

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

**(3 Hours)**

*MANUAL*

**Ministry of Children and Family Development**



## **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.

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## **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)**

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# 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

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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

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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

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**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

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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.

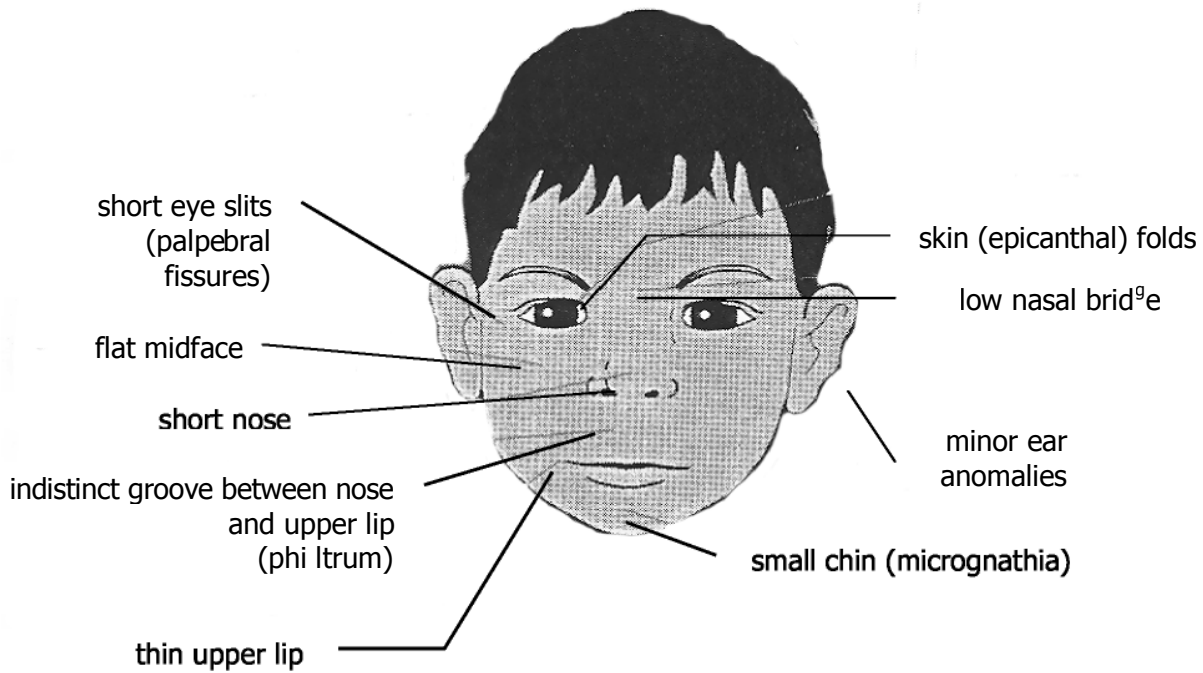
While a definitive diagnosis is valuable, the absence of a diagnosis should not deter caregivers from learning to respond effectively to the particular needs of the child in their care.

**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.

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**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

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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

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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.

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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

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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.

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