

**British Columbia Foster Care  
Education Program**

**CARING FOR CHILDREN:  
AN INTRODUCTION TO  
FETAL ALCOHOL AND  
NEONATAL ABSTINENCE  
SYNDROMES**

**(3 Hours)**

*MANUAL*

**Ministry of Children and Family Development**

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## **About the Author**

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# INTRODUCTION

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# Introduction

## A. RATIONALE

During the last decade there has been a growing awareness of the effects of prenatal exposure to alcohol. There is now more understanding of the effects of Fetal Alcohol Syndrome (FAS) on the development of children. While a major focus has been on creating public awareness to reduce and prevent this condition, increasing efforts are now being made to provide knowledge and advice to families for effective care of children affected by prenatal exposure to alcohol.

Caregivers need to become aware of the likelihood that a child in their care may have been affected by prenatal alcohol exposure, and need to be prepared to provide effective care for such a child.

This introductory module will provide caregivers with an understanding of the nature of FAS, some behavioral manifestations of this condition, and some suggestions on how to respond to the needs of such children. In addition, suggestions are made for further training for those caregivers who are considering accepting into their care a child with FAS. The module also provides a brief introduction to Neonatal Abstinence Syndrome (NAS).

## B. LEARNING OUTCOMES The caregiver can:

- describe some of the effects of prenatal exposure to alcohol and describe some of the characteristics of children with Fetal Alcohol Syndrome (FAS).
  - describe some of the consequences in the neonate of maternal drug and alcohol abuse (Neonatal Abstinence Syndrome - NAS).
  - explain the value of having a diagnosis of FAS and indicate why diagnosis of this condition is difficult.
  - indicate how many children are likely to be affected by FAS and explain why this knowledge is important to caregivers.
  - describe some of the later life problems that may affect children with FAS.
  - describe effective parenting approaches for responding to the particular needs of children with FAS.
  - describe the particular demands on caregivers of children with FAS, and ways of providing support for themselves.
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- identify community and other resources that may be of assistance to families caring for children with FAS.

### **C. PREPARATION**

The “Caring for Children: An Introduction to Fetal Alcohol and Neonatal Abstinence Syndromes” module consists of a single, three hour session. Foster parents should be familiar with the material in the module. Read it thoroughly and imagine yourself going through the various exercises and activities.

# INSTRUCTIONS

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**OVERVIEW FOR CARING FOR CHILDREN:  
AN INTRODUCTION TO FETAL ALCOHOL AND NEONATAL  
ABSTINENCE SYNDROMES**

- 1. Introduction (15 minutes)**
  
- 2. The Nature of Fetal Alcohol Syndrome  
(30 minutes)**
  
- 3. Neonatal Abstinence Syndrome (NAS)  
(10 minutes)**
  
- 4. Diagnosis of FAS  
(20 minutes)**
  
- 5. Number of Children Affected By FAS  
(10 minutes)**
  
- 6. Later Life Issues  
(10 minutes)**
  
- 7. Caring Effectively for Children with FAS  
(45 minutes)**
  
- 8. Support For Caregivers  
(15 minutes)**
  
- 9. Resources (5  
minutes)**
  
- 10. Closure  
(5 minutes)**

# Instructions

## 1. INTRODUCTION

(15 minutes)

### **Objective:**

### **Materials:**

Handouts

- Handout #1 Learning Outcomes

Other

- paper
- pen

### **Instructions:**

This is an introductory module on Fetal Alcohol Syndrome (FAS). Children who are affected by this syndrome form an important group of children in care due to the seriousness of the condition and also due to the significant demands they may place on caregivers. The impact of this condition can range to an extremely serious level.

Fetal Alcohol Syndrome is a complex condition with a number of diagnostic categories. For simplicity, in this module the term FAS is intended to include the range of diagnostic categories to be introduced later in the module (see Handout #5). The symptoms and behaviours of FAS vary with age. In this introductory module the focus will be on young children. The intent of the module is to provide information and suggestions primarily to those caregivers with longer term care settings, although those with short-term placements may also find the suggestions relevant.

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The purpose of the module is to increase participants' awareness of this condition and to encourage them to seek further training should they wish to care for FAS-affected children. Given the difficulty in diagnosing this condition, it is possible that any caregiver could have a child with FAS placed in their home. The caregiver could be the first to notice that the child may have this condition and need additional help.

This module contains a great deal of information but will not cover all the skills and knowledge needed for a caregiver to develop full competence in caring for children with FAS. The focus is on beginning to understand the syndrome and become aware of some of the indicators and effective approaches to responding.

If caregivers believe they have a child affected with this condition, it is essential that they record their observations and report their concerns to the child's worker immediately.

Caregivers who do not have FAS children in their care may wonder why they are being required to take this material. FAS is a difficult condition to diagnose and children entering care may have this condition although it has not yet been recognized or diagnosed. Because the effects of the condition can be so pervasive and serious, and because early diagnosis enhances the likelihood of the child making positive progress, it is essential that all caregivers have knowledge of FAS.

Review the Handout #1, "Learning Outcomes."

## 2. THE NATURE OF FETAL ALCOHOL SYNDROME (FAS) (30 minutes)

### **Learning Outcome:**

The caregiver can describe some of the effects of prenatal exposure to alcohol and describe some of the characteristics of children with FAS.

### **Materials:**

Handout

- Handout #3 The Nature of Fetal Alcohol Syndrome

Overhead

- Overhead #3(A, B, C) The Nature of Fetal Alcohol Syndrome

### **Instructions:**

Refer to the Overheads and note that Handout #3, "The Nature of Fetal Alcohol Syndrome," addresses the key points to be covered in this module.

### **What Is Fetal Alcohol Syndrome (FAS)?**

The term Fetal Alcohol Syndrome (FAS) has been used in the scientific community only since 1973, and awareness of the problems associated with prenatal exposure to alcohol has increased significantly since then. Concern about the dangers of consuming alcohol during pregnancy has been expressed since at least the period of the Ancient Greeks more than 2000 years ago. However, only recently has there been scientifically based understanding of the serious impact that prenatal exposure to alcohol can have on fetal development, leading to later health problems such as heart, kidney and other abnormalities. Of particular concern is the impact of prenatal alcohol exposure on fetal brain development and subsequent behavioural and learning difficulties.

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Fetal Alcohol Syndrome refers to:

“a constellation of physical and mental birth defects that may develop in individuals whose mothers consumed alcohol during pregnancy. It is an organic brain disorder which is characterized by *central nervous system involvement, growth retardation, and characteristic facial features.*”

(Parenting Children Affected by Fetal Alcohol Syndrome: A Guide for Daily Living, p 1.)

### **What Is The Impact Of Alcohol On Fetal Development?**

Alcohol is known as a teratogen. A teratogen is a substance or agent (chemical, disease) that can disrupt normal prenatal development and lead to birth defects when a fetus is exposed to it during pregnancy.

Alcohol has been shown to cross the placenta and affect the development of various parts of the body, but most seriously the development of the brain.

Malformations or other abnormalities of the developing brain can manifest themselves in behavioral effects such as attention deficits, learning disabilities, mental disabilities, and many other behavioral problems which have been described by Streissguth (1997).

The specific effects of alcohol on the development of a particular child depend on a number of factors, including:

- the dosage, timing, and pattern of prenatal alcohol exposure.
- the mother's nutrition and health, and the child's genetic factors.
- other health hazards, such as poly-drug use.

The dosage or the amount of alcohol intake is a major factor in determining the impact on the developing embryo or fetus. Higher levels lead to more severe effects. The timing of alcohol intake during pregnancy also leads to different effects. For example, during the early stages the developing brain is more vulnerable to major structural abnormalities when exposed to a teratogen.

While the developing brain is vulnerable to the effects of alcohol throughout the prenatal period and beyond, the

specific effects vary throughout this developmental period (Ikonomidou, C., et al, 2000).

The pattern of alcohol intake, such as occasional “binge drinking” as opposed to regular daily intake, will also produce variations in effect. Heavy “binge drinking” has been identified as a damaging contributing factor for FAS (Abel, 1998).

Some factors, such as poor health and the use of other drugs, may increase the teratogenic effects of alcohol; others, such as fetal genetic factors and good nutrition, may decrease the impact (Able, 1998, p. 173).

Because different levels or elements of these contributing factors may have impacted each child, there are large individual variations in the manifestations of the effects of prenatal exposure to alcohol. No two children are likely to have exactly the same effects. This is important when considering ways to respond to the particular needs of a child. Great care must be taken to identify and understand the specific needs of a particular child in order to respond appropriately to the child.

### **Characteristics Of Young Children With FAS (Fetal Alcohol Syndrome and Fetal Alcohol Related Conditions)**

There are great variations in the characteristics of children with FAS, ranging from subtle learning disabilities to severe effects requiring constant care. Each child may have a particular set of characteristics.

Draw your attention to the characteristics of FAS outlined in Overheads #3(B) and #3(C) (and in Handout #2) and reflect on the accuracy and comprehensiveness of these lists related to children with whom you have worked: Do these descriptors match your experience? What is missing? What strengths have children you’ve known possessed which balance the challenging traits?

Frequently mentioned behavioural characteristics of preschool children with FAS:

- hypersensitivity to touch
- Attention Deficit Disorder (ADD)
- hyperactivity (“always on the go,” “never sits still,” “never seems to listen”)
- impulsiveness
- accident prone (possibly a combination of hyperactivity and poor coordination)

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- extreme mood changes (laughs or cries too readily)
  - heightened anxiety
  - constantly demanding attention
  - low threshold for frustration
  - unusual aggressiveness
  - frequent temper tantrums over trivial problems
  - disobedient in response to requests from parents
  - unable to adapt easily to changes in routine activities
  - requiring more direct supervision than other children
  - difficulty forming friendships with other children
  - overly friendly and social toward adults
  - not distinguishing friends from strangers; having no fear of strangers
  - overly talkative; little meaningful content to speech
  - talking at inappropriate times
  - sleep problems
  - lack of coordination.

(Note: from Abel, 1998)

While many of these problems continue during the school years, new ones also emerge reflecting the demands of school and the social context of adolescence.

Phrases used by parents when describing their children who have FAS include:

- over-reacts
- chats, no content
- [talks about] unusual topics
- demands attention
- seems unaware of consequences
- does not complete tasks
- likes to talk
- interrupts
- likes to be the center of attention
- touches others frequently
- can't play on a team
- can't take a hint
- has sleeping problems
- is over-stimulated. (Note: based on a selection of descriptions by Streissguth et al, 1998)

Others may also have noticed some of these problems and characteristics, such as teachers or daycare staff. If caregivers believe that a child in their care may have FAS, an appropriate professional should make an assessment.

Generally a physician who is familiar with FAS assessment, working with a diagnostic team of specialists makes a

diagnosis. The child's worker will be able to assist in initiating a referral for assessment.

**3. NEONATAL ABSTINENCE SYNDROME (NAS)**  
(10 minutes)

**Learning Outcome:**

The caregiver can describe some of the consequences in the neonate of maternal drug and alcohol abuse (Neonatal Abstinence Syndrome – NAS).

**Materials:**

Handout

- Handout #4 Neonatal Abstinence Syndrome (NAS)

Overhead

- Overhead #4 Neonatal Abstinence Syndrome (NAS)

**Instructions:**

Refer to Handout #4, “Neonatal Abstinence Syndrome (NAS)” and Overhead #4, “Neonatal Abstinence Syndrome (NAS).” While it is beyond the scope of this module to cover NAS in any depth, participants should have some basic knowledge of this condition.

Prenatal drug use by an expectant mother can have a variety of adverse consequences in the developing child. A serious effect is that the neonate acquires a passive drug addiction through a mother who uses drugs during pregnancy. At birth the infant is deprived of the drug and then may experience drug withdrawal symptoms. This condition is described as Neonatal Abstinence (or Withdrawal) Syndrome. The drug withdrawal period can last up to two or three weeks.

The specific effects of drug withdrawal in the neonate depend on the particular drug(s) the mother was using. Commonly abused drugs are heroin, cocaine, amphetamines, alcohol, or some combination of these or other drugs. Each leads to a number of specific effects. However, the following are common manifestations for a number of these drugs:

- irritability
- excessive crying
- hypersensitivity
- feeding problems.

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There may also be tremors, seizures, and sleep disturbances (Weintraub and Bental, 1998).

Because of the seriousness of this condition, the initial drug withdrawal period needs to be managed in a medical setting. Some of the above symptoms may persist beyond the initial drug withdrawal period and may require specialized care by a knowledgeable caregiver with advanced training.

Longer-term effects have been found to be variable because of the range of contributing factors, such as differences in drug exposure, types of drugs, and quality of post-natal care. However, there have been indications during the preschool years of delayed motor development, lowered cognitive development, distractibility, and hyperactivity (Phelps, 1993).

Note: Additional resources for information on caring for infants with NAS include:

- Safe Babies Programs. British Columbia Ministry for Children and Families (1999); and
- The ABCs of daily care for substance-exposed infants. British Columbia Ministry for Children and Families (1999).

#### **4. DIAGNOSIS OF FAS** (35 minutes)

##### **Learning Outcome:**

The caregiver can explain the value of having a diagnosis of Fetal Alcohol Syndrome and indicate why diagnosis of this condition is difficult.

##### **Materials:**

Handouts

- Handout #5a Diagnosis of FAS
- Handout #5b Diagnostic Criteria for Fetal Alcohol Syndrome (FAS) and Alcohol Related Effects
- Handout #5c The Face of Fetal Alcohol Syndrome in the Young Child

Overhead

- Overhead #5 Diagnosis of FAS

**Instructions:**

**Importance Of A Diagnosis**

When a caregiver believes that a child in care may have FAS, he needs to seek a confirming diagnosis. The caregiver needs to bring such concerns and the need for a diagnosis to the attention of the child's worker.

Think of reasons why diagnosis is important then refer to Overhead #5, "Diagnosis of FAS," and discuss points not previously raised.

A diagnosis of FAS is important for the following reasons.

- It provides directions and guidance for intervention. Many of the problems of FAS have a good chance of being improved with appropriate interventions.
- It will provide opportunities for assistance and support for caregivers.
- In general, the earlier the determination and interventions for FAS, the greater the likelihood for the reduction of associated symptoms.
- It provides a reason for caregivers to become more knowledgeable about FAS and to learn how to assist the child more effectively in her development.
- It provides the basis for an explanation of the child's behaviors.
- It can lead to more realistic expectations about what the child may achieve.

**Diagnostic Categories Of Fetal Alcohol Syndrome**

Referring to Overhead #5, "Diagnosis of FAS," briefly review issues regarding diagnosis, emphasizing the importance to caregivers of relying on professionals for diagnosis.

With increasing knowledge about the nature of the effects of prenatal exposure to alcohol, there has been a need to develop a diagnostic tool that will reliably identify the different manifestations of this condition. In 1996 the U.S. Institute Of Medicine (IOM) (Stratton, Howe, and Battaglia, 1996) developed a diagnostic system that is increasingly being used.

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The following is a listing of the diagnostic categories:

- FAS with confirmed maternal exposure
- FAS without confirmed maternal alcohol exposure
- Partial FAS, with confirmed alcohol exposure
- Alcohol Related Birth Defects (ARBD)
- Alcohol Related Neurodevelopmental Disorder (ARND).

In this module the generic abbreviation FAS will be used to denote the above categories of Fetal Alcohol Syndrome, and Fetal Alcohol Related Conditions (ARBD and ARND.)

Older terms may still be present in the literature, particularly in material published before the development of the current diagnostic system in 1996. Fetal Alcohol Effects (FAE) and Possible Fetal Alcohol Effects (PFAE) were used to describe conditions where some but not all of the indicators of FAS were present. It is advised that foster parents minimize use of the older terms as the new Institute of Medicine system is replacing them.

### **Implications for Caregivers of a Diagnosis of FAS**

The diagnostic descriptions indicate that there are many physical and behavioral traits associated with FAS. Of all these traits, brain damage and consequent difficulties leading to problems in thinking, perceiving and relating to others are most significant and can make caregiving frustrating and challenging.

With increasing age, and particularly during the transition from elementary to middle school, these traits may manifest themselves as learning disabilities, attention problems, speech and language difficulties (particularly in the area of comprehension), mental disability (less than 50% of individuals), and problems with reasoning and judgment. Many children with "Partial FAS" are not easily recognized except through expert diagnosis, and may go through life with their condition unacknowledged.

### **Difficulties with Diagnoses**

Accurate diagnosis is possible when most or all of the typical features of FAS are present. However, diagnosis becomes more

difficult when some of the physical features associated with FAS are absent, and when the prenatal history of the child is unknown or uncertain. Central nervous system impairments due to prenatal alcohol exposure can be subtle and may not be easily identified. Without a history of prenatal alcohol exposure neither Alcohol Related Birth Defects (ARBD) nor Alcohol Related Neurodevelopmental Disorder (ARND) can be diagnosed in the IOM (1996) diagnostic system.

In addition, it has been shown that there can be impairments in attention and learning in children who have been abused or neglected growing up in the homes of alcoholic and abusing parents (Brown, 1996; Sher, 1991). Consequently it may at times be difficult to determine the exact cause of the child's behaviors.

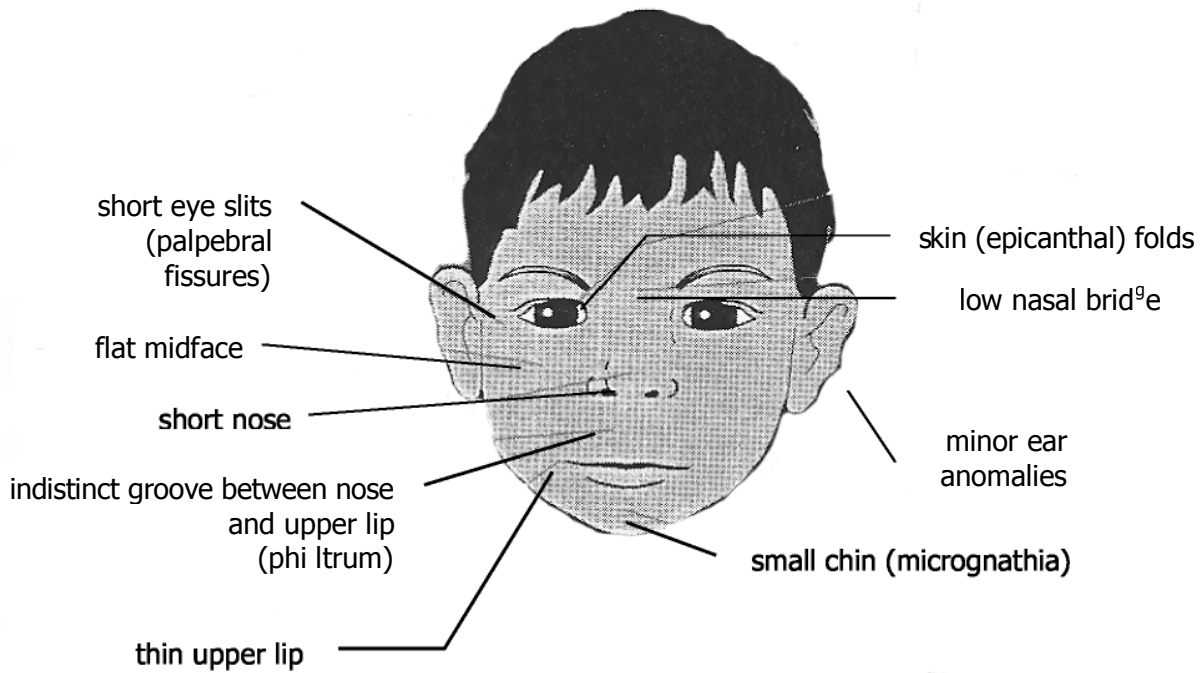
While a definitive diagnosis is valuable, the absence of a diagnosis should not deter caregivers from learning to respond effectively to the particular needs of the child in their care.

Figure 1

# The Face of Fetal Alcohol Syndrome in the Young Child

## Discriminating Features

## Associated Features



Note: These facial features change beyond puberty and are typically no longer recognizable in adulthood.

**Exercise:**

The purpose of the exercise is for participants to consider how they might react to a child in their care being diagnosed with FAS.

Please consider the following:

- how they would initially react to a diagnosis.
- how a diagnosis might affect their expectations for the child, and their way of responding to the needs of the child.
- what steps they would take after a diagnosis.

Compare possible reactions to a diagnosis to those initial reactions to FAS diagnosis identified by Barkley (1995):

- Denial - of the possibility that the child is permanently affected by brain damage.
- Relief - the welcome insight that the child's difficulties are due to brain damage, and not due to the caregiver's parenting or the child's willful obstruction.
- Anger - at those who may have caused the child's impairment, or misinterpreted or misunderstood the child's condition.
- Grief - at the loss of normal development.
- Acceptance - of the child's condition, which may include a recognition of some of the limits the child may have, and the need for creating a supportive environment to allow the child to succeed within his abilities.

Caregivers may take additional steps after learning a child has FAS, such as asking for help from the child's worker, becoming more knowledgeable about FAS, making contact with others in similar situations, and exploring Handout #12, "Resources."

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**5. NUMBER OF CHILDREN AFFECTED BY FAS**  
(10 minutes)

**Learning Outcome:**

The caregiver can indicate how many children are affected by FAS, and explain why this knowledge is important to caregivers.

**Materials:**

Handout

Handout #6 How Many Children Are Affected by FAS

Overhead

Overhead #6 How Many Children Are Affected by FAS

**Instructions:**

Refer to Overhead #6, "How Many Children Are Affected by FAS," and summarize what is known about the incidence of FAS, emphasizing that exact numbers aren't known or particularly critical to them. What is important to them is the frequency of occurrence and the resulting likelihood that they will have FAS children in their care.

The number of children who have FAS at birth has been difficult to determine. Given the complexity of diagnosis and the absence of routine screening, it is believed that FAS often goes unnoticed at birth. Reported occurrences have ranged up to about 3 births per 1000, with higher rates in some communities (Stratton, K., Howe, C. and Battaglia, 1996, p.89). A study in the Seattle region estimated that when

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including both FAS and Fetal Alcohol Related Conditions the rate is almost 1 birth per 100 (Sampson et al, 1997).

In an Alberta Family and Social Services survey of children in care, it was estimated that about 4% were determined to have a confirmed diagnosis of FAS/FAE, and about 11.5% were suspected (but not confirmed) to have FAS/FAE (interpolation from Alberta Family and Social Services, 1997).

Exact rates for the general population as well as for specific communities have yet to be determined. What the above data indicate is that FAS likely is still being under-reported, and that the rate for children in care is significantly higher than in the general population.

Caregivers need to be alert to the possibility that children in their care may have the effects of prenatal exposure to alcohol. Understanding some of the manifestations of this condition will help caregivers decide whether they should discuss the need for professional assessment with the child's worker. It is important to discuss promptly any such concern.

In the past some assumed that the occurrence of Fetal Alcohol Syndrome was limited primarily to children from certain groups (such as low socioeconomic status, First Nations, teen mothers). Recent data (Abel, 1999, p. 213; Bagheri, M., et al, 1998; Dufour, M. and Williams, G., 1994; Miller, L., et al, 1995) have shown that this condition is likely to be encountered across most ethnic and racial groups and across all socioeconomic status backgrounds. While the rate of occurrence may differ across such groupings, none appear to be exempt. Caregivers need to be aware that a child from any background may have the effects of prenatal alcohol exposure.

## 6. LATER LIFE ISSUES (10 minutes)

### **Learning Outcome:**

The caregiver can describe some later life issues that may affect children with FAS.

### **Materials:**

Handout

•Handout #7 Later Life Issues

Overhead

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• Overhead #7 Later Life Issues

**Instructions:**

Growing up with FAS has been associated with many later life challenges. These are not disabilities that the child is born with, but are acquired as a result of the limitations in learning and thinking that result from the neurological effects of FAS and because of insufficient societal support.

Please reflect on the later life progress and difficulties of children with FAS for whom they have cared, and then refer to Overhead #7, "Later Life Issues."

On the basis of observations with hundreds of individuals, Streissguth et al (1997) found significant problems in the following areas:

- mental health problems (90% of sample)
- disrupted school experiences (suspended, expelled, or dropped out of school, 60% of sample)
- trouble with law (charged or convicted, 60% of sample)
- confined for treatment or jail (50% of sample)
- inappropriate sexual behavior (reported or sentenced, 50% of sample)
- alcohol/drug problems (having or having been treated, 30% of sample)
- dependent living (i.e., not living independently, 80% of sample over 21 years of age)
- problems with employment for those 21 years of age or older (80% of sample).

Think of what factors in the home of a child with FAS might reduce the likelihood of these difficulties.

The following is a list of 'protective factors' listed in order of their strength in reducing later life problems, according to Streissguth:

- living in a stable and nurturing home
- being diagnosed before the age of six
- never having experienced violence against oneself
- staying in each living situation for an average of more than 2.8 years.
- experiencing a good quality home from ages 8 to 12 years.
- having applied for and been found eligible for special needs services.

- having basic needs met.

One conclusion that can be drawn from this list as well as other research (e.g., Carmichael, Olson and Burgess, 1997) is that early diagnosis and intervention and a nurturing home can significantly improve the lives of children with FAS. Foster parents can play a critical role in creating these positive conditions for children in their care.

## 7. CARING EFFECTIVELY FOR A CHILD WITH FAS (45 minutes)

### **Learning Outcome:**

The caregiver can describe effective parenting approaches for responding to the particular needs of children with FAS.

### **Materials:**

Handouts

- Handout #8 Caring Effectively For A Child With FAS
- Handout #9 Paradigm Shifts and FAS/FAE

Overheads

- Overhead #8(A) Caring Effectively For A Child With FAS
- Overhead #8(B) Caring Effectively For A Child With FAS
- Overhead #9 Specific Suggestions For Caregiving
- Overhead #10 Paradigm Shifts and FAS/FAE

### **A. General Approaches to Providing Care**

#### **Instructions:**

Providing care for a child with FAS can be extremely challenging and demanding. Caregivers will become involved with the child to an extent greater than they would with other children. They will find themselves seeking out medical professionals, therapists, teachers, and other professionals and community resources for support. They will find themselves having to supervise, monitor, teach, plan, structure, reward, guide and protect the child more than a typical parent.

Sometimes, in spite of an enormous investment in effort and nurturance, caregivers may come to the realization that many of the limitations of the child cannot be overcome and that more modest expectations for the child's future need to be developed. While providing care to a child affected by prenatal exposure to alcohol may at times place stress on the family,

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overcoming some of the perceived limitations and guiding the child towards a degree of independence can also provide a great sense of fulfillment.

Since providing care to a child with special needs leads to many demands, caregivers may need to develop a guide or a plan for a care-giving approach. Refer to Overheads #8(A) and #8(B), “Caring Effectively For A Child With FAS.”

Note that Handout #8, “Caring Effectively For A Child With FAS,” contains detailed notes on this subject. The suggestions are based on parenting advice by Barkley (1995), placed in the context of providing care for a child with the effects of fetal alcohol exposure.

- First seek to understand the child. This may include understanding the child's condition, strengths and limitations. Being a good listener, reflecting on the child's needs and what the child has said, will aid in understanding a situation from the child's point of view.
- Be understood by the child. Ensure that the child understands your expectations. State your expectations in a clear, direct and courteous manner. Repetition of instructions is particularly important with FAS children.
- Be proactive. Anticipate events and plan the setting and your role in the event. Avoid simply having to react to the child's responses. Without a plan, the child's behaviors may become uncontrolled and this could lead to the caregiver feeling unbalanced and reacting in an emotional manner. Taking initiative may not only lead to more predictable actions by the child, but will also lead to a greater sense of empowerment in the caregiver.
- Begin with an end in mind. Consider the goals you hope the child will achieve. The goal may be as specific as solving a homework problem or as large as successfully completing a week of school. Such consideration may aid in the development of a “map” or a strategy of how to achieve the goal.
- Consider yourself the advocate for the child. Providing care for a child with the effects of prenatal alcohol exposure likely will bring the caregiver in contact with a number of professional (teachers, therapists, physicians, etc.), all of whom may provide advice or intervention for an aspect of the child's functioning. Being with the child continuously

places the caregiver in a position to understand what may be in overall best interests of the child.

- Be guided by experience and evidence. There is no handbook covering all possible events a caregiver may encounter. To be guided by experience and evidence means:
  - a) acknowledging that you do not know all you need to know about providing care to a child with FAS.
  - b) seeking further knowledge about FAS which may include seeking advice from professionals, reading materials on FAS, and consulting with others who provide care to children with FAS.
  - c) trying out an approach based on experience and acquired knowledge, and then evaluating the outcome. If the approach was not successful, further knowledge-seeking and revisions may be necessary. Keeping good records (see the Module "Caring for Children: Observing, Recording and Reporting") aids in this process.
  
- Consider the child as an individual. Each child with FAS has unique and particular characteristics. For some, problems can range up to severe levels such that they will need constant care. All will likely have some learning difficulties and behavior problems. Because of these wide variations it is important to focus on the particular needs of the child rather than trying to apply a generalized approach.
  
- Assess the child's progress. In order to determine the value and effectiveness of an intervention or caregiving procedure, there needs to be ongoing observation and assessment of the child's behavior with appropriate adjustments if necessary. When assessing the child's behavior, consider the following:
  - the impact of the disability: at times the child may behave in a particular way or may misbehave because of the limitations produced by FAS. For example, what may appear to be dishonesty may be due to memory loss or lack of understanding of circumstances involved.
  - your expectations: expectations for the attainment of goals by the child may at times have to be adjusted. The child's learning difficulties may interfere with the acquisition of social, academic, and other skills. Consequently caregivers may need to set more realistic initial goals for the child's development.

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- Recognize the child's strengths. Many children with FAS are happy, friendly, and very talkative. For each child, it is important to identify particular strengths and to build on these when developing interventions. In order to create positive self-esteem caregivers should find activities and create opportunities for the child to succeed. Successful completion of a task leads to a sense of fulfillment and raises self-esteem. Caregivers need to identify activities in which the child will do well, and then provide opportunities for the child to succeed in these activities.
  - Recognize that caring for a child with FAS will require a shift in interpreting, understanding and reacting to the child's behavior. Handout #9, "Paradigm Shifts and FAS/FAE," and Overhead #10 "Paradigm Shifts and FAS/FAE," identify some examples of such a shift.

**Exercise:**

We end this section with Overhead #10, "Paradigm Shifts and FAS/FAE," and ask participants to relate this shift to their own experience.

**B. Specific Suggestions For Caregiving**

**Instructions:**

While a formally evaluated set of effective caregiving strategies for children with FAS has not yet been developed, there are many suggestions from caregivers, teachers, and therapists that have been found to be helpful.

The following suggestions about providing care for children with FAS are based on the work of Hartness (1998), Olson and Morse (1996), and Quinby (1997). Further resources are listed in Handout #12, "Suggested Resources." While these suggestions have been found to be helpful, the nature of each particular child and the specific context or setting will determine the extent to which they can be applied and will be found useful.

Review Overhead #9, "Specific Suggestions For Caregiving," reflecting on each type of strategy (and contained in Handout #8, "Caring Effectively For A Child With FAS"):

- a) **Environment** - Commonly observed problems in children with FAS are learning difficulties and limitations in planning skills or anticipating the consequences of their

own behavior. Because of these difficulties it is important to structure the environment of the child to improve learning. For example:

- if there is too much noise and too many objects or people for the child to concentrate, the intensity of this stimulation needs to be reduced.
- if the child is easily distracted and engages in off-task behaviors, a high level of monitoring and encouragement may be required to maintain on-task behavior.

b) **Consistency** - Many caregivers have found it important to maintain familiar routines and consistency in the environment of the child. A structured environment with familiar routines leads to predictability and a sense of security for the child. Examples are:

- establishing predictable and consistent patterns for morning and bedtime routines.
- keeping routines the same at mealtime and for homework activities.

c) **Learning** - Children with FAS may require more focused and deliberate efforts to develop skills and acquire knowledge. Important elements of teaching strategies are:

- a distraction-free environment.
- rewards: on completion of an appropriate task provide immediate rewards, such as praise and attention. Praise and attention should be specific for the behavior to be promoted. For example, when the child has picked up the phone and answered appropriately, before speaking to the caller say: "Tommy, you answered the phone politely, thank-you."
- consequences: make consequences for inappropriate behaviors immediate, natural, and logical. For example, if the child has thrown some food, ask her to help clean it up.
- repetition: children with FAS often require many repetitions to learn a skill. Close supervision and assessment will determine the need for re-teaching. Reminders and other cues to prompt the appropriate behaviors are useful. For example, a list of steps and tasks (written or pictorial) posted in the child's room may guide the child's morning routine. Such posted lists are useful for many tasks and in many settings.
- task analysis: whenever a task is initially too difficult for the child to master, break it down into component steps and work on each component in turn.
- show-by-doing: modeling and other concrete demonstrations may help the child to understand the skill to be acquired.

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- generalization: the child may require learning to occur in different settings in order to be able to apply it in those settings. For example, when teaching a child to “take turns” in play, the child may need repeated instructions in a variety of settings such as at home, playground, school.
- d) **Transitions** - Children with FAS need stability and consistency. New tasks, setting or routines require prior preparation. Examples of such prior preparation are:
- advance notice and discussion with the child for an impending change.
  - breaking up a major change into smaller steps and working through each one in turn.
- e) **Communication** - To facilitate understanding, instructions to the child should be clear and simplified. Instructions should be short, explicit and concrete. If possible, demonstrate and model how something is to be done, rather than simply describing it. Phrase directions in a positive way (rather than telling the child what not to do). Positively phrased directions are more easily understood by the child, and also provide better opportunities for positive consequences by the caregiver. Accompanying visual cues, such as exaggerated facial and body language, and hand signals, may also facilitate communication.
- f) **Sensory hypersensitivity** - Children with FAS may over-react because of their inability to manage an “overload” of sensory stimulation. Reducing the amount or intensity of stimuli will allow the child to calm down and focus. Examples of such sensory reductions are:
- reducing noise level.
  - reducing glare by using sunglasses.
  - avoiding crowded situations.

Other senses, such as touch, may also produce intensified reactions. For example, a even neutral or a light touch may be interpreted as severe or unpleasant.

Please note there are many additional parenting suggestions in: [Parenting children affected by fetal alcohol syndrome: A guide for daily living](#), edited by Graefe, 1998.

**Exercise:**

The intent of this exercise is for participants to reflect on their experience in providing care for children with FAS who have behavioral challenges.

Please consider the following:

- what particular child behaviors you have found difficult.
- what caregiving approaches you found successful.
- what caregiving approaches were not successful.
- how you might put some of the strategies presented in this module into practice.

Please record on a piece of paper items of significance.

## **8. SUPPORT FOR CAREGIVERS** (15 minutes)

### **Learning Outcome:**

The caregiver can describe the particular demands on caregivers of children with FAS, and ways of seeking support for themselves.

### **Materials:**

Handouts

- Handout #10 Support For Caregivers
- Handout #11 Need for Further Training

Overheads

- Overhead #11 Support For Caregivers
- Overhead #12 Need for Further Training

### **Instructions:**

Children with FAS require more monitoring, supervision, and care than other children. Providing care for these children can be demanding and caregivers can easily become exhausted and demoralized.

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Referring to Overhead #11, “Support For Caregivers,” reflect on examples and ideas related to each category of support.

Caregivers need to develop their self-help skills to:

- prevent 'burn-out'.
- manage anger which may arise when dealing with a child's behaviour problems.
- cope with the demands of consistently providing quality care to children with complex needs.
- become more familiar with useful services and resources

Caregivers can minimize stress by:

- anticipating stressful events; identifying upcoming stressful events and planning how best to cope prevents simply reacting to events and feeling powerless and out of control.
- beginning with an end in mind (while ensuring that goals are realistic and do-able). This allows for a broader focus and makes it less likely to become distracted by minor instances of inappropriate behaviors.
- coping with stressful events:
  - delay your response; rather than reacting in a possibly emotional or angry manner to the child's behavior, delay your response to allow for a more considered reaction.
  - practice relaxation.
- practicing personal renewal:
  - take a short break from caregiving (respite) or take a weekend off. This should be discussed with the child's worker to determine what is possible.
  - seek support from friends, relatives (e.g., engage with others in recreational activities).
  - review Module 3 – “Effects of Caregiving” for further suggestions on personal renewal.
- becoming an advocate for the child with FAS:
  - become knowledgeable about FAS.
  - seek the support of the child's physician, therapists, worker, school staff, to help promote and guide the child's personal, educational and social development.
  - provide opportunities for the child to establish relationships with peers and others in the community. A sense of ‘connection’ and 'belonging' is important for the child's self-development. The well-being of other children

need to be part of the consideration of developing such relationships.

- become active in parent support groups and develop common strategies for increasing community support for children with FAS.
- ask your child's worker if she knows of any specific FAS activities in your community.

### **Need For Further Training**

This has been a brief introduction to an understanding of the effects of prenatal exposure to alcohol. Overhead #12 provides some possible topics for additional education and training, for discussion:

- further understanding of altered neurological function due to prenatal alcohol exposure, and the typical behavior patterns that are likely to occur, particularly in the areas of abstract thinking, memory, and attention.
- further details on providing care, with specific reference to the unique demands of children with FAS, age differences, and further insight into the management of daily behaviors
- caring for infants who have experienced drug withdrawal symptoms
- suggestions on how to promote self-regulation skills to guide children's behaviour
- an understanding of attachment problems that may be the result of prenatal exposure to alcohol or may have arisen from the consequences of having been raised in a home with alcohol misusing parents (included would be suggestions for responding to attachment problems)
- suggestions for providing early educational support to a child who likely will experience difficulties in school;
- suggestions for physical care, in areas such as sleeping, eating, pain, and medical problems
- consideration of possible later problems at school, peer relationship difficulties, problems in mental health and with the justice system, and consideration of how to begin early

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to prevent or reduce these risks .  
support for caregivers.

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**9. RESOURCES**  
(5 minutes)

**Learning Outcomes:**

The caregiver can identify community and other resources that may be of assistance to families caring for children with FAS.

**Materials:**

Handout

•Handout #12 Suggested Resources

**Instructions:**

Briefly review the variety of resources included and identify any others of which you are aware.

## **REFERENCES**

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## REFERENCES

- Abel, E. (1998). Fetal alcohol abuse syndrome. New York: Plenum Press
- Alberta Family and Social Services, Child Welfare and the Alberta Association for Community Living (1997). Children with disabilities in care.
- Barkley, R. (1995). Taking charge of ADHD. New York: Guilford Press .
- Bagheri, M., Burd, L., Martsof, J., and Klug, M. (1998). Fetal alcohol syndrome: maternal and neonatal characteristics. Journal of Perinatal Medicine, 26, 263 - 259.
- Bloomquist, M. (1996). Skills training for children with behaviour disorders. New York: Guilford Press.
- British Columbia Ministry for Children and Families (1999). Safe Babies Program.
- British Columbia Ministry for Children and Families (1999). The ABCs of daily care for substance-exposed infants.
- Brown, S. (1996). Treating adult children of alcoholics: A developmental perspective. New York: John Wiley and Sons
- Carmichael Olsen, H. and Burgess, D. (1997). Early Intervention with Children Prenatally Exposed to Alcohol and Other Drugs. In Guralnick, M. (Ed). The effectiveness of early intervention: Second generation research. Baltimore: Paul H. Brookes.
- Dufour, M., and Williams, G. (1994). Knowledge of FAS and the risks of heavy drinking during pregnancy. Alcohol, Health and Research World, (18), 86-91.
- FAS/E Support Network of B.C. (1995). A layman's guide to fetal alcohol syndrome and possible fetal alcohol effects. Surrey, B.C.: FAS/E Support Network of B.C.
- Hartness, C. (1998). A training manual for trainers: Fetal alcohol syndrome and fetal alcohol related conditions. Seattle: Seattle-King County Department of Public Health.
- Ikonomidou, G., Bittigau, P., Ishimaru, M.J., Wozniak, D.F., Koch, C., Genz, K., Price, M.T., Stefovskaja, V., Horster, F., Fenkova, T., Dikranian, K., Olney, J.W. (2000). Ethanol-induced apoptotic neurodegeneration and fetal alcohol syndrome. Science, Feb. 11, 1056-1060.
- Miller, L., Shaikh, T., Stanton, C., Montgomery, A., Richard, R., Keefer, S., Hoffman, R. (1995). Surveillance for fetal alcohol syndrome in Colorado. Public Health Report 110, 690 – 697.

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- Olson, H. and Morse, B., and Huffine, C. (1998). Development and Psychopathology: Fetal Alcohol Syndrome and Related Conditions. Seminars in Clinical News Psychiatry (3), 262 – 284.
- Quinby, R. (1997). Model for children and young adults with fetal alcohol syndrome (FAS) and fetal alcohol related conditions (FARC). Seattle: Seattle-King County Department of Public Health.
- Sampson, P., Streissguth, A., Bookstein, F., Little, R., Clarren, S., Dehaene, P., Hanson, J., Graham, J. (1997). Incidence of fetal alcohol syndrome and prevalence of alcohol related neurodevelopment disorder, Teratology, 56, 317 – 326.
- Sher, K. (1997). Psychological characteristics of children of alcoholics: Alcohol, Health and Research World, (21), 247 – 255.
- Stratton, K., Howe, C., and Battaglia, (Eds.) (1996). Fetal alcohol syndrome: Diagnoses, epidemiology, prevention and treatment. Washington, D.C.: National Academy Press.
- Streissguth, A. (1997). A. Fetal alcohol syndrome: A Guide to families and communities. Baltimore: Paul H. Brooks Publishing.
- Streissguth, A., Barr, H., Kogan, J., and Bookstein, F. (1997) Primary and secondary disabilities in fetal alcohol syndrome, in Streissguth, A., and Kanter, J. (Eds). The challenge of fetal alcohol syndrome. Seattle: University of Washington Press.
- Streissguth, A., Bookstein, F., Barr, H., Press, S., and Sampson, P. (1998). A Fetal alcohol behaviour scale. Alcoholism: Clinical and experimental research, 22, 325 – 333.
- Weintraub, Z., and Bental, Y. (1998). Neonatal withdrawal syndrome and behavioural effects produced by maternal drug use. Addiction Biology, 3, 159- 176.

## **APPENDIX I: HANDOUTS**

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## HANDOUT #1

### LEARNING OUTCOMES

The caregiver can:

- describe some of the effects of prenatal exposure to alcohol and describe some of the characteristics of children with Fetal Alcohol Syndrome.
- describe some of the consequences in the neonate of maternal drug and alcohol abuse (NAS).
- explain the value of having a diagnosis of Fetal Alcohol Syndrome and indicate why diagnosis of this condition is difficult.
- indicate how many children are likely to be affected by FAS and explain why this knowledge is important to caregivers.
- describe some of the later life problems that may affect children with FAS.
- describe effective parenting approaches for responding to the particular needs of children with FAS.
- describe the particular demands on caregivers of children with FAS, and ways of providing support for themselves.
- identify community and other resources that may be of assistance to families caring for children with FAS.

**HANDOUT #3****THE NATURE OF FETAL ALCOHOL SYNDROME****What is Fetal Alcohol Syndrome?**

- the result of prenatal exposure to alcohol
- results in physical abnormalities, such as in the features of the face and reduced size of the newborn
- leads to problems of behaviour and cognition
- found in all economic and racial groups
- not genetic or inherited.

**What is the impact of alcohol on fetal development?**

- Alcohol is a teratogen - it disrupts normal prenatal development and can lead to birth defects.
- Differences in the developing brain can lead to later behavioral effects such as: attention deficits, learning disabilities, mental disabilities, and many other behavioral problems.
- The specific effects of alcohol on the development of a particular child depends on a number of factors, including:
  - the dosage, timing and pattern of prenatal alcohol exposure.
  - the mother's nutrition and health, and the child's genetic factors.
  - other health hazards, such as poly-drug use.
- Because each child may have different levels or elements of these contributing factors, there are large individual variations in the manifestations of the effects of prenatal alcohol exposure.

**Some characteristics of young children with FAS**

There are individual variations in the characteristics of children with FAS. Each child may have a particular set of characteristics. The following is a list of frequently mentioned behavioural characteristics of preschool children with FAS.

- hypersensitivity to touch
- Attention Deficit Disorder (ADD)
- hyperactivity (“always on the go,” “never sits still,” “never seems to listen”)
- impulsiveness
- accident prone (possibly a combination of hyperactivity and poor coordination)
- extreme mood changes (laughs or cries too readily)
- heightened anxiety
- constantly demands attention
- low threshold for frustration
- unusual aggressiveness
- frequent temper tantrums over trivial problems
- disobedient in response to requests from parents

- 
- unable to adapt easily to changes in routine activities
  - requires more direct supervision than other children
  - difficulty forming friendships with other children
  - overly friendly and social toward adults
  - does not distinguish friends from strangers; has no fear of strangers
  - overly talkative; little meaningful content to speech
  - talks at inappropriate times
  - sleep problems
  - lack of coordination
- (From: Abel, 1988)

Parents of children with FAS have described their children in the following way:

- over-reacts
- chats, no content
- [talks about] unusual topics
- demands attention
- seems unaware of consequences
- does not complete tasks
- likes to talk
- interrupts
- likes to be center of attention
- touches others frequently
- can't play on a team
- can't take a hint
- has sleeping problems
- is over-stimulated

(Note: Based on a selection of descriptions by Streissguth et al, 1998)

**HANDOUT #4****NEONATAL ABSTINENCE SYNDROME (NAS)**

Prenatal drug use by an expectant mother can lead to a passive drug addiction in the developing child. At birth the infant is deprived of the drug and then may experience drug withdrawal symptoms.

Drugs that can induce such effects include:

- heroin
- cocaine
- amphetamines
- alcohol
- other drugs.

Depending on the type of drug used, symptoms in the neonate may include:

- irritability
- excessive crying
- hypersensitivity
- feeding problems.

As well there may be tremors, seizures, and sleep disturbances.

Initial treatment of withdrawal symptoms needs to be managed in a medical setting, and may need to be followed by specialized care by a knowledgeable caregiver with advanced training.

Longer term effects in the preschool years are variable, but may include:

- delayed motor development
- lowered cognitive development
- distractibility
- hyperactivity.

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## **HANDOUT #5 (a)**

### **DIAGNOSIS OF FAS**

#### **A diagnosis is important for the following reasons.**

- It provides directions and guidance for intervention. Many of the problems of FAS have a good chance of being improved with appropriate interventions.
- It will provide opportunities for assistance and support for caregivers.
- In general, the earlier the determination and interventions for FAS, the greater the likelihood for the reduction of associated symptoms.
- It provides a reason for caregivers to become more knowledgeable about FAS and to learn how to assist the child more effectively in her development.
- It provides the basis for an explanation of the child's behaviors.
- It can lead to more realistic expectations about what the child may achieve.

#### **Abbreviations:**

**FAS** – Fetal Alcohol Syndrome

**FARC** – Fetal Alcohol Related Conditions

**ARBD** – Alcohol Related Birth Defects

**ARND** – Alcohol Related Neurodevelopmental Disorder

#### **Other Terms: (Older Terms – usage diminishing)**

**FAE** – Fetal Alcohol Effects

**PFAE** – Possible Fetal Alcohol Effects

#### **Difficulties with diagnoses:**

- Some of the central nervous system impairments can be subtle and difficult to measure.
- Some of the child's problem behaviours may be due to abuse and neglect while growing up in the home of alcoholic and abusing parents.
- Absence of diagnosis should not deter caregivers from learning to respond effectively to the needs of the child.

**HANDOUT #5 (b)****DIAGNOSTIC CRITERIA FOR FETAL ALCOHOL SYNDROME (FAS)  
AND ALCOHOL-RELATED EFFECTS**

Diagnostic criteria for Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Related Conditions (FARC), from the Institute of Medicine, 1996. For further details see Stratton, Howe and Battaglia (1996).

**Fetal Alcohol Syndrome**

1. FAS with confirmed maternal alcohol exposure \*
  - A. Confirmed maternal alcohol exposure \*
  - B. Evidence of a characteristic pattern of facial anomalies that includes features such as short palpebral fissures and abnormalities in the premaxillary zone (e.g. flat upper lip, flattened philtrum, and flat midface)
  - C. Evidence of growth retardation, as in at least one of the following:
    - low birth weight for gestational age
    - decelerating weight over time not due to nutrition
    - disproportional low weight to height
  - D. Evidence of CNS neurodevelopmental abnormalities, as in at least one of the following:
    - decrease cranial size at birth
    - structural brain abnormalities (e.g., microcephaly, partial or complete agenesis of the corpus callosum, cerebellar hypoplasia)
    - neurological hard or soft signs (as age appropriate), such as impaired fine motor skills, neurosensory hearing loss, poor tandem gait, poor eye-hand coordination
2. FAS without confirmed maternal alcohol exposure  
B, C, and D as above
3. Partial FAS with confirmed maternal alcohol exposure
  - A. Confirmed maternal alcohol exposure \*
  - B. Evidence of some components of the pattern of characteristic facial anomalies

Either C or D or E

- C. Evidence of growth retardation, as in at least one of the following:
  - low birth weight for gestational age
  - decelerating weight over time not due to nutrition
  - disproportional low weight to height

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- D. Evidence of CNS neurodevelopmental abnormalities, as in:
- decreased cranial size at birth
  - structural brain abnormalities (e.g., microcephaly, partial or complete agenesis of the corpus callosum, cerebellar hypoplasia)
  - neurological hard or soft signs (as age appropriate) such as impaired fine motor skills, neurosensory hearing loss, poor tandem gait, poor eye-hand coordination
- E. Evidence of a complex pattern of behavior or cognitive abnormalities that are inconsistent with developmental level and cannot be explained by familial background or environment alone, such as learning difficulties; deficits in school performance; poor impulse control; problems in social perception; deficits in higher level receptive and expressive language; poor capacity for abstraction or metacognition; specific deficits in mathematical skills; or problems in memory, attention, or judgment.

**Alcohol-Related Effects**

Clinical conditions in which there is a history of maternal alcohol exposure, and where clinical or animal research has linked maternal alcohol ingestion to an observed outcome. \* \*\*

There are two categories, which may co-occur. If both diagnoses are present, then both diagnoses should be rendered:

4. Alcohol-related birth defects (ARBD) List of congenital anomalies, including malformations and dysplasias

Cardiac	Atrial septal defects Ventricular septal defects	Aberrant great vessels Tetralogy of Fallot
Skeletal	Hypoplastic nails Shortened fifth digits Radioulnar synostosis Flexion contractures Camptodactyly	Clinodactyly Pectus excavatum and carinatum Klippel-Feil syndrome Hemivertebrae Scoliosis
Renal	Aplastic, dysplastic, hypoplastic kidneys Horseshoe kidneys	Ureteral duplications Hydronephrosis
Ocular	Strabismus  Retinal vascular anomalies	Refractive problems secondary to small globes
Auditory	Conductive hearing loss	Neurosensory hearing loss
Other	Virtually every malformation has been described in some patient with FAS. The etiologic specificity of most of these anomalies to alcohol teratogenesis remains uncertain.	

5. Alcohol-related neurodevelopmental disorder (ARND)

Presence of:

- A. Evidence of CNS neurodevelopmental abnormalities, as in any one of the following:
- decreased cranial size at birth
  - structural brain abnormalities (e.g., microcephaly, partial or complete agenesis of the corpus callosum, cerebellar hypoplasia)
  - neurological hard or soft signs (as age appropriate), such as impaired fine motor skills, neurosensory hearing loss, poor tandem gait, poor eye-hand coordination

and/or:

- B. Evidence of a complex pattern of behavior or cognitive abnormalities that are inconsistent with developmental level and cannot be explained by familial background or environment alone, such as learning difficulties; deficits in school performance; poor impulse control; problems in social perception; deficits in higher level receptive and expressive language; poor capacity for abstraction or metacognition; specific deficits in mathematical skills; or problems in memory, attention, or judgment.

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\* A pattern of excessive intake characterized by substantial, regular intake or heavy episodic drinking. Evidence of this pattern may include frequent episodes of intoxication, development of tolerance or withdrawal, social problems related to drinking, legal problems related to drinking, engaging in physically hazardous behavior while drinking, or alcohol-related medical problems such as hepatic disease.

\*\* As further research is completed and as, or if, lower quantities or variable patterns of alcohol use are associated with ARBD or ARND, these patterns of alcohol use should be incorporated into the diagnostic criteria.

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**HANDOUT #6**

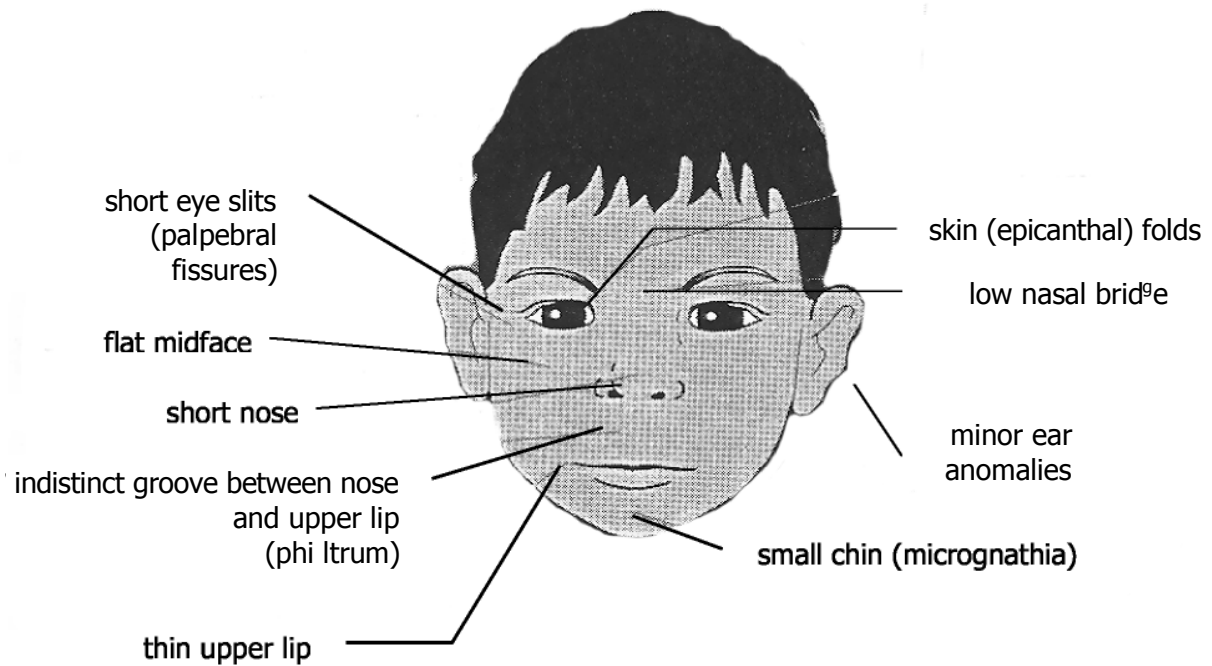
**THE FACE OF FETAL ALCOHOL SYNDROME  
IN THE YOUNG CHILD**

**Discriminating  
Features**

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**Associated  
Features**

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**Note: These facial features change beyond puberty and are typically no longer recognizable in adulthood.**

**HANDOUT #6****HOW MANY CHILDREN ARE AFFECTED BY FAS?**

The number of children with FAS has been difficult to determine. The following are some estimates:

- up to 3 births per 1000 (Institute of Medicine, 1996 )
- about 1 per 100 births in Seattle region (Sampson et al, 1997)
- an Alberta Family and Social Services Survey ( 1997 ) of children in care estimated 4% with confirmed diagnosis for FAS/FAE; 11.5% suspected; this data shows that children in care have a significantly higher rate of fetal alcohol syndrome than those in the general population.

Implication for caregivers: there is a significant likelihood that a child in your care may have the effects of fetal alcohol syndrome.

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## HANDOUT #7

### LATER LIFE ISSUES

In a survey of individuals with Fetal Alcohol Syndrome, Streissguth, 1997 found many had later life issues:

- mental health problems (90% of sample)
- disrupted school experiences (suspended, expelled, or dropped out of school, 60% of sample)
- trouble with law (charged or convicted, 60% of sample)
- confined for treatment or jail (50% of sample)
- inappropriate sexual behaviour (reported or sentenced, 50% of sample)
- alcohol/drug problems (having or having been treated, 30% of sample)
- dependent living (i.e., not living independently, 80% of sample over 21 years of age).
- problems with employment for those 21 years of age or older (80% of sample).

She also found that the likelihood of these problems was reduced with the presence of these “protective factors”:

1. living in a stable and nurturing home
2. being diagnosed before the age of six
3. never having experienced violence against oneself
4. staying in each living situation for an average of more than 2.8 years
5. experiencing a good quality home from ages 8 to 12 years
6. having applied for and been found eligible for special needs services
7. having basic needs met.

**HANDOUT #8****CARING EFFECTIVELY FOR A CHILD WITH FAS**

## Caregivers:

- will need to seek the support of professionals, such as physicians, therapists and teachers.
- will need to supervise, monitor, teach, plan, structure, reward, guide and protect the child more than a typical parent.
- may have to readjust their expectations for the child's future.

## Guidelines for caregiving:

- First seek to understand the child - the child's condition, strengths and limitations, and point of view.
- Be understood by the child - state expectations in a clear, direct and courteous manner; confirm that the child has understood you; repetition of instruction is important.
- Be proactive - anticipate events and plan the setting and your role in the event.
- Begin with an end in mind; consider the goals you seek for the child to achieve. The goal may be as specific as solving a homework problem or a larger goal such as successfully completing a week of school. Such consideration may aid in the development of a "map" or a strategy on how to achieve the goal.
- Consider yourself the "advocate" for the child; providing care for a child with the effects of prenatal alcohol exposure likely will bring the caregiver in contact with a number of professionals (teachers, therapists, physicians, etc.), all of whom may provide advice, or intervention for an aspect of the child's functioning. Being with the child continuously places the caregiver in a position to understand what may be in the overall best interest of the child.
- Be guided by experience and evidence. There is no handbook that could cover all possible events a caregiver may encounter. To be guided by experience and evidence means:
  - a) acknowledging that you do not know all you need to know about providing care to a child with FAS.
  - b) seeking further knowledge about FAS - this may include seeking advice from professionals, reading materials on FAS and consulting with others who provide care to children with FAS.
  - c) trying out an approach based on experience and acquired knowledge, and then evaluating the outcome. If the approach was not successful, further knowledge seeking and revisions may be necessary. Keeping good records (see the Module "Caring for Children: Observing, Recording and Reporting") aids in this process.

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- Consider the child as an individual. Each child with FAS will have unique and particular characteristics. For some, problems can range up to severe levels such that they will need constant care. All of them will have some learning difficulties and behaviour problems. Because of such wide variations it is important to focus on the particular needs of the child rather than trying to apply some general approach.
  - Assess the child's progress. In order to determine the value and effectiveness of an intervention or caregiving procedure, there needs to be ongoing observation and assessment of the child's behaviour with appropriate adjustments if necessary. When assessing the child's behaviour, consider the following:
    - a) knowledge of disability; at times the child may behave in a particular way or may misbehave because of the limitations produced by the FAS conditions. For example, what may appear to be dishonesty may be due to memory loss or lack of understanding of the circumstances involved.
    - b) goals; expectations for the attainment of goals by the child may at times have to be adjusted. The child's learning difficulties may interfere with the acquisition of social, academic, and other skills. Consequently caregivers may need to set more realistic goals for the child's development.
  - Recognize the child's strengths. Many children with FAS are happy, friendly, and talkative. For each child it is important to identify particular strengths and to build on these when developing interventions. In order to create positive self-esteem caregivers should find activities and create opportunities for the child to succeed. Successful completion of a task leads to a sense of fulfillment and raises self-esteem.

Specific suggestions for caregiving include the following.

- a) **Environment:** Commonly observed problems are learning difficulties, limitations in planning skills and anticipating the consequences of one's behaviour. Because of these limitations it is important to structure the environment of the child to improve learning. For example:
  - if there is too much noise and too many objects or people for the child to concentrate, the intensity of this stimulation needs to be reduced.
  - if the child is easily distracted and engages in off-task behaviours, a high level of monitoring and supervision may be required to maintain on-task behaviour.
- b) **Consistency:** Many caregivers have found it important to maintain familiar routines and consistency in the environment of the child. A structured environment familiar routines leads to predictability and a sense of security for the child.

Examples are:

- establishing predictable and consistent patterns for morning and bed-time routines.
- keeping routines similar at mealtime and for homework activities.

c) **Learning:** Children with FAS may require more focused and deliberate efforts to develop skills and acquire knowledge. Important elements of teaching strategies are:

- Distraction-free environment
- Rewards: On completion of an appropriate task, provide immediate rewards, such as praise and attention. Praise and attention should be specific for the behaviour to be promoted. For example:
  - when the child has picked up the phone and answered appropriately, before speaking to the caller say: “Tommy, you answered the phone politely, thank-you.”
- Consequences: Make consequences for inappropriate behaviours also immediate, natural, and logical. For example: if the child has thrown some food, ask the child to help clean it up.
- Repetition: Children with FAS may require many repetitions to learn a skill. Close supervision and assessment will determine the need for re-teaching. Reminders and other cues to prompt the appropriate behaviours are useful. For example: a list of steps and tasks (written or pictorial) posted in the child's room may guide the child's morning routine. Such posted lists are useful for many tasks and in many settings.
- Task analysis: If a task is initially too difficult for the child to master, break it down into component steps and work on each component in turn.
- Show-by-doing: Modeling and other concrete demonstrations may help the child to understand the skill to be acquired.
- Generalization. The child may require learning to occur in different settings in order to be able to apply it in different settings. For example: When teaching a child to “take turns” in play, the child may need repeated instructions in a variety of settings such as at home, playground, school.

d) **Transitions:** As many children with FAS need stability and consistency, new tasks, settings or routines require prior preparations. Examples of such prior preparations are:

- advance notice and discussion with the child for an impending change.
- breaking up a major change into smaller steps and working through each one in turn.

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- e) **Communication:** To facilitate understanding, instructions to the child should be clear and simplified. Instructions should be short, explicit and concrete. If possible, demonstrate and model how something is to be done, rather than simply describing it. Phrase directions in a positive way (rather than telling the child what not to do). Accompanying visual cues, such as exaggerated facial and body language, and hand signals, may also facilitate communication.

Note: There are many additional parenting suggestions in Parenting children affected by fetal alcohol syndrome: A guide for daily living, edited by Graefe (1998).

- f) **Sensory hypersensitivity:** Children with FAS may over-react because of their inability to manage an 'overload' of sensory stimulation. Reducing the amount or intensity of stimulation will allow the child to calm down and focus on what to do. Examples of such sensory reductions are:
- reducing noise level
  - reducing glare by using sunglasses
  - avoiding crowded situations.

**HANDOUT #9****PARADIGM SHIFTS AND FAS/FAE**

As our understanding of the meaning of 'organic brain differences' is integrated into everyday life, at home and in the community, parents and caregivers undergo a personal and professional paradigm shift in how they understand and feel about children with FAS/FAE. The shift includes moving from:

**From Seeing Child As:****To Understanding Child As:**

Won't .....	Can't
Bad .....	Frustrated, defended, challenged
Lazy .....	Tries hard
Lies .....	Confabulates/fills in
Doesn't try .....	Exhausted or can't start
Mean .....	Defensive, hurt, abused
Doesn't care, shut down.....	Can't show feelings
Refuses to sit still .....	Over-stimulated
Fussy, demanding .....	Oversensitive
Resisting .....	Doesn't 'get it' Can't
Trying to make me mad .....	remember
Trying to get attention .....	Needing contact, support
Acting younger .....	Being younger
Thief .....	Doesn't understand ownership
Doesn't try .....	Tired of always failing
Inappropriate .....	May not understand proprieties
Not trying to get the obvious.....	Needing many re-teachings

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Source: Diane Malbin

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## HANDOUT #10

### SUPPORT FOR CAREGIVERS

Caregivers can minimize the stress by:

- anticipating stressful events; identifying upcoming stressful events and planning how best to cope prevents simply reacting to events and feeling powerless and out of control.
- beginning with an end in mind (while ensuring that goals are realistic and do-able). This allows for a broader focus and makes it less likely to become distracted by minor instances of inappropriate behaviors.
- coping with stressful events:
  - delay your response; rather than reacting in a possibly emotional or angry manner to the child's behavior, delay your response to allow for a more considered reaction.
  - practice relaxation.
- practicing personal renewal:
  - take a short break from caregiving (respite) or take a weekend off. This should be discussed with the child's worker to determine what is possible.
  - seek support from friends, relatives (e.g., engage with others in recreational activities).
  - review Module 3 – “Effects of Caregiving” for further suggestions on personal renewal.
- becoming an advocate for the child with FAS:
  - become knowledgeable about FAS.
  - seek the support of the child's physician, therapists, worker, school staff, to help promote and guide the child's personal, educational and social development.
  - provide opportunities for the child to establish relationships with peers and others in the community. A sense of ‘connection’ and ‘belonging’ is important for the child's self-development. The well-being of other children need to be part of the consideration of developing such relationships.
  - become active in parent support groups and develop common strategies for increasing community support for children with FAS.
  - ask your child's worker if she knows of any specific FAS activities in your community.

**HANDOUT #11****NEED FOR FURTHER TRAINING**

To knowingly accept into care a child with FAS caregivers need to become more knowledgeable in the following areas:

- further understanding of altered neurological function due to prenatal alcohol exposure, and the typical behavior patterns that are likely to occur, particularly in the areas of abstract thinking, memory, and attention.
- further details on providing care, with specific reference to the unique demands of children with FAS, age differences, and further insight into the management of daily behaviors
- caring for infants who have experienced drug withdrawal symptoms
- suggestions on how to promote self-regulation skills to guide children's behaviour
- an understanding of attachment problems that may be the result of prenatal exposure to alcohol or may have arisen from the consequences of having been raised in a home with alcohol misusing parents (included would be suggestions for responding to attachment problems)
- suggestions for providing early educational support to a child who likely will experience difficulties in school;
- suggestions for physical care, in areas such as sleeping, eating, pain, and medical problems
- consideration of possible later problems at school, peer relationship difficulties, problems in mental health and with the justice system, and consideration of how to begin early to prevent or reduce these risks
- support for caregivers.

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## HANDOUT #12

### SUGGESTED RESOURCES

The following is a beginning selection of resources that may be of interest to caregivers. A number of the organizations and internet sites listed provide access to more extensive resource lists.

#### **Books/Guides:**

FAS/E Support Network of B.C. (1995). A layman's guide to fetal alcohol syndrome and possible fetal alcohol effects. Vancouver, B.C.: FAS/E Support Network of B.C. Contact: 604-589-1854. This organization has also published: Assessment tools (for six different age groups), FAS/E and education: The art of making a difference, and other resources.

Graefe, S. (Ed.) (1998). Parenting children affected by fetal alcohol syndrome: A guide for daily living. Vancouver, B.C.: The Society of Special Needs Adoptive Parents (SNAP). Contact SNAP: 604-687-3114

Kleinfeld, J., and Wescott, S. (Eds.) (1993). Fantastica Antone succeeds: experiences in educating children with fetal alcohol syndrome. Fairbanks: University of Alaska Press. Contact: B.C. FAS/E Support Network, 604-589-1854.

McCreight, B. (1997). Recognizing and managing children with fetal alcohol syndrome/fetal alcohol effects: A guidebook. Washington, D.C.: CWLA Press.

Normand, C., and Rutman, D. (1996). Caring for children with fetal alcohol syndrome. Victoria, B.C.: School of Social Work, University of Victoria. Available through: Child, Family and Community Research Program, School of Social Work, Box 1700, University of Victoria, Victoria, B.C., V8W 2Y2 (e-mail [cfcpr@hsd.uvic.ca](mailto:cfcpr@hsd.uvic.ca))

Streissguth, A., and Kanter, J. (Eds.) (1997). The challenge of fetal alcohol syndrome: overcoming secondary disabilities. Seattle: University of Washington Press. Available through: UBC Press, Vancouver; phone 604-822-5959.

Streissguth, A. (1997). Fetal alcohol syndrome: A guide for families and communities. Toronto: Brooks Publishing.

Turpin, J., and Schmidt, G. (Eds.) (1999). Fetal alcohol syndrome/effect: developing a community response. Halifax: Fernwood Publishing. Available through: Mosquito Books - 1-800-451-6495.

**Suggested Resources (cont'd)****Videos:**

David with FAS (1996). Kanata Productions in cooperation with the National Film Board of Canada and CBC Newsworld.  
Available through: NFB, 1-800-267-7710

Fetal alcohol syndrome and effects: Stories of help and hope. (1994)  
Available through: Hazelden, 15251 Pleasant Valley Road,  
Box 176, Center City, MN, 55012-1176.

Helping families - helping children (1997). Yellowknife Films.  
Available through: Yellowknife Association for Community Living,  
P.O. Box 981, Yellowknife, NT, X1A 2N7  
Phone: 403-920-2644.

Living and learning with FAS (1991). LENA Productions for the British Columbia FAS Resource Group.  
Available through: B.C. Learning Connections.  
Phone: 604-324-7752.

**Newsletters:**

About FAS/E  
FAS/E Support Network of B.C.  
Phone: 604-507-6675, [e-mail: fasnet@istar.ca](mailto:fasnet@istar.ca)

Society of Special Needs Adoptive Parents Newsletter  
SNAP, 205-409 Granville Street, Vancouver, B.C. V6C 1T2,  
Phone: 604-687-3114, [e-mail: info@snap.bc.ca](mailto:info@snap.bc.ca)

Iceberg  
P.O. Box 95597, Seattle, W.A. 98036, U.S., Phone: 206-827-1773.  
An educational newsletter about FAS.

FAS Times: Fetal Alcohol Syndrome/Family Resource Institute Newsletter.  
FAS/FAE, P.O. Box 2525, Lynnwood, WA, 98036, U.S.

Growing with FAS  
7802 S.E.. Taylor, Portland, OR, 97215, U.S.  
Information for parents and professionals.

Notes from NOFAS  
National Organization on Fetal Alcohol Syndrome,  
418 C Street North East, Washington, D.C. 20002, U.S.,  
Phone: 202-785-4585, [e-mail: information@nofas.org](mailto:information@nofas.org).

**Suggested Resources (cont'd)**

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**Organizations:**

• Provincial FAS/E Prevention Coordinator

Ministry of Children and Family Development  
Community Services and Program Supports  
3<sup>rd</sup>. Floor  
737 Courtney Street  
Victoria, B.C.  
V8W 9S1

Phone: 250-952-6056, Fax: 250-953-4556

The coordinator provides information and referral services for the public and professionals on how to access information resources, expertise and services related to FAS; also provides technical support to groups and organizations that are initiating activities at a community level to address FAS issues.

• FAS/E Support Network of B.C.

13279 72nd Ave.  
Surrey, B.C.  
V3W 2N5

Phone: 604-507-6675, Fax: 604-507-6685

[e-mail: fasnet@istar.ca](mailto:fasnet@istar.ca) [www.fetalalcohol.com](http://www.fetalalcohol.com)

The FAS/E Support Network, a provincial organization funded by the Ministry of Children and Family Development, provide information, support, consultations and advocacy services for individuals, families and professionals and the broader community around prevention, intervention and treatment issues pertaining to alcohol related birth defects (FAS/E) caused by alcohol used during pregnancy. It operates a 24 hours a day 'Warm Line'.

- Society of Special Needs Adoptive Parents (SNAP)  
205-409 Granville Street  
Vancouver, B.C.  
V6C 1T2  
Phone: 604-687-3114; Toll free; 1-800-663-7627; FAX: 604-687-3364 [e-mail: snap@ibm.net](mailto:snap@ibm.net)  
SNAP is a provincial organization dedicated to assisting special needs adoptive families through mutual support, information sharing and advocacy. SNAP provides support groups and one-on-one contact resources parents throughout B.C. The society provides a newsletter as well as other resources.
- B.C. Aboriginal Network on Disability Society  
1179 Kosapsum Crescent  
Victoria, B.C.  
V9A 7K7  
Phone: 250-381-7303, Fax:: 250-381-7312
- YWCA Crabtree Corner FAS/NAS Prevention Project  
101 East Cordova Street  
Vancouver, B.C.  
V6A 1K7  
Phone: 604-689-2808, FAX 604-689-5463  
[www.ywca.van.org](http://www.ywca.van.org)  
The YWCA Project provides FAS/INAS educational workshops, a resource lending library, a peer support group for mothers with children with FAS/NAS, and information and crisis counselling.
- FAS/FAE Information Service  
Canadian Centre on Substance Abuse  
75 Albert Street, Suite 300  
Ottawa, Ontario  
K1P 5E7  
Phone: 1-800-559-4514 or 613-235-4048, ext. 223  
FAX 613-235-8101  
[e-mail: tas@ccsa.ca](mailto:tas@ccsa.ca)  
internet: [http: / /www.ccsa.ca/fasgen.htm](http://www.ccsa.ca/fasgen.htm)

**Note:** A complete listing of FAS activities in B.C. is available from the Provincial FAS/E Prevention Co-ordinator. Another source of information is "Moving Forward": FAS Activities in B.C., published by the Ministry of Children and Families (also now on the Internet).

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**Internet Sites:**

- B.C. Ministry of Children and Families Library Resource Center for FAS/FAE.  
[http://www.mcf.gov.bc.ca/library/subjects/sub01\\_1b.html](http://www.mcf.gov.bc.ca/library/subjects/sub01_1b.html)
- Canadian Center on Substance Abuse, provides directories, resources.  
<http://www.ccsa.ca/fasgen.htm>
- FAS Link List Serve, provides resources, teaching guide.  
[www.acbr.com/fas/faslink2 .htm](http://www.acbr.com/fas/faslink2.htm)
- NOFAS, a US organization providing training and resources  
<http://www.nofas.org/>
- There are many other internet sites that can be accessed by typing in 'fetal alcohol syndrome' or 'FAS' using any of the search engines such as Altavista or Yahoo.

## **APPENDIX II: OVERHEADS**

## LEARNING OUTCOMES

### **The caregiver can:**

- describe some of the effects of prenatal exposure to alcohol and describe some of the characteristics of children with Fetal Alcohol Syndrome.
- describe some of the consequences in the neonate of maternal drug and alcohol abuse (NAS).
- explain the value of a diagnosis of Fetal Alcohol Syndrome and indicate why diagnosis of this condition is difficult.
- indicate how many children are likely to be affected by FAS and explain why this knowledge is important to caregivers.
- describe some of the later life problems that may affect children with FAS.
- describe effective parenting approaches for responding to the particular needs of children with FAS.
- describe the particular demands on caregivers of children with FAS, and ways of providing support for themselves.

- 
- identify community and other resources that may be of assistance to families caring for children with FAS.
-

**OVERHEAD #3(A)****THE NATURE OF FETAL ALCOHOL SYNDROME**

- **What is Fetal Alcohol Syndrome?**
- **What is the impact of alcohol on fetal development?**
  - **Teratogen**
  - **Can lead to effects such as:**
    - **Attention deficits**
    - **Learning disabilities**
    - **Mental disabilities**
  - **Specific effects of alcohol depend on:**
    - **Dosage, timing, pattern of alcohol exposure**
    - **Mother's nutrition, health, child's genetic factors**

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OVERHEAD #3(B)

## **The Nature of Fetal Alcohol Syndrome**

### **Characteristics of young children with FAS**

- **hypersensitivity to touch**
  - **Attention Deficit Disorder (ADD)**
  - **hyperactivity (“always on the go,” “never sits still,” “never seems to listen”)**
  - **impulsiveness**
  - **accident prone (possibly a combination of hyperactivity and poor coordination)**
  - **extreme mood changes (laughs or cries too readily)**
  - **heightened anxiety**
  - **constantly demands attention**
  - **low threshold for frustration**
  - **unusual aggressiveness**
  - **frequent temper tantrums over trivial problems**
  - **disobedient in response to requests from parents**
  - **unable to adapt easily to changes in routine activities**
  - **requires more direct supervision than other children**
  - **difficulty forming friendships with other children**
  - **overly friendly and social toward adults**
  - **does not distinguish friends from strangers; has no fear of strangers**
  - **overly talkative; little meaningful content to speech**
  - **talks at inappropriate times**
  - **sleep problems**
  - **lack of coordination**
-

**OVERHEAD #3(C)**

## **The Nature of Fetal Alcohol Syndrome**

### **Parents' description of children with FAS**

- **Over-reacts**
- **Chats, no content**
- **Talks about unusual topics**
- **Demands attention**
- **Seems unaware of consequences**
- **Does not complete tasks**
- **Likes talk**
- **Interrupts**
- **Likes to be center of attention**
- **Touches others frequently**
- **Can't play on a team**
- **Can't take a hint**
- **Has sleeping problems**
- **Poor manners**
- **Is over-stimulated**

## **Neonatal Abstinence Syndrome (NAS)**

- **What is Neonatal Abstinence Syndrome (NAS)?**
  - **Drugs that can induce NAS:**
    - **heroin**
    - **cocaine**
    - **amphetamines**
    - **alcohol**
    - **other drugs.**
  - **Common symptoms in the neonate:**
    - **irritability**
    - **excessive crying**
    - **hypersensitivity**
    - **feeding problems**
    - **may also occur: tremors, seizures, sleep disturbances.**
-

- **Initial treatment for withdrawal symptoms is in a medical setting, followed by care by a knowledgeable caregiver with advanced training.**
  
- **Longer term effects – variable, may include:**
  - **delayed motor development**
  - **lowered cognitive development**
  - **distractibility**
  - **hyperactivity.**

## DIAGNOSIS OF FAS

- **Importance of diagnosis:**
    - **direction for intervention**
    - **opportunities for assistance and support**
    - **early detection can lead to significant improvement**
    - **reason to learn about FAS**
    - **basis for understanding the child**
    - **can lead to realistic expectations for the child.**
  
  - **Three types of Fetal Alcohol Syndrome (FAS) diagnoses:**
    1. **FAS with confirmed maternal exposure.**
    2. **FAS without confirmed maternal alcohol exposure.**
    3. **Partial FAS, with confirmed alcohol exposure.**
  
  - **Two types of Alcohol Related Effects**
    1. **Alcohol Related Birth Defects (ARBD)**
    2. **Alcohol Related Neuro-Developmental Disorder (ARND)**
  
  - **Difficulties with diagnosis:**
    - **Some impairments are difficult to measure.**
    - **Some of the child's problems may be due to abuse, neglect.**
-

**OVERHEAD #6**

**HOW MANY CHILDREN ARE  
AFFECTED BY FAS**

- **up to 3 births per 1000 (Institute of Medicine, 1996)**
- **1 birth per 100 in Seattle region (FAS and ARND) (Sampson et al, 1997)**
- **children in care in Alberta: 4% confirmed with diagnosis for FAS; 11% suspected (Alberta Family and Social Services, 1997)**

## LATER LIFE ISSUES

### **Streissguth (1997) survey of later life problems:**

- **mental health problems**
- **disrupted school experiences**
- **trouble with law**
- **confined for treatment or jail**
- **inappropriate sexual behaviour**
- **alcohol/drug problems**
- **dependent living**
- **problems with employment.**

### **Protective factors (Streissguth, 1997):**

- **stable and nurturant home**
  - **diagnosis before age six**
  - **no violence against self**
  - **living situations have been stable (more than 2.8 years)**
  - **good quality home between ages 8 – 12 years**
  - **eligible for special needs services**
  - **basic needs met at least 13% of life.**
-

**OVERHEAD #8(A)****CARING EFFECTIVELY FOR A CHILD  
WITH FAS**

- **Will need to supervise, monitor, teach, plan, reward, guide, and protect child more than typical parent.**
- **May need to adjust expectations for child.**
- **Guidelines for caregiving:**
  - **understand child**
  - **be understood by child**
  - **be proactive**
  - **begin with an end in mind**
  - **consider self as an “advocate”**
  - **be guided by experience and evidence**
    - **seek out further knowledge about FAS**
    - **try out approach**
    - **revise as necessary.**

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**OVERHEAD #8(B)**

## **CARING EFFECTIVELY FOR CHILDREN WITH FAS**

- **Consider the child as an individual.**
  - **Assess the child's progress taking into account:**
    - **the child's disability**
    - **attainable expectations.**
  - **Recognize the child's strengths.**
-

## OVERHEAD #9

## **SPECIFIC SUGGESTIONS FOR CAREGIVING**

- **Environment:** may need to modify to reduce stimulation.
- **Consistency:** structure and consistent routines.
- **Learning:**
  - **distraction – free environment**
  - **immediate rewards**
  - **immediate, natural consequences**
  - **repetition**
  - **task analysis**
  - **use of modeling**
  - **generalization.**
- **Transitions, new tasks, settings:**
  - **prepare for transition**
  - **break into smaller steps.**
- **Communications:** clear and simplified.
- **Sensory hypersensitivity:** may need to reduce sensory overload.

## Paradigm Shifts and FAS/FAE

As our understanding of the meaning of 'organic brain differences' is integrated into everyday life, at home and in the community, parents and caregivers undergo a personal and professional paradigm shift in how they understand and feel about children with FAS/FAE. The shift includes moving from:

### **From Seeing Child As:**

### **To Understanding Child As:**

Won't .....	Can't
Bad .....	Frustrated, defended, challenged
Lazy .....	Tries hard
Lies .....	Confabulates/fills in
Doesn't try .....	Exhausted or can't start
Mean .....	Defensive, hurt, abused
Doesn't care, shut down .....	Can't show feelings
Refuses to sit still .....	Over- stimulated

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Fussy,	Oversensitive
demanding .....	. Doesn't 'get it'
Resisting .....	. Can't remember
Trying to make	. Needing contact,
me mad .....	attention..... support
Trying to get	. Being younger
attention.....	. Doesn't understand
Acting younger ...	ownership
Thief .....	. Tired of always failing
Doesn't try .....	. May not understand
Inappropriate ....	proprieties
Not trying to get	. Needing many re-
the obvious .....	teachings

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Source: Diane Malbin

## **SUPPORT FOR CAREGIVERS**

- **Anticipate stressful events.**
  - **Use coping strategies.**
  - **Learn more about FAS.**
  - **Practice personal renewal:**
    - **take a break from caregiving**
    - **engage in recreational activities with friends, relatives.**
  - **Advocate for child with FAS:**
    - **become knowledgeable about FAS**
    - **seek support**
    - **join parent support group.**
-

## **NEED FOR FURTHER TRAINING**

- **further knowledge about FAS**
- **further details on providing care**
- **developing self-regulation**
- **attachment problems**
- **physical care**
- **educational support for child**
- **consideration of possible later problems at school, peers**
- **support to prevent 'burn-out'**

