support available to help children who have been diagnosed with FASD. Contact the CHIP office.

[Hey! Check This Out! FAS Family Resource Institute Pamphlet]

27) What kind of support is there for a parent of a child with FASD?

The parent (birth, foster, adoptive) of a child with FASD assumes a responsibility far beyond that normally associated with parenting. The physical, intellectual, and behavioural challenges for children with FASD can create a very demanding situation for any family. The children often require constant supervision. Parents require an extraordinary amount of energy, love and most of all, consistency. Therefore, these parents need support in their efforts. Information about FASD is needed in order to understand the physical, intellectual, and behavioural repercussions of their child's diagnosis. Parents must have a realistic view of the child's functioning in order to develop reasonable expectations. Support is available via newsletters ie: FAS Times, Iceberg, The Fen Pen. Local parent support groups are also in existence in the East Kootenays. CHIP's Early Intervention Planners and Youth Workers can also provide support and advocacy as needed.

[Guinta, C. (1999) Patients with Fetal Alcohol Syndrome and their Caretakers, Journal of Contemporary Social Work]

27) Can you recognize a child with FASD?

Not all children with FASD will have obvious facial characteristics. Learning difficulties and behavioural challenges signal problems for many professionals and parents. Children with FASD will often show impulsiveness at a young age (before and in kindergarten), especially in situations where the activity level is high. Children with FASD will often struggle with 'choice making' during these periods and show elevated levels of stress during transition periods or periods in which they have to sit quietly in a group.

Children with FASD may have difficulty with social skills and may struggle with learning the 'social rules of play' with other children. By seven years of age they usually begin to show learning difficulties, especially in verbal, written and auditory processing and memory.

As the child grows older and moves through school, these problems may become more pronounced as the child struggles with trying to assimilate new information with his reduced capacity to quickly process this information. Behavioural problems become more pronounced as the child becomes increasingly frustrated with his inability to learn and the perceived injustice of discipline, failure and blame. Their inability to remember and to follow through without assistance is often viewed as

manipulation and laziness. This frustration and anger often lead to teens leaving school without a high school diploma, addiction, alienation from family and friends, which are further barriers to their success.

[FASAT (2002) Fun and Free Resources for Families with Special Needs]

29) What is the long-term outcome for children with FASD?

Damage is permanent. Most children with FASD will never be financially or socially self-sufficient. They are at high risk for neglect, physical abuse, sexual abuse, violence, maternal death and abandonment. They are more likely to be in foster care, require special education, and develop secondary disabilities such as early school drop-out, substance use disorders, mental health problems, and trouble with the law. Research does however, indicate that there are several protective factors which can lead to better outcomes for individuals with FASD. A protective factor is a characteristic or condition that decreases the odds of a secondary disability occurring. While there are eight universal protective factors, it is notable that being diagnosed before the age of 6 years is a strong protective factor for all secondary disabilities except mental health problems. The eight universal protective factors are:

- Living in a stable and nurturant home for over 72% of life
- Being diagnosed before the age of 6 years
- Never having experienced violence against oneself
- Staying in each living situation for an average of more that 2.8 years
- Experiencing a 'good quality home' from ages 8 –12 years
- Having applied for and been found eligible for BC's Services to People with Mental Handicaps
- Having a diagnosis of FAS (rather than pFAS)
- Having basic needs met for at least 13% of life

[Streissguth A. (1997) The Challenges of Fetal Alcohol Syndrome: Overcoming Secondary Disabilities]

30) Can children with FASD grow up and live independently?

Due to their poor social judgment, underdeveloped independent living skills and impaired intellectual functioning, most children with FASD will require a structured, sheltered living situation throughout their lives. The most severely affected may require a completely supervised and sheltered environment. For more functional individuals, a group home or halfway house for developmentally disabled adults may be appropriate if continued residents with a family is not possible or desirable.

[Guinta, C. (1999) Patients with Fetal Alcohol Syndrome and their Caretakers, Journal of Contemporary Social Work]

31) Are adolescents with FASD more at risk for addiction?

Children with FASD are at high risk for becoming chemically dependent because of family histories of alcoholism. Children of alcoholics are four times more likely than other children to become alcoholics *[American Academy of Child and Genetics of Alcoholism, 1999].* Studies show that it is possible to pass on alcoholism from generation to generation, due to genetics. Adolescents are particularly vulnerable as they are exposed to many more negative influences. A teen's desire to fit in, coupled by poor judgment and impulsivity, can lead to substance abuse. It is important for parents/caretakers to show them alternate ways of having fun, dealing with feelings, and being accepted by others.

[MCFD (1999) Parenting Children Affected by FAS: A Guide for Daily Living]

32) Are youth and adults with FASD at risk for affective disorders, including depression?

Youth and adults with FASD may be socially isolated because of immature behaviour and unacceptable interactions with peers. They also appear to be at risk for affective disorders, such as depression. When depression is compounded by poor job prospects and a lack of social support, a downward spiral can result. Building and maintaining self-esteem and confidence are ongoing needs for everyone, but they tend to be more fragile in young adults with FASD. There are success stories among youth who have found supportive relationships, developed job skills and maintained confidence and self-esteem. Some have also found satisfying relationships and acceptance through church groups, Special Olympics, and other youth groups.

[Ministry of Children and Family Development, Government of BC. Community Action Guide]

33) Are individuals with FASD at high risk for being sexually exploited/abused?

Males and females with FASD are often easy targets for sexual exploitation, both as a victim and a victimizer. They have a normal sex drive, which can cause problems when coupled with their poor judgment and impulsivity. Both males and females with FASD are at high risk for being sexually inappropriate with peers, younger children and in some situations with older people. The social consequences of indiscriminate sexual activity can lead to unplanned pregnancies, sexually transmitted infections and sometimes, to prostitution. The best protection from abuse is effective education about sex and about their right to assert themselves in refusing sexual advances *[American Academy of Pediatrics - Policy Statement – Sexuality Education of Children and Adolescents with Developmental Disabilities, 1996].* Teaching of sexuality, sexual development, contraception, and the role of social skills when it comes to sexual interactions needs to be very concrete. The use of clear language, repetition, visual aids and simple exercises helps reinforce teaching.

[Ministry of Children and Family Development, Government of BC. Community Action Guide]

34) Is there special schooling or job training available to youth/adults with FASD?

Because many youth with FASD are verbally fluent, they are sometimes informally assessed as having more ability than they actually have. They may struggle with the demands of an academically oriented school program. An appropriate school program takes these factors into account:

- Good vocational counselling
- Supervised work experience
- Clear expectations
- Consistent routines
- The students limitations in language, memory and basic skills are outlined for the employer

The program should stress basic life skills, including how to handle money, how to be time-conscious, how to apply for jobs, how to interact with employers and fellow workers in a positive way, how to approach social agencies, how to feed and clothe oneself in a healthy way.

[Ministry of Children and Family Development, Government of BC. Community Action Guide]

35) What can men do to help prevent FASD?

Although FASD is caused by maternal alcohol consumption during pregnancy, a man does play a social role in supporting his mate's decision not to drink. Pregnant women are more likely to drink if their partners drink. Men can help their partners by not drinking alcohol themselves or by decreasing the amount they do drink. Providing emotional support throughout pregnancy is directly linked to healthier outcomes for both mom and babe.

[Pediatric and Child Health, March 2002]

36) What are the costs?

It is impossible to measure the human costs of each child born with FASD. Costs are high to birth and adoptive parents, social services, corrections system, education system, and most of all the person affected with FASD. The cost to the health care system, including neonatal complications, assessment & diagnosis, and intervention, has been conservatively estimated at more than $1 million over one child's lifetime. Based on these conservative 1991 estimates, $142 million will then be required to care for the 142 children born with FAS each year in BC. If pFAS/ARND is half the cost (and it may not cost less) then an additional $355 million will be required to care for these individuals. This only includes health care costs and does not include social costs (foster home placement, unemployment, corrections system, etc.) If the birth rate for FAS in BC continues to be the same each year then these costs will continue to multiply.

[Adapted from MacDonald and Ass. (1991) A Report to Communications & Education Branch BC Ministry of Health]