

FAS

**Parenting Children Affected
by Fetal Alcohol Syndrome**

A Guide for Daily Living

**Ministry for Children
and Families Edition**



BRITISH
COLUMBIA

Ministry for Children and Families



SOCIETY OF
SPECIAL
NEEDS
ADOPTIVE
PARENTS

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A previous edition of this book, edited by Rana Shaskin, was published by the Society of Special Needs Adoptive Parents (SNAP) in 1994.

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This special MCF edition is based on the second, national edition, revised and expanded, published by SNAP in 1998 in both official languages, in cooperation with the Adoption Council of Canada and with the support of Queen Alexandra Foundation for Children.

Copyright acknowledgements follow the Bibliography.

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Published by the Society of Special Needs Adoptive Parents in cooperation with the B.C. Ministry for Children and Families Child Protection Division.

ISBN0-9698617-5-3

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Introduction

The Society of Special Needs Adoptive Parents (SNAP), a non-profit, provincially-funded organization in British Columbia, produced the first edition of this booklet in 1994 in response to many requests from parents and professionals caring for children affected by Fetal Alcohol Syndrome (FAS) and other alcohol-related birth defects (ARBD, ARND). The first edition received an overwhelming response from the community.

In the four years since this book was first published, there have been significant advancements in the field. Research in the field continues, and although there is still a long way to go, awareness has been growing in society at large. In 1996, Health Canada issued a groundbreaking, joint statement on the prevention of FAS, co-signed by eighteen national associations representing medical, nursing and midwifery disciplines, aboriginal and multicultural groups, and other organizations known for their extensive work in the area of FAS and other alcohol-related birth defects. Meanwhile, south of the border, the United States Congress mandated the Institute of Medicine of the National Academy of Sciences to form an international committee to review FAS in response to confusion around terminology, diagnostic practices, and the disorder itself. A panel of fourteen experts in fields ranging from Pediatrics to Psychiatry—including Dr. Joanne Weinberg, Professor of Anatomy at the University of British Columbia—examined issues including those surrounding diagnostic categories and techniques, the prevalence of FAS and related disorders, and the availability of treatment programs for affected individuals. In 1996, based on the panel's recommendations, the Institute of Medicine published new terminology and diagnostic procedures for FAS.

In 1998, SNAP produced a new edition of the guide, to keep in step with the changing times and the latest terminology and diagnostic criteria. With research assistance from the Adoption Council of Canada (ACC) and the Canadian Centre on Substance Abuse (CCSA), the material in the first edition was expanded and updated. There are also new sections outlining special considerations for parenting infants and adolescents, as well as a section on parent's needs and caring for the caregiver—an important task that often gets overlooked when parenting children with special needs.

Many sources of information written by parents and professionals contributed to the contents of this publication. Their efforts to help children with FAS cope with special challenges are gratefully acknowledged.

The information in this booklet represents the latest, most up-to-date information at the time of publication. However, research and theories will continue to evolve, and you are encouraged to contact agencies such as SNAP, ACC, CCSA, and other resources for updates. *(Please see the Resource List at the end of this manual)*

*Sara Graefe, MFA
Publications Coordinator
Society of Special Needs Adoptive Parents
editor and principal writer
September 1999*

Foreword by Ross Dawson

I am pleased to provide you with the FAS Guide for Daily Living. Developed in partnership with the Society of Special Needs Adoptive Parents (SNAP), this guide book provides the most up to date and accurate information on Fetal Alcohol Syndrome.

Fetal Alcohol Syndrome (FAS) is the leading cause of preventable birth defects. Consistent and accurate information on FAS is essential in prevention, recognition and intervention of FAS. Caregivers and others working with children with FAS will find valuable information in this guide including how to obtain assessments and referrals and where to find supports for children and families affected by FAS. Further information on resources available to social workers, foster parents and parents are included at the back of the booklet.

I hope you will find this guide useful in your work with children and families affected by FAS.

*Ross Dawson
Director of Child Protection
Ministry for Children and Families*

Foreword by Dr. Conry

In 1994, the Society of Special Needs Adoptive Parents published the first edition of *Parenting Children Affected by Fetal Alcohol Syndrome: A Guide for Daily Living*. Over 5,000 copies of this manual have been distributed across Canada and the United States which points to the tremendous interest and need for information about this life-long disability. Requests for this guide have come from parents, teachers, social workers, doctors and other interested professionals.

In British Columbia, the Society of Special Needs Adoptive Parents has been instrumental in increasing our understanding of FAS/FAE by supporting workshops, disseminating information and making resources available to the parents of these children.

In 1996, the first comprehensive long-term follow-up into adolescence and adulthood of individuals with a diagnosis of FAS/FAE was published by the University of Washington (“Understanding the Occurrence of Secondary Disabilities in Clients with FAS and FAE”). The anecdotal stories we had been hearing from families raising a child with FAS/FAE were borne out by the research. Many individuals with FAS/FAE, but not all, are prone to mental health problems, disrupted school experiences, trouble with the law, alcohol and drug problems and difficulties living independently in adulthood. On the positive side, the factors protecting the child from this outcome include—not surprisingly—a nurturing, stable home environment and an early diagnosis so that interventions can be put in place at an early age. This is where the advocacy by determined individuals and organizations such as SNAP have played such an important role in reducing the impact of FAS/FAE and improving the outcomes for families having children affected by this disability.

Complex problems such as FAS/FAE do not have simple and quick solutions. There is no single “right” way to parent a child with FAS/FAE. Each child is unique. Nor do we need to “reinvent the wheel” in devising techniques to teach a child with FAS/FAE. By recognizing each child’s particular strengths and weaknesses, it becomes possible to devise ways of teaching and parenting that will allow him/her to be successful. We recognize now that this is a life-long effort and success is measured in small increments. Support for children, their families and communities begins with knowledge and understanding of this invisible disability.

*Dr. Julianne Conry, PhD
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July, 1998*

What is FAS?

Definitions and Facts

Learning about Fetal Alcohol Syndrome and then applying it to our son was quite a task. It reminded me of one of those “Choose Your Own Adventure” books I often read to Luke. You thought you knew where the journey was taking you and then they threw in three or four different paths and endings. I thought I knew my boy and I did... but I grew to know him better when I understood the diagnosis of FAS.

—Luke’s Mom

Alcohol and Pregnancy

When a pregnant woman consumes alcohol, she does not drink alone. Alcohol is a known teratogen, which means it is a substance that can damage and disrupt the developing embryo and fetus. The brain and central nervous system of the unborn child are particularly sensitive to prenatal alcohol exposure (Health Canada, 1996; Streissguth, 1997).

What is FAS?

Fetal Alcohol Syndrome (FAS) 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** (Stratton, Howe, & Battaglia, 1996).

FAS is a medical diagnosis that can only be made when a child has signs of abnormalities in each of these three areas, plus known or suspected exposure to alcohol prenatally. Other physical defects caused by prenatal exposure to alcohol may include malformation of major organs (including heart, kidneys, liver) and other parts of the body (e.g. muscles, genitals, bones) (Stratton, Howe, & Battaglia, 1996).

FAS is often called a “hidden” or “invisible” disability because its physical characteristics can be subtle and may go unrecognized. Many alcohol-affected children are endearing and affectionate, and these qualities can mask the seriousness of this lifelong neurological disability. In their early years, children with FAS are often described as the cutest child in their class.

FAS Diagnostic Categories

Fetal Alcohol Syndrome (FAS) was first defined over twenty years ago. Since then, researchers and clinicians have encountered some confusion and clinical problems arising from certain terminology used to describe the spectrum of effects caused by exposure to alcohol in the womb (Clarren, 1996; Stratton, Howe, & Battaglia, 1996; Streissguth, 1997).

The United States government recently recognized the need to establish clear, consistent diagnostic criteria that more accurately reflects the range of disorders caused by prenatal exposure to alcohol. In 1996, the US Institute of Medicine (IOM) published new diagnostic procedures for FAS, based on the recommendations of a panel of experts from Canada and the USA.

In the past, a diagnosis of FAS required confirmation of the mother's alcohol use during pregnancy, to make the distinction between FAS and other syndromes and conditions that look very much like it. However, in the presence of clear features of FAS and the strong suspicion of prenatal alcohol exposure, an experienced clinician may make a diagnosis of FAS in one of three distinct categories.

The following is a brief introduction to the new terms. For full diagnostic criteria, please see Appendix on page A-1, or refer to the IOM text *Fetal Alcohol Syndrome: Diagnosis, Epidemiology, Prevention and Treatment* (Eds. Stratton, Howe, & Battaglia), published in 1996 by the National Academy of Sciences (*see Bibliography, page 70*).

1. FAS with Confirmed Maternal Alcohol Exposure

A diagnosis is made in this category when there is known, significant prenatal exposure to alcohol and the child exhibits three characteristics:

- i. growth retardation (i.e. delayed prenatal and / or post-natal growth)*
This delay must result in height and/or weight very much below normal—below the tenth percentile.
- ii. central nervous system involvement*
This can result in one or more of the following conditions being observed in the child: head circumference below the third percentile, developmental delay or intellectual disabilities, and/or other less prevalent conditions.
- iii. characteristic facial features*
These include short eye slits, elongated mid-face, thin upper lip and flattened facial bone structure. These features are most noticeable during early childhood. (*See diagram on page 5*)

2. FAS without Confirmed Alcohol Exposure

This category is assigned to a child who has the necessary characteristics for a clear diagnosis of FAS, as above, but where there is no way to accurately verify the mother's alcohol use. This new diagnostic category (1996) is helpful for the many children with FAS in foster and adoptive homes, where details about their prenatal histories may be unavailable.

3. Partial FAS with Confirmed Maternal Alcohol Exposure

This applies to a child with a confirmed history of prenatal alcohol exposure who has some, but not all, of the characteristics of FAS. The child does not display all of the characteristic facial features, but exhibits other signs such as growth deficiency, damage to the central nervous system, and/or a complex pattern of behaviour and cognitive abnormalities inconsistent with developmental level and cannot be explained by family background or environment alone. *Partial* does not mean that the condition is less severe than FAS. In fact, Partial FAS can have equally serious implications for education, social functioning and voca-

tional success.

Many children diagnosed as Partial FAS would have been designated **F****A****E** (“**F****e****t****a****l** **A****l****c****o****h****o****l** **E****f****f****e****c****t**”) under the old system. This new category, like FAE, still requires knowledge of the child’s pre-natal history, which is not always available in adoption situations. However, because children with Partial FAS do not exhibit all of the distinguishing characteristic facial features of full-blown FAS, the birth mother’s drinking history becomes a crucial piece of the puzzle from a medical point of view—a piece needed to rule out other medical conditions that may be present. Nevertheless, the lack of a definitive diagnosis can be frustrating for adoptive parents whose children are exhibiting troubling behaviours.

The Institute of Medicine has included two additional categories which are used to describe very specific outcomes of prenatal alcohol exposure:

4. Alcohol-Related Birth Defects (ARBD)

This refers to a child who displays specific physical malformations resulting from confirmed maternal alcohol exposure. These may include heart, skeletal, sight, hearing and visual problems.

5. Alcohol-Related Neurodevelopmental Disorder (ARND)

This applies to a child with a confirmed history of prenatal alcohol exposure who exhibits central nervous system damage as in FAS, inconsistent with developmental level and cannot be explained by family background or environment alone (e.g. learning difficulties, poor impulse control, poor social skills, problems with memory, attention and judgement). As children with disabilities due to prenatal alcohol exposure frequently come from environments where there has been neglect and/or abuse, it can be difficult or impossible to separate which problems are due to alcohol effects and which can be explained by the family living situation. Usually there is a combined effect.

Other Terms

You may still encounter older terms relating to FAS. Previously, the term *Fetal Alcohol Effects (FAE)* was used to describe an individual with a history of prenatal alcohol exposure, but not manifesting all the physical or behavioural symptoms of FAS (Streissguth, 1997). *Possible Fetal Alcohol Effects (PFAE)* was an equivalent clinical term (Astley & Clarren, 1995; Streissguth, 1997).

However, these terms were sometimes misinterpreted as meaning that FAE was less severe than FAS. While a child designated FAE does not have all the physical abnormalities of FAS, the cognitive and behavioural characteristics are similar. As a result, FAE poses similar life-time challenges (Astley & Clarren, 1995; Clarren, 1996; Streissguth, 1997).

Clinicians and researchers discourage the use of FAE and PFAE because of these misunder-

standings, as well as other clinical problems the terms create. Further, FAE and PFAE are no longer used in formal diagnostic procedures. With the gradual introduction of the new Institute of Medicine Criteria in clinical practice, the terms Partial FAS, ARBD and ARND will come into more common usage. Some professionals suggest that better terminology is still needed, and that these new definitions may evolve over time (Clarren, 1996).

Please note that this booklet only uses the term FAE if it was included in the original source being cited, or in the name or description provided by an agency or organization. Terminology aside, it is important not to minimize the impact of any alcohol-related birth defect.

For more information on diagnosis, please see the section on Assessment and Referral Information, page 48.

Figure one

Facial Characteristics

Did you know?

A Few Facts...

Then...we saw a news clip about FAS/E on TV. Shortly after we read The Broken Cord and the missing pieces began to come together. With the discovery of the probable cause of the behaviours of our children, came relief followed by stages of grief. The questions that periodically haunt me about these times are: "Why did we have to find such vital information through the media? Where were the teachers, social workers and doctors? Why didn't they share this knowledge with us?"

—adoptive parent

- √ FAS is **100% preventable**.
- √ It is one of the **leading causes** of **preventable birth defects** and **developmental delay** in Canada and most countries of the world. It is also one of the **leading known causes** of **mental retardation**, although not all persons with FAS are mentally retarded.
- √ FAS leads to problems with **learning, behaviour, and community living**.
- √ It is found in **all economic and racial groups**.
- √ Health Canada (1996), based on incidence rates found in the United States, estimates that there are **one to two per 1000 children** born with FAS in Canada.
- √ FAS is **not genetic** or **inherited**. A woman who has FAS can give birth to unaffected children.
- √ FAS is more likely to occur following **continuous** or **heavy intake** of alcohol during pregnancy. However, some women who binge or drink sparingly have babies with alcohol-related damage. There is **no definitive information regarding a safe quantity of alcohol use** during pregnancy. *Health Canada (1996) advises women who are or may become pregnant to abstain from alcohol.*
- √ FAS prevention is **not just a women's issue**. Many pregnant women need support from their partners, extended family members and community in order to abstain from alcohol. The role of paternal alcohol consumption is unclear. While the term FAS describes the damage to the fetus caused by maternal alcohol exposure, recent research also suggests that a father's use of alcohol may cause damage to the sperm. *The US Institute of Medicine (1996) indicates that further research is required to clarify this issue. Since it is not yet known whether this damage affects a fetus, it is advisable for men to abstain from alcohol when planning or risking a pregnancy.*

Children with FAS

Common Manifestations

*I wish I could repair myself;
I wish people didn't throw me on the shelf.
I wish people wouldn't use me soooo much,
I wish people would take advantage of how precious I am.
And...I wish they wouldn't use too much touch.*
—Nigel, age 16: “This refers to FAS/E people
as well as to electrical appliances.”

No two children with FAS are affected in exactly the same way. However, as a group, children with FAS display more developmental and behavioural problems than other children. The child with FAS may exhibit a number of the characteristics described here, but likely not all of them. The clustering of these characteristics and behaviour patterns coupled with the history of pre-natal exposure to alcohol are strong cues for identification.

Parents who identify reasons for their children's problems are best equipped to plan effective treatment and education strategies. The following is not an exhaustive list of FAS characteristics, but rather a place to start. However, an *accurate diagnosis is important*. There are other disorders that have similar characteristics. *Parents are advised to consult with a physician, pediatrician, pediatric neurologist, dysmorphologist or geneticist who has experience with FAS—or a willingness to learn. For more information about diagnosis, please see the section on Assessment and Referral Information on page 48 of this manual.*

This list has been compiled from a number of sources and represents items common to several reference sources. Please refer to the bibliography and resource list at the back of this manual for further reading.

Infancy

When dealing with infants, you might also encounter the term, “Neonatal Abstinence Syndrome (NAS), which refers to infants suffering through drug withdrawal after birth. We recognize that many women are multiple drug users, and that the mother of a baby with NAS has likely been using alcohol as well. Affected infants may exhibit a combination of lasting NAS symptoms and emerging FAS symptoms.

- often tremulous and irritable; may cry a lot
 - weak sucking reflex and muscle tone
 - highly susceptible to illness
 - feeding difficulties: often disinterested in food, feeding can take hours
 - erratic sleep patterns; no predictable sleep-awake cycle
-

- sensitive to sights, sounds, and touch
- failure to thrive
- slow to master developmental milestones (e.g. walking, talking, imitating sounds)
- problems with bonding

Preschool

- disinterest in food and disrupted sleep continue
- poor motor coordination
- flits from one thing to another with “butterfly-like” movements
- more interested in people than objects
- overly friendly, highly social; indiscriminate with relationships
- expressive speech may be delayed; may have less in depth language than peers *or* may be excessively talkative and intrusive, giving the superficial appearance that speech is not impaired
- unable to comprehend danger; does not respond well to verbal warnings
- prone to temper tantrums and non-compliance
- short attention span
- easily distractible or hyperactive
- does not respond well to changes; prefers routines

Early School

- reading and writing skills during the first two years may not be noticeably delayed
 - arithmetic may be more of a problem than spelling and reading
 - attention deficits and poor impulse control become more apparent as the demands for classroom attention increase
 - inability to transfer learning from one situation to another—to learn from experience—without more repetition than normal
 - requires constant reminder for basic activities at home and school
 - “*Flow through*” phenomena—information is learned, retained for a while and then lost; poor performance of “learned” tasks may appear deliberate
-

- gross motor control problems (e.g. clumsy)
- fine motor problems (e.g. trouble with handwriting, buttons, zippers, shoe laces, etc.)
- difficulties with social skills and interpersonal relationships: may be unable to share, to wait for turn, to follow the rules or to cooperate; may be inappropriately intrusive
- poor peer relations and social isolation may be noted; may prefer to play with younger children or adults rather than with peer group
- memory deficits
- exists in the “here and now,” seems to lack an internal time clock
- unable to monitor his/her own work or pace him/herself
- sleep disturbances continue

Middle School

- delayed physical and cognitive development
- reading and spelling skills usually reach peak
- increased difficulty maintaining attention, completing assignments and mastering new academic skills
- usually a very concrete thinker, may have trouble working with ideas—tends to fall farther behind peers as the world becomes increasingly abstract and concept based
- continuing fine motor problems may make volume work production impossible
- good verbal skills, superficially friendly social manner and good intentions often mask the seriousness of the problem
- psychological evaluation and remedial placement may be necessary
- a pattern of school suspensions may start

Adolescence

- increased truancy, school refusals and school dropouts
- increased behavioural disruption in school
- reading comprehension is poorer than word recognition
- math tends to be the most difficult task, suggesting poor memory, poor abstract thinking, and difficulty with basic problem solving

- may be able to “talk the talk” while unable to “walk the walk”—for example, they may tell you they understand your instructions, but are unable to carry them out. They may have learned to *act* as though they understand, but cannot follow through on their own.
- often misjudged as being lazy, stubborn and unwilling to learn
- faulty logic; lacks basic types of critical thinking and judgement skills
- increased problems with abstract thinking and the ability to link cause and effect
- impulsive, total lack of inhibition and easily influenced, subject to peer manipulation and exploitation
- difficulty showing remorse or taking responsibility for actions
- frequently behaves in ways that place him/herself or others at risk
- high risk for problems with the law and involvement in the criminal justice system
- problems managing time and money
- difficulty identifying and labelling feelings
- low motivation
- low self-esteem
- clinical depression may become evident

Adulthood (18+)

- perseverates with ideas or activities, may appear compulsive and rigid
 - difficulty holding down jobs
 - may be unable to live independently or parent children
 - problems managing money
 - poor social skills
 - lack of reciprocal relationships
 - unpredictable behaviour
 - depression/suicidal ideation
 - withdrawal and isolation
 - drug or alcohol abuse; susceptible to chemical dependency
-

Additional Behavioural Characteristics and Secondary Disabilities

*The frequently disabling characteristics of FAS often cause secondary disabilities—problems that arise **after** birth as a result of the neurological deficits. These secondary conditions come at a high cost to the individual, their family, and society, but may be reduced by early diagnosis, appropriate intervention, better understanding, and a stable, nurturing home environment.*

Additional behavioural characteristics and secondary disabilities that may be associated with FAS include the following:

- behavioural deficits reported in many areas, including interpersonal relationships, communication, daily living skills, sexuality and adaptive skills
- communication deficits, including the inability to listen to a story for five minutes or longer, to relate to an experience, to use a table of contents or to address an envelope
- problems with social skills include:
 - talking too much and too quickly, but having little to say
 - liking to be the centre of attention
 - outgoing and friendly manner, often seen as positive in early childhood, often becomes problematic as the child grows older because they are indiscriminate and/or overly intrusive;
 - impulsiveness, lack of inhibition, and naiveté regardless of age and gender
 - difficulty telling time, knowing the value of money, and interpreting social cues
 - problems sequencing tasks or instructions
 - low tolerance for frustration
 - difficulty distinguishing fantasy from real life
 - tending to gravitate to young children or adults rather than people their own age
- depression
- anger and aggression
- low self-esteem
- other mental health problems
- school problems and/or disrupted school experience
- running away
- substance abuse
- inappropriate sexual behaviour
- trouble with the law
- dependent living

- problems with employment
- violent or threatening behaviour

Overlapping Diagnoses

Disabling characteristics of FAS may also be compounded by “overlapping diagnoses,” meaning that the child has been diagnosed with other conditions as well as FAS. Accurate identification is important for developing an appropriate intervention and treatment plan.

Common overlapping psychiatric diagnoses include:

- Attention Deficit Disorder (ADD)/Attention Deficit Hyperactivity Disorder (ADHD)
- Attachment Disorder
- Autism
- Oppositional Defiant Disorder
- Conduct Disorder

Positive Characteristics

Characteristic features or behaviours associated with FAS may also serve as strengths. It is important to recognize and reinforce these strengths so that they don't wane. Some positives may include the following:

- creative intelligence (e.g. artistic, musical)
- perseverance (determined, persistent, willing, committed hard workers, involved, energetic)
- highly moral, deep sense of fairness, rigid belief systems
- strong sense of self
- friendly, trusting
- loyal, loving
- affectionate, compassionate, gentle
- tactile, cuddly
- concerned, sensitive
- love children, animals, nurturing—devoted partners and parents
- highly verbal

- exceptionally good long term visual memory
- spontaneous, have lots of energy
- curious and questioning, have sense of wonder
- rich fantasy life (poets, writers, wonderful story tellers)
- great sense of humour

Myths Myths

Common Misconceptions

*Our lives would have been
So much less complicated
If all those born with A.R.B.D.
(Alcohol Related Birth Defects,)
Were also born with F.B.H.
(Flourescent Blue Hair.)
—Leon's Mom*

Dr. Ann Streissguth (1997) identifies seven common myths surrounding FAS—based on more than twenty years of work in the field—which she shares with us here:

There are several widespread misconceptions that can be detrimental to understanding the complicated life circumstances of individuals with FAS/FAE and responding appropriately to their needs. Before people can effectively help these individuals, they must understand the true nature of their disability. The following seven statements that are frequently assumed to be true are, in fact, common misconceptions:

1. Myth: People with FAS/FAE always have mental retardation.

Although it is true that FAS/FAE is caused by prenatal brain damage and every person with FAS/FAE has specific, individualized cognitive strengths and weaknesses, not all people with FAS/FAE have mental retardation. For example, as one study (Streissguth, Barr, Kogan, & Bookstein, 1996) found, only 25% of 178 individuals with the full FAS were classified as having mental retardation by an IQ score below 70. In fact, it is possible for an individual with FAS/FAE to have an IQ score within the normal range. FAS/FAE diagnostic centers such as the one at the University of Washington Medical School, see individuals with broad spectrum of IQ scores. Only the most severely affected children—those with clear microcephaly and other physical malformations—are easily detected at birth.

2. MYTH: The behavior problems associated with FAS/FAE are the result of poor parenting or a bad environment.

Because people with FAS/FAE are born with some brain damage, they do not process information in the same way as most people and do not always behave in a manner that others expect them to. This brain damage, in fact, can permeate even the best environments to cause behaviour problems and present parenting challenges. Parents and caregivers need help and support, not criticism. Of course, a loving and understanding environment helps a child with FAS/FAE. But its absence isn't the primary cause of the disability.

3. MYTH: Admitting that children with FAS/FAE have brain damage means that society has given up on them.

Some people believe that acknowledging the brain damage that accompanies FAS/FAE will depict these individuals as hopeless and devoid of treatment options. Yet, society spends millions of dollars developing treatment procedures for children born with more obvious

birth defects and for people sustaining brain damage in more noticeable ways (e.g. auto accidents). As of 1997, the research to understand and ameliorate the specific neuropsychological and cognitive impairments associated with FAS/FAE has not yet been conducted. These individuals are in no way hopeless, but their needs have been sadly overlooked in the allocation of societal resources.

4. MYTH: Children eventually outgrow FAS/FAE.

FAS/FAE lasts a lifetime, although its manifestations and associated complications vary with age. Children with brain damage (including those with FAS/FAE) usually require a longer period of sheltered living, and many need a stronger than usual support system to achieve their best level of adaptive living. Understanding this can help families plan effectively for structured transitions between school and work and can help them spare their children with FAS/FAE the expectation that they should be or must be independent at age 18 or that it is shameful to ask for help.

5. MYTH: Diagnosing children with FAS/FAE will thwart their development.

Diagnosing is the art or act of recognizing a disease from its symptoms. At a practical level, it is a method of grouping people with some common characteristics together so others like them can be identified, the cause can be identified, and treatments can be provided. The problem is not the diagnosis, but the current lack of scientific knowledge about how to treat the disease. An accurate diagnosis does not thwart development in any way whatsoever; it simply alters unrealistic expectations. Most individuals who are diagnosed, and their families, actually feel a sense of relief.

6. MYTH: It is useless to diagnose FAS/FAE because there is no "real" treatment approach.

This attitude isn't taken toward any other incurable diseases (e.g., childhood autism). Why should it be invoked for FAS/FAE? Any family is in a better position to raise a child once members know the child's diagnosis. Once an individual is diagnosed with FAS/FAE, family members and social services workers can customize developmental approaches and goals to ensure that the individual reaches his or her personal potential. A diagnosis helps everyone to understand behaviors that would otherwise be incomprehensible and helps families explain these behaviors to others and to respond more appropriately themselves. A diagnosis helps families build networks of support with others experienced with FAS/FAE. Parents and the individuals themselves need diagnostic information in order to behave rationally and respond realistically. In addition, when no treatment is known, then the acknowledgment of people with this diagnosis motivates the development of appropriate treatments and remediations. Diagnosis provides visibility, and visibility prompts solutions.

7. MYTH: People with FAS/FAE are unmotivated and uncaring, always missing appointments or acting in ways that society considers irresponsible or inappropriate.

People with FAS/FAE usually care tremendously about pleasing others and want desperately to be accepted, but their basic organic problems with memory, distractibility, processing information and being overwhelmed by stimulation all work against their desires. They simply have difficulty understanding the meaning and interrelationships of a complex world

that complicate their daily lives. In addition, the repeated experience of failing to meet expectations can generate a general reluctance to meet challenges, even in someone with the best intentions. Some people with FAS/FAE are now learning strategies and techniques for working around these problems.

Brain wiring

Information Processing

*I am a brain cramp, never thinking of the right subject at the right time.
It seems like my brain goes on screen saver
or my input device has put a virus in my brain
to clear my memory of my train of thought
and needs a jolt to snap out of it.
But my brain is always chugging away.*

—Ken, age 17

FAS significantly impairs information processing. This is one of the most devastating characteristics of FAS, since our ability to process information impacts so many areas of our day-to-day lives.

FAS affects at least four important components of information processing (adapted from Morse, 1993):

1. Cause and effect

the ability to translate information into appropriate action, or judge the link between action and consequence

2. Generalization

the ability to take information learned from one situation and apply it to another

3. Sorting, classification, inference and abstraction

the ability to perceive and understand similarities and differences in people, places, things and events.

4. Prioritization, prediction, production and sequencing

the ability to assess a situation, request direction, or identify similar circumstances and take appropriate step-by-step action.

The Effect

FAS involves a serious information processing deficit.

The brain link between understanding the information supplied (*request*) and performing the action required (*response*) is defective.

An individual with FAS has difficulty translating knowledge learned from one situation into another. For the FAS child, a similar situation is new and may bear no resemblance to anything which s/he may have previously experienced. Previous rules do not necessarily apply in the new situation.

Asking a child with FAS to repeat instructions does not ensure compliance or understanding, but asking them to demonstrate or to explain in their own words will help to ensure understanding.

Developmental delays become more obvious with age, as the gap widens between the alcohol-affected child and their age-peers.

The problems are *neurologically-based*, caused by damage to the developing brain. Affected children often have behavioural and emotional problems—secondary disabilities. A good environment may reduce the impact of the neurological damage.

Structure, Supervision, Simplicity, Steps and Context

The FAS/FAE child is not a hopeless case, he/she is simply a nowhere child, never quite fitting into any setting.... There needs to be radical changes in our classroom structures and attitudes if we are to give these children a chance to develop and maximize their unique potential.

—Maureen Murphy

Taking these information processing deficits into account, clinicians and educators who have worked with children affected by FAS stress the importance of the following factors, “The 4 S’s + C,” as described by Maureen Murphy (1991):

Structure

Create a structured environment for children with FAS which includes choices within clear and predictable routines.

Supervision

Carefully supervise children with FAS so that they do not get into trouble or place themselves in dangerous situations.

Simplicity

Offer simple directions and orders, stated briefly in simple language that you know the child understands, rather than the elaborate verbal justifications and explanations often given by parents and teachers.

Steps

Break down tasks into small steps and teach each step through repetition and reward.

Context

Teach skills in the context in which the skills are to be used, rather than assuming children will generalize from one context to another or understand in which situations the behaviour is appropriate and when it is not.

A place to start

Parenting Suggestions

If you've told a child a thousand times and he still does not understand, then it is not the child who is a slow learner.

—Walter Barbee

It is important to remember that all children, alcohol affected or not, are first and foremost individuals with distinct personalities, preferences, and temperaments. Parenting tips which may work wonders with one child may prove inappropriate and ineffective for another.

The following section offers suggestions for parenting a child with FAS which have been effective for some children. Based on the input of many parents and professionals, these strategies focus on effective communication and positive parenting.

Please note that this is *not* a definitive list which will always lead to good communication and daily living skills. *Remember that you are the expert on your own child.* You likely know which parenting techniques may or may not work with your child. Keeping individual differences in mind, we invite you to adapt the ideas to suit your children.

Effective Communication

Offer simple directions. Break down tasks into small steps and teach each through repetition and concrete reward.

- Begin all conversations with the child's name and make eye contact.
- Be specific when telling the child what to do, such as “*sit on that chair*” rather than “*get out of the kitchen,*” and “*hang your coat on the hanger in the closet*” rather than “*put your coat away,*” etc.
- Realize that many words or expressions have more than one meaning and teach these meanings. Children with FAS may be very literal in their understanding.
- Use the same words to express directions for daily routines, such as “*brush your teeth*” rather than “*clean your teeth*” or “*get your teeth done.*”
- Be brief and keep directions short. The child may have a short attention span, even though they may appear to be listening. Multi-step directions should be given gradually and only as the child exhibits the ability to follow more complex directions. There is no definite time-line as to when this may occur. For some children, understanding multiple directions may remain a problem throughout their life.
- Give the FAS child separate instructions using their name. The child may not realize that s/he is to follow group-directed instructions.

- Speak slowly and pause between sentences to allow for processing. Auditory processing may lag behind rate of speech. Repeat and restructure information as needed.
- When the child needs to focus on a task or listen to you, you may need to keep the environment as free from the distractions as possible (i.e. TV, radios, video games, other people, etc.) An F/M transmitter/receiver (known as a body pack hearing aid) is very useful for screening out distracting noise at school.
- Lists for older children that give step-by-step simple instructions on how to do things can be a useful lifeskill for both common and unexpected situations. Teach the child how to use a list and practice with role-play and simulation games.
- If the child does not know what to do next, jog their memory. Tell, demonstrate, show and then find a visual way to tap into their memory. If the child cannot remember, remind them and move on.
- Gentle reminders help produce a positive attitude.
- Link one task with another to help establish sequences (e.g. *dinner comes after homework; the bus comes after breakfast; story time comes after the bath.*)
- Use expressive gestures when talking. Try varying loudness, inflection, tone, coupled with hand signals.
- Use as many visual cues as possible to trigger memory and to aid comprehension. Be specific when labelling inappropriate behaviour (e.g. *“John doesn’t kick”* with an exaggerated shaking of the head) and include visual cues to emphasize the desired action.
- Touch can be useful for teaching appropriate social distance from others. (e.g. place your hand straight on the child’s shoulder and say *“This is where we stand when we stand to talk.”*)
- Teach the child a visual or verbal cue to help them understand it is time to begin the task. For example, you might end instructions with the word *“now.”* Use exaggerated facial and body language. Use hand signals for behaviour cues with language.
- Help the child interpret social and behavioural cues of others. (e.g. *“That person looks happy because...”*) Encourage the child to self monitor and to recognize context, social cues (i.e. facial expressions, tone of voice, posture, etc.) and their own feeling state. Model these skills (e.g. *“How do you think you are (I am) doing right now? Things are getting wild. You (I) need to slow down and take ten deep breaths while doing nothing.”*)
- Help the child to express their emotions in acceptable ways.
- Encourage the use of positive self talk: *“I can do this!” “I need to pay attention.” “I’m smart!” “I can figure this out!”*
- Help the child develop skills for safe expression of feelings through use of metaphor, art, play, and anger management strategies to provide a bridge to verbalizing issues.

Consequences and Positive Feedback

Processing deficits may make it difficult for the child to connect consequences and feedback to their behaviour. Creating structure in expectations and consequences will aid the child in predicting outcomes and feeling secure in their environment. FAS children may disobey instructions due to lack of comprehension, memory impairment, or—like any child—wilful disobedience. Ask yourself if the child’s misbehaviour is due to lack of comprehension or wilful lack of compliance. Recognize your child’s unique strengths and weaknesses, build on their abilities and interests, and set realistic goals for performance. (for more on structure, see pages 19 and 24)

- Often children with language disabilities have difficulty with “*why*”-type questions. Help them learn this format by using alternate forms such as “what is the reason?” or “what caused this to happen?”, or restating as *who, what, where, how* and *show me* to invite input.
- Spend time discussing cause and effect relationships. Be patient with their delayed ability to learn this relationship.
- Tell the child what *to* do, not just what not to do. Letting children know what to do gives them a direction to take the behaviour and focuses on the positives while defusing the negatives (e.g. “*Chris, put your feet on the floor, not on the table.*”)
- Encourage the child to “help” as a valued member of the family.
- Give immediate rewards or consequences and remind the child what the consequence is for. Parents of children with FAS often notice that rewards lose their effectiveness, and are constantly searching for new ways to motivate behaviour. For some children, stars and stickers on a chart work well, while for others time on the computer or videos are effective. Older children often accept the “cost” for the behaviour (e.g. *no telephone privileges or being grounded for breaking curfew*) as worth it. The goal may simply become keeping the child out of harm’s way.
- Be firm. Set clear, consistent limits. Don’t debate or argue over rules. Post family rules in simple words and/or with pictures.
- Separate the child from the behaviour. The action may be “*bad*,” but the child must never feel that s/he is a “*bad*” person.
- When removing a child from a situation to diffuse and calm down, once again separate the child (not a bad child) from the inappropriate behaviour (e.g. “*Your behaviour tells me you need a time-out.*”) Always return to the child when calm and reinforce that s/he is a good person.
- Do not make threats that you cannot carry out. These children may take you literally. Also, the child learns that there is no consequence when the threat is not carried out.
- Be very specific with praise and criticism. (e.g. “*Joey, good sitting*” or “*Susie, good listening*” with a smile and a touch rather than simply “*Good boy/girl.*”)

- Intervene before inappropriate behaviour escalates (this is a difficult thing to do—the caregiver must be tuned into the child’s feeling state and behavioural cues *all the time*.)
- Designate a place for “quiet time” when the child feels overwhelmed. Encourage the child to choose a place where s/he will feel comfortable and secure.
- Give the child positive acknowledgement and regard for just being themselves—as well as for desirable behaviour.

Transitions... Things Change

Changes in a child’s life, such as moving or starting school, can be traumatic. Children with FAS may also experience difficulty in the simple changes that occur every day, such as moving from one activity to another. This may even be the case when the child is being asked to change their focus from a less pleasant task to a more pleasant one.

For the major changes:

- Develop “hello” and “farewell” rituals between you and your child.
- Use photographs of actual people, places, and important things to prepare a child for such events as moving to a new home, going to the dentist/doctor, going to the hospital or going to a new school.
- The absence of a family member can be upsetting to the child. Use photographs of the person and the place where they will be to explain their absence.
- If a child must move to a new foster or adoptive home, or is even attending a sleep-over, try to keep the child’s daily routines as normal as possible. Consistency and routine will minimize negative impact.
- Acknowledge the child’s fears about abandonment and other separation issues. Be as reassuring as you can while still being realistic. Help them work through separation issues in advance of an impending move.

For more minor changes:

- Establish routines so that your child can predict coming events.
- Offer structured, limited choices and encourage decision making. Help the child shape their environment.
- Teach the child a visual or verbal cue to help them understand it is time to begin the task.
- Egg timers are a useful way to clearly define the length of an activity.
- Give the child advance warning that an activity will be over soon.
- Prepare the child for school the night before and allow the child to direct as much of this activity as possible. For example, in planning what to wear, offer some limited and structured choices.

Structure and Routines

Build security into the child's day by maintaining consistency. Create a structured environment for children with FAS which includes choices within clear and predictable routines.

- Write down or diagram what needs to be done for the completion of a task. For example, you might post photographs of the child engaged in each step of an activity such as brushing teeth.
- Break down daily activities into specific steps—plan mini-routines within the larger routine. Do everything in the same way and in the same order every day (e.g. wake the child in the same predictable way each morning.) This may help the child become more comfortable moving between activities, and able to operate more independently.
- Encourage imitation of daily activities through representational play.
- Avoid situations where the child will be overstimulated by people, sound, light or movement.
- Have a place for everything and everything in its place. Allow only one item out at one time if the child is overwhelmed by excessive stimulation. Storing things together by a system (e.g. *by type, size, colour, etc.*) may assist the child in developing independence within their own environment. For example, if all the blocks are stored together, the child may learn where to go get them without your assistance.
- Place labels on the outside of drawers, cupboards, shelves, and so on. Use single words or pictures to indicate contents.
- If the child has difficulty understanding boundaries and private spaces, such as shared bedrooms, marking off areas with masking tape may be helpful.
- Create a homework corner in a quiet place. Have the minimal but necessary “tools of the trade” there at all times. Use creative language to name this separate, personal space (e.g. the child's “*office,*” “*workshop,*” “*private library,*” etc.)
- Alternate active times with relaxation.
- Help your child to meet children who will be positive role models.

Supervision

Alcohol-affected children may need careful supervision so that they do not get into trouble or place themselves in dangerous situations.

- Remember that it is impossible to be everywhere all the time and that structures in the environment can help support supervision.
- Because children with FAS have trouble understanding the link between behaviour and consequences, they are typically the child in the group who gets caught, even though they may not have been the child who initiated or carried out the action.

- Given that you too must sleep, keeping the child's bedroom fairly sparse can minimize the potential for disaster! For the child who wanders at night, an alarm on the bedroom door may be necessary.
- If the child approaches strangers, deal with it immediately in front of the stranger (e.g. *"This is a stranger, this is someone we do not know. We do not talk to people we do not know."*) This may be difficult and embarrassing, but essential for reinforcing the concept.

Advocacy

The ability to work effectively with schools, doctors and support workers may be challenging but is critical. As a parent, you are likely the best advocate for your own child. Expand your advocacy skills. Look for advocacy resources and workshops in your own community, and check your local library for books on self-advocacy.

- Continue learning about FAS. Search out magazines, books, newsletters, movies and tapes for information and support. Attend workshops and conferences. Share your information with professionals involved in your child's life. (see the Resource List on page 55 of this manual for some ideas and a place to start.)
- Work beyond the label. Remind yourself and others that a diagnosis of FAS should not be used to label limitations. Each child has different potential. The goal is to facilitate their development so that their fullest potential is realized.
- Recognize that FAS is a relatively new area, and that it will take time for a formal "system" to develop to help affected individuals and their families. Find people who share an interest in the area to work with you and help you through the existing system.
- Join a support group and share your information. Parents in some communities have started FAS-focused self-help groups. Other parents have found much comfort and support in groups for parents/adopted parents of special needs or high risk children. Check your local community resource directory or self-help resource association for listings of groups in your area.
- Find a child advocate if necessary, someone who will champion your cause within a system—be it the school system, the legal system, the medical system or social services. There are formal child advocates within the system, such as the Child, Youth and Family Advocate for the Province of British Columbia, as well as outside help, such as community advocacy groups. You can also tap into the support of an "informal" advocate—such as the friend who walks into the principal's office at your side when you lobby for better supports for your child at school.
- Become active in efforts to shape legislation and support research endeavours.
- Make sure you get support for yourself! (see section on Parents Needs, page 45)

Day to day basics

Guidelines for Daily Living

*We're the mothers who are "different,"
Special Needs Adoptive Parents.
—And the uninformed will find us
As peculiar as our children
Who are daily being challenged
With birth defects they can't manage....
—Leon's Mom*

Expanding on the parenting suggestions outlined in the previous section, here are some strategies for dealing with specific situations that make up daily living.

Please keep in mind that these are *loose* guidelines only, a place to start. Once again, these suggestions have been effective with some children, but do not necessarily work for everybody. *Remember that each child is unique. It is important to analyse your child's problem areas as well as their strengths and adapt the environment accordingly.*

Routines

Daily routines are essential. They help maintain consistency, and build structure and security into the child's day. Without them, little gets done.

- Break down daily activities into specific steps. Plan mini-routines within the larger routine. Do everything in the same way and in the same order every day. For example, wake the child up at the same time and in the same predictable way every morning. This could look something like this:
 - enter room and say “Chris, time to get up.”
 - open drapes
 - turn on light
 - gently nudge, stroke child
 - pull covers back to ease transition from sleep to awake
 - aid child in sitting up; make sure their feet are on the floor
 - tell them what comes next

- Use calendars in the kitchen and bedrooms to list events. Write down or diagram what needs to be done. For example, morning needs before school might be listed like this:
 - get up
 - get dressed
 - eat breakfast
 - personal hygiene (wash face, brush teeth, comb hair)
 - get school things together (books, backpack)
 - prepare a lunch
 - put on coat and shoes

- Post key family rules in simple words:
 - no hitting
 - gentle hugs
 - sit when eating
- Alternate active times with relaxation. Limit the time the child is expected to work quietly at a desk. Take “action” breaks.
- Prepare the child for school the night before:
 - choose clothes
 - make lunch
 - put homework in a designated spot

Dressing

Again, dressing is a task that needs to be handled in a routine, concrete manner to help the child learn and retain the skill.

- If a child can’t choose clothing, put entire outfits together on individual hangers in the order they go on. Teach the child to put on clothes in the same order.
- Teach children how to sort clothing by a system, to help them learn to coordinate what they wear.
- Teach buttons from bottom to top to help the child “see” the match better. Try velcro instead of buttons.
- Teach how to tie shoe laces, but if this is difficult for the child, use velcro instead, elastic coil laces that do not require tying, or slip-on shoes.
- Keep outer clothes in the same place (e.g. *only* the front hall closet or *only* the mud-room.) Have a hook, at the child’s level, with the child’s name on it for their coat. Label a place for their boots.
- For winter climates, pin a hand drawn thermometer beside the door (inside) with a red line drawn on it at the temperature where heavy clothing must be worn. On the outside of the door hang a real thermometer. If the outside thermometer reads the same as or lower than the hand drawn line, winter clothing is put on.
- Have an extra supply of mitts, hats, lunch bags, shoes and any other items likely to get lost.
- If your child wears eyeglasses, have two pairs and keep one at school.

The Bathroom

Structure and routine are also helpful in the bathroom.

- Keep all personal grooming aids together in a container. Assign a colour to the child to indicate their toothbrush, comb, and so on.

- If overly long showers are a problem, put a timer on the shower that shuts it off. If overflowing the tub is a problem, use indelible ink to draw a line on the bathtub to prevent the child from overflowing the bath.
- Post bathroom routines on the mirror. Use simple words with pictures. Use a colour code system for hot and cold taps (e.g. red and blue) or pictures (e.g. a sun and a snowman).
- Keep the hot water tank temperature down or invest in a scald-guard faucet. This is essential for children who do not have a normal sense of pain and temperature!

Mealtime

Eating problems are common for alcohol-affected children. Some children over-eat, some under-eat, some eat very slowly, while others never seem to feel hungry. Many children use food as a comfort. Also, since children with FAS have poor impulse control, mealtime itself can be a problem because the dinner table is full of impulsive things—play things like silverware, napkins, glasses and food. Anticipate that meals could be a problem and be flexible in your expectations.

- Children with FAS are often slow to gain weight, despite good nutrition. However, if the child starts to lose weight for no obvious reason, or has persistent vomiting or diarrhea, a medical check-up is needed.
- Allow ample time to eat.
- Establish a firm routine for meals at the table (e.g. *we all choose what we eat from what is prepared*; the child must ask to be excused; etc.)
- Avoid spicy foods for young children if they react to strong flavours. Some children do not have a distinct taste sense and prefer strong flavours, like lemon.
- Require that the child take at least one bite of everything. Have reasonable expectations of portion size.
- If “eating all night long” or late night eating is a problem, establish rules about eating at the table only and one light snack just before bed. You may find that sugar and food additives are a problem.
- Use plastic tags on frozen food and use non-metallic wrap on left-overs or convenience foods so that children do not inadvertently damage the microwave. Get rid of plates, mugs and other dishes with metallic rims.
- A child with FAS may eat slowly because of poor muscle control or poor swallowing reflex. Accept that FAS children may be sloppy eaters and have sensitive gag reflexes.
- Carefully control the temperature and texture of foods. The child may have hypersensitivity toward certain food textures. Food without some sort of texture may be rejected. Try mixing in something a little rough. Conversely, a rough texture may be rejected.

- Some infants seem not to “feel” nipples or spoons in their mouth. Some have a high palate which hampers the use of a nipple.
- Manipulating forks and knives may be a problem. Allow use of fingers or a spoon, even for older children.
- If the child is agitated or confused at meal time, you may need to keep routines the same every meal:
 - Use the same dishes for the child at every meal.
 - Serve meals at the same time daily.
 - Give the child a specific seat at the table. If possible, seat the child at the end of the table away from others’ elbows. Seat the child beside a high tolerance child and avoid the one(s) with whom the FAS child fights.
 - Consider having the same meals on the same days. This helps children with sequencing difficulties to “know” the day of the week. You can try this for school lunches, as well.
- Serve the FAS child first if they have trouble waiting for others to be served first. You may want to try having the child serve: this lets them get up and do something physical several times during the meal and gives them an important role to play during dinner time.
- Avoid putting dessert on the table until after dinner.
- If the child cannot reach the floor when seated and finds this uncomfortable, allow the child to stand instead or place a step-stool under the child’s feet.
- Work on one kind of table manner at a time. Integrate a new “manner” only when the previous one has been successfully used for a time.
- Avoid fast food restaurants at peak times when eating out. Look for quiet eateries with low light and minimal noise.
- Reduce distractions at mealtimes. Avoid TV, radio and too much conversation. Save distracting socializing for after the meal—although this may be difficult to do as meals are often a key socializing time for families.

Bedtime

Children with FAS often have difficulties with transitional periods and activities where there is little or no structure. Bedtime contains elements of both, and can pose problems for children with FAS from a very early age. Again, the key is to establish a firm and calm routine, as in the following examples.

- Establish a definite bedtime and stick to it, even during summer holidays.
 - Have a calming routine that starts an hour *before* bedtime (the child picks up their toys, has a bath, brushes their teeth, gets into their pj’s, gets their hugs, goes to their room for story time/quiet time, etc.)
 - If the child wishes, have one light in the room, by the bed—all lights out except that light.
-

- The child may have one toy or book in bed with them—only the one they choose for that night.
- If they wish, the child can have the radio on very low with reasonable relaxing music. “White” noise in the bedroom (such as a fan or humidifier, very low music, or anything that makes a low hum) can be calming. This helps relax them so they can go to sleep.
- *Every time* the child gets out of bed repeat the same identical words like a broken record. (e.g. “*This is your bed. This is where you are supposed to be.*” If another light is turned on, “*This is the only light left on.*”) Accept that the child might be in bed but not sleeping.

Sleep

Sleeping problems are also common, particularly for younger children. Patterns vary from child to child. Many children with FAS need extra hours of sleep each night, while others seem to require little sleep.

- A warm bath before bed may help the child fall asleep. A warm bath after a stressful day of school can also be calming.
- Snug bedclothes are also helpful.
- A rocking crib can be useful.
- Establish bedtime rituals for saying goodnight which visually allow a transition from the “getting ready for bed” routine to the bed itself.
- Keep furnishings in the child’s bedroom to a minimum.
- For children who wake up at night, have a list of acceptable things for the child to do in an acceptable place.
- Safety-proof the house for night time wandering. Lock doors. Place locks near the top of the doors so the child cannot reach the lock. Consider installing a single alarm system that lets you know when the child has passed a certain point. Before that point, let the child wander. Make sure that this area is entirely child-proofed. A gate across the bedroom door may be useful.
- Encourage the habit of having the child sleep in their own bed.
- Many parents have found that it *does* get easier as the child gets older!!

Laundry

Laundry is an example of a complex life skill that may present difficulties for a child with FAS. Laundry can be challenging as it involves following an elaborate sequence of steps, making judgment calls (e.g. sorting clothes appropriately) and generalizing (e.g. dealing with different combinations of clothing each time). Again, it is helpful to teach this skill step by step, with demonstration and simple language.

- Teach the child/teen to do laundry sorting by *colour* of clothing.
-

- Break down laundry into specific steps. [i.e. open door, put in clothes, add 1 soap (only have 1 measuring cup available), shut lid, turn dial to dot, push in knob, etc.] Provide visual cues with drawings.
- Buy an iron with an automatic shut-off.

Supervision

Children with FAS can easily get themselves into trouble due to poor impulse control and difficulties understanding cause and effect. They also tend to be overly friendly and trusting, even towards strangers. It is important to supervise children with FAS so that they do not get into trouble or place themselves in dangerous situations.

- Small children and most pre-teens should be in direct line of vision at all times. One-to-one supervision is mandatory in strange places, on field trips, in stores, and so on. Do the best you possibly can, but keep in mind that even supervision is bound to occasionally fail to prevent problems.
- Some parents use a bungee cord to keep a small child close to them in public.
- If hyperactivity for the FAS child tends to increase with the day, shop with them first thing in the morning. Shop at small stores where there is low noise, fewer people and good service.
- Teach your child how to protect themselves from danger. For example, meeting a new person on the street does not mean that the person is no longer a stranger.
- Help the child to be aware of their environment. Walk in your neighbourhood together and point out the landmarks. Make trial runs of new trips on foot or on the bus. It is helpful to do this repeatedly from pre-school to adulthood.
- Make a telephone book for the child with addresses and phone numbers. This should be small enough for the child to keep in their pocket. Keep a copy for yourself.
- Safety-proof the home. Place locks on outer doors. Lock up all medication, household cleaners, other potential poisons and power tools. Safely store knives, scissors, matches and lighters. Cover electrical outlets. Erect high fences and keep gates locked. Give away any poisonous plants. Never leave a lit cigarette unattended and dispose of used cigarette butts.
- Fire extinguishers are advisable in the kitchen.
- Always be on hand if a child/teen is cooking.
- Never leave a child with someone you do not know well.
- Assess whether the child can be left alone. Even some teenagers need supervision.
- Escort children to and from all activities.

- Arrange for recess and noon hour supervision at school.
- Try not to let the child know that you are supervising all the time. The child needs to feel as independent as other children. Plan concurrent activities that legitimately keep you in the child's proximity.

Managing Hyperactivity

Hyperactivity is a common problem for children with FAS. Parents can help control the problem by carefully structuring the child's activities and by reducing the amount of external stimulation.

- Limit TV-watching and avoid video games if this causes the child to become overstimulated. Keep in mind that highly-charged social activities such as birthday parties may be overwhelming for a child with FAS.
- Alternate activities requiring attention (e.g. studying, washing dishes, etc.) with physical exercise (e.g. running, tumbling, dancing, trampoline, etc.). Give your child opportunities to be physically active. Sports such as soccer and gymnastics—and skiing/snowboarding for older children—are excellent ways to use all that energy. These activities also promote healthy self-esteem. Swimming is also a good physical outlet for many hyperactive children. However, group swimming lessons may be counter-productive. Private lessons may be preferable.
- Avoid cluttered space. Clutter may increase hyperactivity.
- Make the home a calm place.
- Calming music is preferable to loud, frenetic music.
- Fluorescent lights may be bothersome. Children with FAS may be more sensitive to flicker that others don't notice. Use low or recessed lighting.
- Avoid situations where the child may be overstimulated by light, movement, sound, toys, noise, colour, activities or crowds.
- Designate a calm, cosy, comfortable place for “quiet time” where the child can go when they are overwhelmed. Make it clear that “quiet time” is *not* a punishment. It is best that an adult be present while the child calms down.
- Avoid trying to have a child concentrate for long periods of time. Concentration is hard work and physically tiring.
- Limit the number of visitors if this is overwhelming for the child. Try to have people over when the child is asleep or not at home. Many parents have found a substantial increase in energy levels when extra people are around, especially people the child doesn't know.
- If anger is a problem, have a safe place for the child to express it in some physical manner (i.e. screaming, kicking a ball.)

- Avoid activities such as pillow fighting or wrestling which can cause over-stimulation. Make sure extracurricular activities do not cause over-stimulation. At the same time, do not deprive your child of extracurricular opportunities. Sports or Boy Scouts/Girl Guides may provide an excellent channel for the child's energy, while boosting self-esteem and encouraging personal interests. The child needs the outlet, and you probably need the break!
- Ask yourself, "*Does it really matter?*" Don't sweat the small stuff.

Managing Impulsivity

Children with FAS and Attention Deficit Hyperactivity Disorder (ADHD) tend to have poor impulse control. They often have difficulties understanding cause and effect relationships, or foreseeing long-term consequences for their actions.

- Teach the concept of "your turn" by using a physical object such as a "talking stick" which could be a pebble or any small, portable object that is easily passed around—"if the object is in your hand, it's your turn."
- Teach "*walk, don't run*" by counting numbers between steps.
- Verbally label and redirect unacceptable impulsive behaviour as early as possible in the child's life (i.e. toddlerhood) and on each occasion. Do so in a calm, consistent manner with visual cues.
- Learn to recognize the signs that the child is going to have a "*negative event*" and step in as soon as the signs begin. *Avoid, anticipate, act!*
- If time out is needed, consistently use the same designated place. Avoid places used for other important or fun activities (e.g. bedroom, play table, book corner, etc.). If possible, choose a calm, uncluttered space that is used for no other purpose.
- Don't hook into tantrums!! Allow each one to run its course. Help the child to calm. Make sure the child is in a safe place where they cannot hurt themselves. If necessary, move the child to a safer place (i.e. a carpeted floor.)
- In order to "*look before they leap*" (reflection), a child must have the language (words) for the situation. Try to teach in simple terms with visual cues.
- FAS children have "good" days and "bad" days. Do not expect compliance today because they had it yesterday. *Always have a fall-back plan.*
- Limit choices. Inability to choose from a variety of options causes intense frustration and impulse control problems.

Sensory Considerations

Many children with FAS are hypersensitive to noises, touch, bright lights, hot and cold, sudden movements, and pain. They may also be sensitive to small amounts of various stimuli (e.g. people, noise and movement) all at once. This problem of overstimulation is noted in newborns,

especially those with NAS, and apparently some alcohol-affected individuals remain hypersensitive to sensory stimulation most of their lives. On the other hand, some individuals with FAS are hyposensitive, meaning they have extremely high tolerance to sensory input and may even seem impervious to pain.

- If the child is hypersensitive, avoid itchy clothing. Soft, loose material is more easily tolerated. Elastic, sock seams, ties under the chin, labels in the neck, tags, jeans seams, appliqués with a scratchy backside, hair bands, barrettes and stiff shoes may cause problems. Solutions include:
 - Remove tags from clothing.
 - Wash all clothes 2 or 3 times before wearing.
 - Turn socks and gloves with seams inside out.
- Avoid bright lights (particularly fluorescent) and sunlight reflecting from water, snow or vehicles.
- Use sunglasses and tinted glasses (prescription and non-prescription) to reduce glare.
- Loud noises may be quite painful for the child's ears, but use earplugs only under supervision.
- Loud music is often distracting because it seems to "switch off" what is being seen visually. It is as though the child can have either visual stimulus or auditory stimulus, but not both at once.
- Avoid crowded situations. Place child at the beginning or end of a line, not in the middle.
- Learn which foods seem to be too smooth or too rough. (*see section on mealtime, page 28*)
- Use soft play-dough or other smooth surfaces with which the child can feel and play.
- Use routine calming techniques when the child is overstimulated (e.g. sitting in a bean bag chair, rocker, or hammock; taking a warm bath or shower; listening to quiet music through headphones; etc.)

Social Skills

Individuals with FAS have difficulty relating cause and effect, generalizing, and learning from non-verbal cues. As a result, a child with FAS may have trouble picking up social cues and may not realize when they are acting inappropriately. Other children and adults tend to reject peers who are not skilled socially or who act differently. Teaching social competence and how to communicate with others serves to bolster their self-esteem and enhance their social well-being.

- Teach social skills carefully, consistently, and repetitively through modelling, role play and/or practice.
- Teach appropriate social skills, such as:
 - how to share and take turns
 - how to ask for help

- how to interpret facial expressions, tone of voice, posture, etc.
- how to deal with rebellious behaviour in peers
- how to react when there is a disagreement with a supervisor
- how to make choices
- how to ask others if they can join in an activity
- how to say “no”

and so on. Talk about each situation in some detail. Try to seize “teachable moments.” Keep the tone light and natural, and the “lesson” brief.

■ Teach what is inappropriate, such as:

- standing too close
- interrupting and talking non-stop
- throwing things
- not asking for help

■ For a child who requires excessive body contact, structure the physical contact so that the child learns what is acceptable and what is not. Gradually replace the excessive amount of physical contact with visual and verbal assurances (i.e. a key word, phrase or sign).

Telephone

Telephone manners and taking messages pose problems for children with FAS because these skills require memory work as well as understanding abstract concepts and appropriate social skills. Teach by role-play:

- Have a large, erasable message board next to the telephone.
- Have an answering machine with a “record” function so that messages do not get lost or numbers mixed up. Some parents have found the voice mail service through their local telephone company very effective.
- You may consider having two phone lines, one for the children and a second which only the adults answer.

Handling Time

Children with FAS have great difficulty telling time and understanding how much time has passed. Dealing with time involves abstract concepts, and understanding abstract concepts is a common difficulty for people with FAS. A 12 year-old child with FAS may still be unable to tell time on an analog watch.

- Make time visual with paper chains, time-lines or other concrete objects to represent periods of time (e.g. 5 minutes). The adult takes responsibility for removing one object/link every 5 minutes so the child can “see” time pass. Sand-timers and egg timers also work well.
- Teach time using an analog watch or a clock face with hands that the child can manipulate. Digital watches seem to work only if the child is looking at the watch when the specific time rolls around.

- Even when a child has started to master telling time, they may still have difficulty understanding the concept that 9:45 is the same thing as quarter to ten, or that 10:30 and 10:40 are roughly the same time.
- The child may also have a poor *sense* of time. The idea of *when* time occurs has no meaning. “*Dinner is at 5 o’clock*” means nothing, while “*Dinner comes after...*” may be easier for the child to comprehend. Always relate events to other events to create a sense of the day and the usual order of things. The words “*after*” and “*before*” are helpful when referring to time.
- FAS children who are in an established routine will follow that routine regardless of the time. The fact that dinner may be delayed due to a late lunch is complicated information for the child with FAS to process.
- Do not have high expectations about handling time. It may not be reasonable to expect a child to be able to complete a certain amount of work in a specific amount of time. It is also best to send a child from point A to B with an escort if you need them to be there at a specific time. Give the child lots of time to get ready for an event and supervise closely.
- The responsibility for making sure FAS children/teens are where they are supposed to be on time rests with the adult. Even some adults with FAS may require help in this area, although many find this skill improves with age.

Teaching Ownership

Similarly, ownership and personal belongings are abstract concepts that are difficult for many alcohol-affected children to understand. A child with FAS will often pick up something that catches their eye and then drop it whenever they lose interest. Or, the child may take something they recognize as having been left by someone else with the good intention of returning it. Unfortunately, short term memory dysfunction, distractions and other problems may cause them to forget, leaving them open to charges of stealing. Work on teaching the child to ask before they touch anything that is not theirs.

- Teach the child what belongs to them by placing a colour code or an initial on all their possessions. The child then knows what to take (e.g. the item with the purple “J”) and what *not* to take (everything without the purple “J”).
- Connect ownership to visual cues. The child may understand that a specific person owns a specific item as long as the person and object are together, but not if the two are apart (e.g. the child finds an object that’s been left somewhere.)
- If the child takes something that is not theirs, do not get caught up in an argument. Simply state, “*This belongs to*” and return the object. Stealing should be dealt with firmly with appropriate consequences.
- Objects of value should not be left around where a child may come across them.
- Keep in mind that malls are neither recreation centres, nor suitable places to hang out. It is best not to allow unsupervised trips to stores. You cannot expect store managers to understand FAS.

Handling Money

Money, and the value associated to it, are also abstract concepts. Not surprisingly, FAS-affected children do not typically handle money well. The ability to handle money has a significant impact on the potential for independent living.

- Children with FAS do not associate value to items and have difficulties making judgements about the sum of money asked for an item. For example, \$10 for a candy bar or for a bicycle may both appear acceptable to a child with FAS.
- FAS children are at risk for being victimized by others. Children and teens should have a very limited access to money without direct supervision. Money should be given in small amounts. Pay for lunches at school ahead of time, or be at the store when expensive items are being purchased. Use an account book to record every cent the child spends with the child present.
- Monitor the child's money. Where did it come from? The child may have sold a personal or household item just because they were asked.
- Teach the child about money whenever you go to the store or in other real life situations.
- Be very cautious about the use of cheques, credit cards or banking machines. Set up a bank account where cheques are not allowed and withdrawal amounts are limited. Many parents suggest that bank cards and cheques should not be used because they are open to misuse.

Babies with FAS

Special Considerations for Infants

*The Social Worker brought him;
A little warm blue bundle
With straight silky hair and huge dark eyes.
She said, "His mother had some problems,
But he will be fine....*

—Leon's Mom

The difficult task of caring for any newborn (adjusting sleep routines, feeding, etc.) is multiplied when caring for an infant with FAS. FAS affected babies tend to have a very hard time during their first few months. They can be difficult to care for because of their various developmental problems (see *Common Manifestations section, page 7*). Most significantly, they have troubles sleeping regularly, and eating and napping at predictable times.

Here are some additional parenting suggestions geared specifically to the special needs of infants with FAS. Again, please keep in mind that these are suggestions only—not every technique will work with every alcohol-exposed infant. *Adapt to suit the needs of your own baby.*

Sensitivity

Infants with FAS, and especially those with NAS, may be extra-sensitive to the stimulation around them, particularly to sound and touch.

- Speak softly and hold them gently. Don't rush when picking them up.
- Many babies with FAS are unable to "screen out" all the stimulation around them. Control the amount of stimulation the baby is exposed to.
- Each baby is unique in how they are affected by sound and touch. Notice what upsets them, as well as what calms them.

Illness

Some infants with FAS have weaker immune systems and are more susceptible to illness than other babies.

- The infant should not be exposed to environmental irritants such as tobacco smoke.
- Keep the infant away from people who are sick because of their compromised immune system response.

Crying

Alcohol-affected babies are often tremulous and irritable. It may seem that they are crying constantly. Avoid, if you can, letting your baby get to a state of frantic crying. Get to know what your baby likes, and tell other caregivers how the baby likes to be handled.

- Wrap the infant snugly in a receiving blanket, with the arms tucked in close to the baby's chest and legs wrapped in a bent position towards their tummy.
- Babies are soothed by sucking. Guide the child to its thumb. A pacifier may also be helpful. Do not add incentives such as honey on a pacifier or leave the child to nurse alone on a bottle of juice or formulae/milk, because this may cause ear infections and/or serious tooth decay. It is advisable to consult with your dentist.
- Other kinds of gentle motion, such as walking or slow movement in a baby swing or stroller may help. A car ride may be soothing, as well as any motion that produces gentle vibration and a low, soothing, humming sound.
- Comforting sounds may also help. Try quiet music, singing or gentle talking.
- If your baby usually enjoys being bathed, a warm bath may help to settle and calm them.

Feeding

Feeding difficulties are common. Infants with FAS often have poor coordination and weak sucking reflexes which contribute to nursing difficulties. They can easily become fussy because they can't get the nourishment they need—nourishment which is crucial because of their low birth weights.

- Reduce external stimulation. For example, feeding the baby in a darkened, quiet room will help them relax and focus on sucking.
- Wrapping them in a blanket may help to calm them during feeding.
- Press chin upward in a gentle, rhythmic pattern.
- Stroke lips and gums gently before giving breast or bottle.
- If bottle feeding, try nipples with different shapes until you find one that works well.

Sleep

Infants with FAS may have erratic sleep patterns, and no predictable sleep-awake cycle. They may have trouble getting and staying asleep. Also, many tend to have short sleep periods, both day and night. This can be exhausting for parents.

- During sleep times, place in a quiet area, lower lights, and wrap snugly in a blanket.
- When the baby starts to wake up, gently rock the bed or rub the infant's back, either to ease back to sleep or to aid transition to being awake.

- Bedtime routines are very important (*see Guidelines to Daily Living*). Put them to bed in the same bed each night, and provide a constant soft sound to drown out other noise (e.g. gentle music, humming of a fan, etc.)
- If your baby usually enjoys being bathed, a warm bath may help them sleep.
- Singing softly to them may also help.

Take Care of You

Caring for any infant is tiring, but looking after a baby with FAS can be particularly exhausting. In the first few weeks and months, when everything's still so new, parents of infants with FAS often experience frustration and feelings of inadequacy. It is important to take care of yourself to avoid burnout. Your baby depends on you. Building a support structure and connecting with health professionals can help you feel more successful in meeting your infant's special needs. Organizing supports and arranging for respite care is crucial for your own well-being.

- If the baby's crying happens at the same time every day, try to call someone before it starts to give yourself a change before you reach your limit. If you have a partner, take turns with the baby. Treat yourself with extra kindness. Sleep when your baby sleeps, take a hot bath and make sure you eat properly.

Please refer to the section Parent's Needs on page 45 for more ideas on taking care of yourself.

Teens with FAS

Special Considerations for Adolescents

Driving north along Highway 101, from northern California into Oregon, we see spectacular scenery.... On a recent trip with my husband, Ron, along that route, I noticed a relationship to our lives as parents of 14 year-old twins with ARBD. At the time, I had no idea of the crisis we would face when we returned home from that trip nor the months of panic and pleading for help just ahead of us. Rather, I had a brief glimpse of beauty rather than tragedy, of being formed rather than falling apart.

Soon we were home again, and reality struck a heavy blow. The lesson I had begun to learn was forgotten as we faced anger, swearing, being called losers, doors slamming, being pushed out of the way, stealing from us and friends, lying, and running away repeatedly for different lengths of time. Most of these behaviours were new and we panicked. We had no idea how to deal with them.

—Bev, adoptive parent

Adolescence is a transitional period from childhood to adulthood. Like any major life transition, it is usually accompanied by crisis. People with FAS often experience many of the same crises as other adolescents—adjusting to sexual maturity, becoming less reliant on parents and family, establishing areas of independence, and planning for a fulfilling role in society as an adult (Streissguth, Ladue & Randels, 1988).

It is often difficult to separate these “typical” teen issues from the disability issues caused by FAS. However, teens with FAS—like those with any developmental disability—have special needs during adolescence.

Parents of a teen with FAS are faced with a range of challenging issues such as:

- sexual maturity in a developmentally disabled person
 - their teen’s plateauing academic skills and decreasing satisfaction with school, and need for work and social skills
 - their teen’s high risk for exploitation, peer manipulation, school expulsion and/or involvement in the criminal justice system
 - managing their adolescent’s leisure time, interpersonal relationships and independence
- (Please see section on adolescents in Common Manifestations, page 9.)*

The following strategies build further on the Parenting Suggestions and Guidelines for Daily Living outlined earlier in this guide, and are geared for coping with adolescents with FAS. Again, while these suggestions have been effective with some adolescents, they may not be appropriate for everybody. *As always, remember that your teen is unique. Adapt your strategy to suit their individual needs.*

Structure and Supervision

Streissguth, Ladue & Randels (1988) summarize the best method of coping with adolescents with FAS in three words: “STRUCTURE! STRUCTURE! STRUCTURE!” Parents have the difficult task of finding a balance between permitting freedom appropriate to the child’s developmental level, while providing enough structure for protection and growth. Follow your instincts and resist pressure from family members, other adults involved with your child, and the teen him / herself to lessen control and let the teen “learn from their mistakes.” The risks are too great.

- Continue to provide a safe, structured environment and clear, predictable routines.
- Clear, consistent expectations and behavioural consequences are still necessary.
- Supervision *cannot* be decreased in adolescence. Although a child may be chronologically fifteen, their mental/emotional functioning may be at a lower level.
- Teens with FAS are easily influenced, and vulnerable to peer manipulation and negative, destructive behaviours such as sex, drugs, alcohol and crime. Carefully monitor social activities and structuring of leisure time. Do not leave alone for an extended period of time.
- Encourage the teen’s talents (e.g. music, art, athletics, Special Olympics, etc.) to discourage non-constructive use of leisure time. Identifying strengths and interests is also useful when looking for an appropriate job setting.

Life Skills

As the teen’s academic skills plateau, it is important to emphasize work, social and daily living skills. Adolescents need help with day-to-day language skills, interpersonal relationships, managing money, making purchases, looking after their own health, looking after their appearance and clothes, and so on.

- Teach the teen about sex and birth control as you would any hygiene or care issue (i.e. be open, use language and concepts appropriate to the child’s developmental age, repeat regularly, seize the teachable moment, have appropriate teaching aids and methods available, etc.) Sex and birth control are important issues for teens with FAS. They have a normal sex drive, which causes problems when coupled with their poor judgement and impulsivity—they are often easy targets for sexual exploitation, both as a victim and a victimizer. Again, supervision is key—like all teens, don’t expect that they won’t want to try sex just because they’ve been told not to.
- Children with FAS are at high risk for becoming chemically dependent because of family histories of alcoholism. Studies show that alcoholism is a disease that is passed on from generation to generation, whether the child lives with the alcoholic parent(s) or not. Adolescents are particularly vulnerable as they are exposed to many more negative influences. A teen’s desire to fit in, coupled by poor judgement and impulsivity, can lead them to substance abuse. Show them alternate ways of having fun, dealing with their feelings, and being accepted by others.
- Help the teen find “sheltered” employment opportunities where the employer understands that they have hired an individual with a significant disability. The job environment should

be one where there is structure, order, and routine, and where the adolescent will be supervised by adults who are patient and understanding of the teen's limitations.

- You may need to accompany your teen to and from work to make sure they get to their destination, or designate someone else to do this.
- Individually structured volunteer placements can help a teen with FAS contribute to the community and develop a sense of participation, accomplishment and responsibility.
- You may always have to “remind” the individual with FAS when things must be paid, even into the adult years. Ideally, establish the routine of paying bills as soon as possible.
- Teens with FAS are susceptible to depression and loneliness. They may be rejected by their peers due to impaired social skills or because they are different. For people who have difficulties making and keeping friends, holding down a job or achieving at school, depression, loneliness and low self-esteem are normal. Psychological counselling is a healthy option to deal with depression and other mental health issues that may arise. It is important to find a counsellor who is experienced working with individuals with FAS or other neurologically-based disabilities.
- Let go of high expectations. Relax about your child's level of achievement and focus on their feelings of self-worth, satisfaction and well-being.

Adolescents with FAS in the Justice System

As children with FAS reach adolescence, they are at increased risk for involvement with the justice system. Their poor judgment, impulsiveness, inability to anticipate consequences, and seeming inability to alter their behavior as a result of those consequences appears to make them particularly susceptible to trouble with the law. Streissguth et al.'s (1996) follow-up study of adolescents and adults with FAS /FAE found that approximately 60% had experienced some involvement with the law. Forty percent did not!

Teens with FAS/FAE have been charged with offences ranging from vandalism or mischief to more serious offences of theft and assault. They may be easily led and manipulated by more street-wise teens. However, in a recent study in B.C., youth with FAS were no more likely to commit the offence with a group than on their own.

Teens with FAS/FAE are also victims. Their inability to anticipate dangerous situations may put them in the wrong place at the wrong time. They may be too trusting of people, including strangers, whom they consider to be “friends”. Inappropriate social skills may make them the scapegoats in the teen peer group.

For both perpetrators and victims, alcohol and drug use is often the driving influence.

It is important to remember that having FAS in and of itself does not cause criminal behaviour. Many other factors combine to result in this outcome. The advice to parents to closely monitor their teen's activities is the key factor in preventing involvement with the justice system.

Take Care of You

Respite care is just as important for caregivers of adolescents affected by FAS as it is for parents of younger children. The adolescent years can be particularly exhausting as you are dealing with new stressors on top of the many special needs you have been coping with since infancy and childhood.

Please see section on Parents' Needs on the next page.

Take care of you!!

Parents' Needs

We felt like prisoners in our own home because we dared not expect friends or grandparents to manage the children in our absence. We had never heard the word “respite.”

—adoptive parent

Parenting can be challenging even at the best of times. Parenting a child with FAS is often even more demanding, frustrating and exhausting. As a parent, it's important not to lose sight of your *own* needs—those things that get lost or overlooked when you're preoccupied with meeting your child's special needs on a day to day basis. Taking good care of yourself is a crucial part of your job. After all, you are probably the most important person in your child's world. How can you effectively support your child if you burn out yourself?

Take Care of You

- Get adequate sleep. Children with FAS have difficulty sleeping, so you will likely have trouble getting enough rest for yourself. Learn to rest when your child is napping. If your child doesn't nap, arrange for someone to take over once a day so you can rest.
- Develop a repertoire of stress reduction strategies that work for you. Most people have difficulty making time to deal with stress, but it's so important for your physical, emotional and mental health—particularly if you're dealing with the extraordinary stress of caring for a child with special needs.
- Make time for yourself (and your partner). Get some fresh air, keep a journal, or read a book.
- Do something physical (e.g. walk, jog, swim, etc.)
- Nurture yourself.
- Maintain a sense of humour. Let yourself laugh.
- Maintain a sense of yourself beyond your child.
- Don't forget to breathe.
- Let the crisis pass. There may be another, but keep in mind that *this too will pass*.
- Try to maintain a positive attitude about your ability to manage the day-to-day and long-term stresses associated with parenting your child.

- Establish reasonable expectations. Don't expect yourself to be able to do *everything* for your child. Focus on what you *can* do and seek help for things you can't.
- Let go.

Respite

- Arrange time away for yourself on a regular basis. Caring for children, adolescents or even adults with FAS can be demanding and tiring. If you are co-parenting, make an arrangement with your partner so that one of you gets a night or afternoon off while the other stays at home, and vice-versa. You might also consider trading time with another family raising a child with FAS. It is also important to consider arranging substitute child care or longer term respite care which can be arranged through a social worker or formal program. Many parents of children with FAS find that respite care is crucial to the well-being of the family.
- Babysitters typically burn out because they often don't have the experience of dealing with children with FAS. Have the sitter come to visit a few times when you are home, and give them tips on how to deal with your child's behaviour. Prepare your child for the babysitter by talking about what s/he will be like, and rehearsing appropriate behaviours.
- Speak to a social worker at the Ministry for Children and Families to find out more about respite care or other family support services that are available.

Get Support

It is important to get support for your own needs, issues and feelings.

- Make a list of every person you know who can help you. Include family, friends and community groups. You have an important, difficult job, and you don't have to face it alone—it takes a whole community to raise a child, particularly a child with special needs.
- Tap into available resources, like the ones listed at the back of this booklet.
- Find other parents in your community who have children with FAS. Nobody understands your struggle like someone who's "lived it." Share information and support. Join or create a support group. Surround yourself by people who "get it."
- The Warm Line (604) 589-1854 volunteers are knowledgeable and experienced caregivers of children with FAS. Staff can provide information and support on caring for children affected by FAS. The Warm Line staff are available, on call, 24 hours a day.
- If you have access to the INTERNET, join an FAS chat group or listserv like *FASLink*, hosted by the Canadian Centre on Substance Abuse in Ottawa. (*for more information, see page 60 of the Resource section*)
- Talk to a counsellor. Consider getting counselling for the rest of the family as well. Be sure to find a therapist who has experience with FAS and other neurologically-based disabilities. Unfortunately, there are still professionals who are not sensitive to FAS and related issues who may simply see families struggling with challenging children as dysfunctional families.

Get referrals to appropriate professionals through FAS resources (*see listing in the back of this manual, starting on page 55*) or from other families touched by FAS.

- Keep on educating yourself about FAS. Books, magazines, newsletters, movies and tapes can provide not only practical information but also a source of support and inspiration.
- Take a realistic and practical approach to getting professional and community support. Recognize that FAS is a relatively new area—it will take time for a formal system to develop to meet the needs of people with FAS and their families. Advocate for yourself and your child. Educate the professionals who work with your child, and the community at large. Find people with a strong interest in the area to work with you and help you through the system. (*for more on advocacy, please see page 25*)
- If you are a foster parent, contact the After Hours Foster Families Support Line at 1-888-495-4440. (*for more information, see page 66 of the Resource section*)
- The 53 hour B.C. Foster Care Education Program includes a module on FAS/E, NAS for foster parents. This module assists foster parents in understanding the implications of caring for children whose development and behaviours may be influenced by these conditions.

Hang In There

You've already demonstrated your commitment to your child and to yourself by making it this far—by weathering the struggles of parenting a child with special needs, hanging in there no matter how much your child has tested or challenged you, and even just by picking up this book. It's probably been hard, but you've made it this far. Keep on hanging in there the best you can, and don't forget to take care of yourself.

Even if you're faced with what seems like the worst case scenario—the interventions have failed or come too late, the child has left home or the child has been removed from the home—this doesn't mean you've failed as a parent. It is helpful to remember that you're not there to make a person's life—you're there to be with them while they live it. You can help them, hold their hand and support them, but there are some things you cannot control. Being a parent doesn't mean you have to live with the child twenty-four hours a day. Being a parent means being an advocate, somebody sending that child love from somewhere in the world, making sure that the child gets services, and providing a safe place for the child to phone home to. In some circumstances, parenting from a distance is the best way of taking care of yourself and taking care of your child.

Getting a diagnosis

Assessment and Referrals

*Sunnyhill Hospital, in Vancouver.
A gloriously blue and gold September day...
But I felt myself dying, just a little,
With that first positive diagnosis...
—Leon's Mom*

A medical diagnosis of FAS is important. There are other disorders that have similar symptoms to FAS (“look-alike” syndromes such as Williams Syndrome, Noonan Syndrome, DiGeorge Syndrome, etc.) that may need to be ruled out before a diagnosis is made.

An accurate diagnosis helps parents and professionals better plan for the child’s needs and care. It is important for implementing appropriate medical, educational and social strategies, and for accessing needed services and supports.

Early diagnosis is recommended to help maximize the potential outcome for the child. Also, by adolescence, many physical features change, making diagnosis more difficult. However, *it is never too late. If you suspect your older child or teen has FAS, it is still important to get an assessment as soon as possible.*

FAS is a medical diagnosis—not a label

Some parents worry that a diagnosis will place a negative “label” on the child—a label which will handicap them unfairly in school and in social situations.

However, FAS is an invisible disability—it is still not widely known, nor is it easily recognizable by physical characteristics. For example, when a child is in a wheelchair, there is no question that the child has a disability. When people do not recognize what is different about a child with an invisible disability, they may be inefficient in trying to help that child reach their potential. The child may *already* be labelled as “bad,” “slow,” or “hyper” by a teacher or other adults who wrongly attribute the child’s misbehaviour to laziness, lack of motivation, obstinacy or bad parenting rather than a deficit in information processing. An accurate diagnosis is a relief for many parents, as it helps to explain the academic, social and behavioural difficulties they have been encountering at home and at school. It serves as an important first step for getting outside recognition and support for the child’s special needs.

It is also important to remember that each child with FAS is first (and foremost) a child—a child who happens to have symptoms of an invisible disability. As a parent, you can choose which people you tell that your child has FAS. You may decide only to tell people in those situations (e.g. school, hospital, respite care, social worker’s office, etc.) where it may be helpful to you and your child.

Referrals

Assessment at any age should be multi-faceted and cover all aspects of functioning. It is recommended that your child be assessed by a doctor who has experience with FAS. A background in dysmorphology (birth defects), paediatric neurology or genetics is especially important where Partial FAS, ARBD and ARND are concerned. A diagnosis of Partial FAS or ARND is usually made in conjunction with a psychologist after a psycho-educational evaluation. Again, it is important that the psychologist be knowledgeable about FAS.

In British Columbia, Sunny Hill Health Centre for Children offers medical assessment and referrals through its Child Development and Rehabilitation Program—call (604) 453-8300 for more information. Questions relating to clinical service, consultation or educational support may be directed to one of the five geographic liaison staff or the Team Leader of the Substance Exposure Resource Team (S.E.R.T).

If you are a foster parent and believe that the child placed in your care could benefit from an assessment of FAS, talk to the child's social worker about arranging a referral for the child.

Keep in mind that FAS is still a growing area, and it is taking time for the medical community to develop a fully-coordinated response. In some parts of the country, there are very limited services available. When services do exist, there are frequently long wait-lists. Don't let this discourage you. If you are told there are no options in your region, keep looking! Provincial contacts listed in the Resource section of this guide can help direct you to the nearest available help. The *FASLink* service on the INTERNET may be useful for connecting with other people (both parents and professional) who can guide you to resources.

See Resource List on page 55.

Medical Assessments

Unfortunately, there is currently no "laboratory test" that confirms whether or not a child has FAS. Diagnosis is a clinical judgement based on assessment of the child with regard to specific symptoms and criteria (*see FAS Diagnostic categories, pages 2-3, and the Appendix, A-1-A-3*), and a medical history which may include the mother's drinking pattern during pregnancy.

To prepare for an assessment, gather an extensive history of the child and their family background. If possible, include the following information:

- maternal alcohol, drug or tobacco use during pregnancy
- mother's illnesses during pregnancy
- birth and health history (birth weight, developmental milestones)
- placement history
- assessments by other professionals
- records of height and weight over the years
- photographs (it's helpful to provide one good full-face picture per year if available)
- any siblings known to have FAS or other alcohol related birth defects
- any history of Neonatal Abstinence Syndrome (NAS)
- a list of "problem" areas in social, behavioural and adaptive functioning (a compilation of information by parents, other caregivers and professionals)

Assessments should be updated every 2-3 years.

Adoptive parents can request pertinent data about their adopted child through the agency or provincial Ministry office that finalized the adoption—usually in the city where the adoption occurred. In British Columbia, you may obtain non-identifying information about your child’s birth family and pre-natal history through Vital Statistics in Victoria. Send the relevant office or agency proof of your adoptive parent status, and ask for information pertaining to alcohol/drug use in the birth family. This should be done well before proceeding with an assessment.

Adopted persons over the age of eighteen in most provinces (fourteen in Quebec) may place their names on a provincial adoption disclosure registry to start the process of obtaining identifying information and possible contact and/or reunion with birth relatives. They must register in the province in which their adoption was finalized.

Dealing with a Diagnosis

Receiving a medical diagnosis is typically an intense, emotionally charged process. While it may be a relief to have a *reason* for the child’s behaviour, it is normal for parents to experience a range of emotions and discomfort when they first hear that their child has been diagnosed with FAS.

As a parent, you may experience intense guilt or anger about your child’s condition. You may feel anxious about the medical outcome, and be worried about future complications and risks. You might be overwhelmed with feelings of helplessness and panic about how to manage the condition, and be anxious about how to plan for the future. You will likely have to grieve the loss of certain life goals for your child, and come to terms with the necessary changes in living patterns due to the condition (Rathbun, n.d.b).

Dealing with a diagnosis of FAS or other medical conditions in children involves phases of grief—impact, denial, anger, bargaining, mourning, acceptance and focusing outward. Families need recognition and support to work through this grieving process (*see section on Parents’ Needs*). Families can move towards acceptance and management of their child’s condition by learning about the condition, getting support through the stages of grief and adjustment, and actively developing strategies based on family and individual strengths.

Rathbun (n.d.d) has identified the following psychosocial tasks for successfully coping after diagnosis:

1. Maintaining emotional distress within manageable limits (learning how to care while detaching from overreaction)
2. Understanding medical and developmental needs, and how to meet them with new knowledge, motivation and skills
3. Preserving important relationships with others in a support network (stepping out of isolation)
4. Regaining hope for the future (alleviating burnout)

5. Encouraging adaptive development for the child with FAS in family, peer, and school roles/responsibilities by building on the child's potential (including the characteristics of having a chronic condition)
6. Maintaining stable, equitable family functioning (learning solution-focused instead of problem-focused ways of coping)

Dealing with NOT Getting a Diagnosis

Some parents, after years of concerted effort, remain unable to get an accurate diagnosis for their child. This can be extremely frustrating, distressing and invalidating. You may feel stuck in limbo, unable to get on with the grieving process described above. The child's difficult behaviour continues without an explanation, and others may continue to blame your parenting.

An accurate diagnosis may be impossible to obtain for a number of reasons. There may be limited information about the child's pre-natal history, particularly in adoption situations, making it impossible to confirm the birth mother's use of alcohol during pregnancy. Also, it may be difficult to accurately diagnose an adolescent or adult because many of the physical features—particularly the characteristic facial features and growth deficiency—change and become less pronounced with age. This is why childhood photographs are recommended to accompany the diagnostic process, but even these are not always reliable as smiling faces can distort the appearance of some of the classic facial features.

In situations where an accurate diagnosis is not possible due to gaps in the prenatal history, the new Institute of Medicine diagnostic category "FAS without confirmed Alcohol Exposure" may now be applied in some circumstances. In other cases, medical professionals have been able to construct evidence of pre-natal exposure through the information that *is* available in order to make a diagnosis of Partial FAS or ARND (e.g. alcohol consumption during pregnancy may not be confirmed, but if the birth mother is a known alcoholic, that may be sufficient evidence to presume she drank during the pregnancy).

Other parents who have been unable to get a diagnosis due to gaps in the child's prenatal history, or features obscured by growth in an older child, have found it useful to act *as if* their child has a diagnosis. *This is NOT to be confused with self-diagnosis, which can be dangerous. An inaccurate diagnosis can be more damaging than no diagnosis!* Your child should be assessed by a knowledgeable doctor. Some parents have obtained a professional opinion that their child has "suspected FAS" or "unexplained neurological damage," which at the very least has opened the door to helpful services, supports and intervention strategies. It also goes a long way to taking the pressure off you, the parent, by reminding yourself and others that the problem *isn't* poor parenting.

Talking to your Child about FAS

*Most parents who decide to “tell”
Add an important bottom line—
“This is a medical condition
And it’s not your fault.”
—Leon’s Mom*

It is important to discuss FAS with your child, in order to help them better understand and face the challenge of their chronic condition. Children with disabilities often know they are different from their peers, which typically causes feelings of anger and frustration. Self-esteem increases when children’s truths about themselves are talked about, listened to, and taken into consideration.

Talk about FAS openly and honestly in a safe environment, using language and concepts appropriate for the child’s age and developmental level. Talking about common symptoms can be a unifying place to start. Discussions may be revisited as the child grows older. Some parents have found that as they personally became more comfortable with the reality of FAS, the child began to ask more questions about how they were affected and what to expect.

Rathbun (n.d.e) offers some suggestions for talking to your child about FAS at different ages:

Young Children

Young children are very immediate. They need consistent, warm, reassuring support from parents and medical personnel.

- Use concrete language (“picture-talk”) about animals or plants to describe differences (e.g. *dogs have special ears that hear things well, owls like things darker and wake up at night, flowers have tender petals like tender skin, etc.*)
- Help the child belong in the natural world with other living things by pointing out and appreciating differences (i.e. differences are normal in nature, not sameness)
- The child needs to know that they are accepted and not blamed when they get stuck. They need to know that they are safe. They have as much trouble accepting themselves when things aren’t working as adults do, only they have less ability to put this into words.

School-Aged Children

The child may understand simple explanations of the condition and want to know what is different about their bodies. Children are often concerned about what caused their difficulties.

- Talk about symptoms and strengths, while validating struggles and successes. Use visual metaphors (instead of medical slides designed for adult audiences) to help the child describe their experiences (e.g. “*it’s like a wall in my brain and sometimes a mouse gets through*” or “*it’s like snow on a TV screen in my head—it’s hard to tune in on one thing.*”)
- The child may ask you if any other children have it or if they are the only one. It is often helpful for them to know that someone else has felt the same way they have. They also may want to know how other children with FAS cope with their feelings and their condition.
- Help the child come to terms with the realness of the condition. The child will probably want to know if it will go away. Be honest with your child, and use specific examples that they will understand. (e.g. “*Some things might change, and some won’t. Your ears will always hear noises better than mine. You might always like activity the child likes better than some other activity like math,*” etc.) Minimizing or pretending that *it will all go away* or *there’s nothing to worry about* patronises the child’s effort to make sense out of their daily reality.
- Repeated questions about why the birth mother drank during pregnancy may be less about *why* (because life is not about fairness), and more about *how sad* and *frustrated* the child feels when things are hard for them. The child may be struggling to accept what is unacceptable—that they were hurt by someone they depended on. The child often needs honesty, encouragement and reassurance more than technical explanations. Use simple answers and ask what it’s like for them.
- Encourage children to take a role in their own self-care. At all ages, children feel more powerful when they help to create solutions for coping with their tougher symptoms. This may include choosing certain soothing methods when agitated or facing challenging circumstances.

Adolescents

Talk honestly, realistically, and constructively about the dilemmas posed by the condition. Discuss possible options. Questions need to be answered honestly and respectfully. Be direct. Adolescents generally hate to be patronised—they have low tolerance for adults who beat around the bush.

- Teens may want to know what to tell their friends if asked. Encourage simple, honest discussion. (e.g. “*I do it this way instead because that works better for me. Everybody’s different and people do things different ways.*”) Walk it through and role play if the adolescent wants to, or explore situations in your own life and ask for your teen’s advice as a teachable moment.
- Help them set clear boundaries—let them know that *they* get to choose what they want others to know (e.g. only telling helpers but not peers if the teen is worried about being teased.) Respect choices about disclosure.

- Adolescents may benefit from talking with other adolescents or even adults who are successfully coping with FAS. This will not only help the teen feel less alone, but also provide an opportunity for them to learn from role models who embody “togetherness” and good functioning. Peer support groups are also helpful, as they can provide guidance and mutual encouragement while supporting diversity.

Help & Support

Resource List

In this new edition of *A Guide for Daily Living*, we have updated and substantially expanded our Resource List.

Compiling an extensive list of this nature requires hours of research and attention to detail. We would like to acknowledge the following individuals for their contribution: Elspeth Ross, Adoption Council of Canada; Verna Booth, Society of Special Needs Adoptive Parents; Carole Legge, Provincial FAS/E Prevention Coordinator, British Columbia; Carole Julien and Karen Palmer, Canadian Centre on Substance Abuse.

The books, other media, and organizations listed here are intended as suggestions about where to look for help, not as endorsements. Please use care and sound judgment when selecting an information source, organization or program. *Does the resource meet your individual needs? Does the information you receive come from an accurate source?* Pay attention to your instincts, get a second opinion when necessary, and be open to “shopping around.”

Resource guides tend to get dated very quickly. By the time you read this, some of the information may be out of date. Books go in and out of print; publishers go out of business; organizations move, rename themselves or go under; contact people change. And in a growing field like FAS, new resources will become available.

Also, it’s impossible to include everything that may be relevant—the SNAP library alone has hundreds of materials related to FAS. But what we’ve listed here provides a solid place to start.

We will continue to update these resources in later editions of the *Guide*, and on the SNAP web site (currently <http://www.snap.bc.ca>). Please help us keep up to date by providing your feedback. Let us know if you encounter a book that is out of print, a phone number out of service, an information source providing inaccurate information, or an organization that is not very helpful, or perhaps even disrespectful—and so on. Also, please send in your suggestions for additions—your favourite book that we left out, the resource in your community that we didn’t know about, or a new resource you would like us to consider listing. Contact us at SNAP, 1150-409 Granville Street, Vancouver, B.C. V6C 1T2, Canada, phone (604) 687-3114, toll-free (in B.C.) 1-800-663-7627, fax: (604) 687-3364, e-mail <snap@snap.bc.ca>.

Books

Alberta Alcohol and Drug Abuse Commission. *Fetal Alcohol Syndrome & Other Birth Defects*, 2nd Edition. Edmonton: AADAC, 1996.

Alberta Alcohol and Drug Abuse Commission, Production and Distribution, 200 Pacific Plaza, 1099 Jasper, Edmonton, AB T5J 3M9. 1-800-280-9616 or (403) 427-7319; fax (403) 422-5237; email: aadacrdm@compusmart.ab.ca. Features a comprehensive literature review. The identification, effects, safe drinking level, father's contribution, incidences, labelling children and the prevention of FAS/E are covered.

British Columbia, Ministry of Education and Training, Special Programs Branch. *Teaching Students with Fetal Alcohol Syndrome / Effects: A Resource Guide for Teachers*. Victoria: British Columbia, Ministry of Education and Training, 1996.

Contact Crown Publications (250) 386-4636; fax (250) 386-0221. Available in full-text on the Internet at <http://www.est.gov.bc.ca/specialed/fas/title.html>. Dr. Julie Conry (see *Foreword* in this copy of SNAP'S *Guide for Daily Living*) is the principal writer and researcher for this valuable teacher's resource.

Burd, Larry. *Fetal Alcohol Syndrome*. Grand Forks, ND: Author, 1995.

Larry Burd, 1300 S. Columbia Road, Grand Forks, ND 58202. This handbook covers: diagnosis of FAS; development of children with FAS; behaviour; costs; treatment; medication; attention deficit hyperactivity disorder and FAS; the future; prevention; management; education; support; and social skills.

Copeland, Brenda and Deborah Rutman. *Young Adults with Fetal Alcohol Syndrome or Fetal Alcohol Effects: Experiences, Needs and Support Strategies*. Victoria, British Columbia: School of Social Work, University of Victoria, 1996.

Child, Family and Community Research Program, School of Social Work, Box 1700, University of Victoria, Victoria, BC V8W 2Y2; email cfcpr@hds.uvic.ca. Living with FAS is a life long challenge. This study addresses issues faced by young adults with FAS, such as pregnancy, parenting, and developing independent living skills.

Dorris, Michael. *The Broken Cord*. New York: Harper Collins, 1989.

Dorris recounts his struggle to find the cause of his adopted son Adam's physical, behavioural and learning difficulties. This is *the* groundbreaking book that had a huge impact on public awareness of FAS when it was first published in the late 80s.

Edelstein, Susan. *Children with Prenatal Alcohol and/or Other Drug Exposure: Weighing the Risks of Adoption*. Washington, D.C.: CWLA Press, 1995.

Child Welfare League Press, 440 First Street, NW, Suite 310, Washington, DC 20001-2085, phone (202) 638-2952; fax (202) 638-4004. Designed primarily for professionals, this book offers practical suggestions, recommendations, and food for thought for preparing, counselling, and working with those who are considering adoption of a child who has been prenatally exposed to alcohol or drugs.

Fernandez Villarreal, S. *Handle with Care: Helping Children Prenatally Exposed to Drugs and Alcohol*. Scott Valley, CA: ETR, 1992.

ETR Associates, 19 Janis Way, Scott Valley, CA 95066-4200. Suggestions for teachers, parents and other care providers of children to age ten.

Fetal Alcohol Syndrome/Effects (5 part series): Booklet 1: *Identifying FAS/FAE*; Booklet 2: *Parenting Children (0-12 Years) Affected by FAS/E*; Booklet 3: *Parenting Adolescents Affected by FAS/E: A Guide for Daily Living*; Booklet 4: *Educational Approaches for Children with FAS/E: A Guide for Caregivers*; and Booklet 5: *Working with FAS/E Adults*. Compiled by Nykola Dubiensi. Winnipeg: Association for Community Living, 1996-97.

This series features information compiled from existing publications, including substantial material from the first edition of SNAP's *Guide for Daily Living*. To order, please contact (204) 786-1607; fax: (204) 786-1607.

George, Anne. *FAS, FAE, NAS Resource*. Includes: FAS/FAE & NAS Community Prevention Guide; Guide for Parents, Teachers and Others Caring for Children with FAS/FAE or NAS; FAS/FAE and NAS Guide to Resources. Vancouver: YWCA Crabtree Corner, Fetal Alcohol Syndrome, Neonatal Abstinence Syndrome Prevention Project, 1996, 1993.

Contact YWCA Crabtree Corner for more information, at (604) 689-2808; fax: (604) 689-5469.

Kleinfeld, Judith and Siobhan Wescott, eds. *Fantastic Antone Succeeds! Experiences in Educating Children with Fetal Alcohol Syndrome*. Fairbanks: University of Alaska Press, 1993.

Available from the B.C. FAS/E Support Network. (604) 525-5069; fax: (604) 521-1958 or through NOFAS (National Organization on Fetal Alcohol Syndrome U.S.) (202) 785-4585; fax: (202) 466-6456. The reality of FAS is far more hopeful and far more complex than the stories we hear about those with FAS.

Leon's Mom. *And Have Not Love*. Duncan, BC: Metaphor Publishing, 1997.

Available through the SNAP office, 1150-409 Granville Street, Vancouver, B.C. V6C 1T2, phone (604) 687-3114 or toll-free (in BC) 1-800-663-7627, or directly from the Duncan SNAP FAS/E Parent Support Group, Box 1217, Lake Cowichan, B.C. V0R 1G0. Leon's Mom began writing poetry in 1995 in her FAS/E Parent Support Group as a way of sharing the difficulties of parenting teens and young adults struggling with alcohol related birth defects. A selection of poems have been put together in this collection to share these experiences more widely, and to increase public awareness.

Malbin, Diane. *Fetal Alcohol Syndrome Fetal Alcohol Effects Strategies for Professionals*. Hazelden. Center City, MN: Author, 1993.

15251 Pleasant Valley Road, Box 176 Center City, MN 55012-176. Ideal book for the professional who deals with FAS clients. Some information for the adult with FAS.

McIntyre-Palmer, Florence. *Two Sides of the Coin*. Calgary: Author, 1995.

The author shares her daughter's story. Available through Florence McIntyre-Palmer, (403) 276-1577; fax: (403) 277-2933.

Normand, Claude and Deborah Rutman. *Caring for Children with Fetal Alcohol Syndrome*. Victoria, British Columbia: School of Social Work, University of Victoria, 1996.

Child, Family and Community Research Program, School of Social Work, Box 1700, University of Victoria, Victoria, BC V8W 2Y2; email cfcrrp@hsd.uvic.ca. This book covers: getting a diagnosis, financial costs, emotional toll, education issues, advocacy, attachment issues, and long term support needs. The issues for the families who have children with FAS that are addressed are: disbelief, isolation, blame, denial, access to information and access to services (including the need for respite) and resources.

Rutman, Deborah and Claude Louise Normand. *Working with Families Affected by Fetal Alcohol Syndrome / Effects*. Victoria, British Columbia: School of Social Work, University of Victoria, 1996.

Child, Family and Community Research Program, School of Social Work, Box 1700, University of Victoria, Victoria, BC V8W 2Y2; email cfcpr@hsd.uvic.ca. This is a collaborative research project funded by the B.C. Ministry for Children and Families, out of the University of Victoria School of Social Work Child, Family and Community Research Program. Several recommendations are made regarding the needs of those working with families who either foster or adopt children affected by FAS.

Slinn, Jim. *FAS/FAE a Practical Guide for Parents*. Anchorage, AK: PARENTS, 1994.

Call SNAP office for purchasing information, (604) 687-3114 or toll-free in B.C. 1-800-663-7627. A small book full of practical tips for parents of FAS affected children.

Stratton, Kathleen, Cynthia Howe, and Frederick Battaglia. *Fetal Alcohol Syndrome: Diagnosis, Epidemiology, Prevention And Treatment*. Washington, DC: National Academy Press, 1996.

National Academy Press, 2101 Constitution Avenue, NW Washington, DC 20418. A source book for clinicians and researchers, this book presents the 1996 findings of the Institute of Medicine's Committee to Study Fetal Alcohol Syndrome. This volume discusses diagnosis, surveillance, prevention, and treatment of FAS and other possible alcohol-related effects from a broad perspective, problems associated with FAS epidemiology, and surveillance.

Streissguth, Ann. *Fetal Alcohol Syndrome: A Guide For Families and Communities*. Baltimore: Paul H. Brookes, 1997.

Based on the life work of Dr. Streissguth, one of the pioneers in the field, this guidebook presents an overview of FAS and explains how to identify the disorder, how to work with children (and adults) who have it, how to talk to parents about it, and how to prevent its occurrence through sensitive education of prospective mothers and society at large.

Streissguth, Ann, Fred L. Bookstein, Helen M. Barr, and Paul D. Sampson. *The Enduring Effects of Prenatal Alcohol Exposure on Child Development*. Ann Arbor: University of Michigan Press, 1996.

University of Michigan Press, 839 Green Street, Box 1104, Ann Arbor, MI 48106-1104 Phone (313) 764-4392. Alcohol is the most common neurobehavioural teratogenic drug used by pregnant women. Its effects are particularly harmful if it is consumed during the fetus's early gestation period. This volume reports the results of a study of the systematic effects of prenatal alcohol exposure on 500 children, followed from gestation for seven years. It is the first major longitudinal inquiry designed within the framework of behaviours teratology to illustrate the long-term effects of alcohol on the development—both mental and physical—of a child.

Streissguth, Ann, and Jonathan Kanter. *The Challenge of Fetal Alcohol Syndrome: Overcoming Secondary Disabilities*. Seattle: University of Washington Press, 1997.

In Canada, available through UBC Press, Vancouver, phone (604) 822-5959. In this book, various experts describe how to help people with FAS. A summary of recent findings and recommendations is presented by the team who conducted the largest study ever done on people of all ages with FAS and FAE. Twenty two experts, conference participants from the field of human services, education, and criminal justice, respond by describing their solutions to this problem of a birth defect that targets the brain and has lifelong consequences.

Streissguth, Ann, Robin A. Ladue, Sandra P. Randels. *A Manual on Adolescents And Adults With FAS With Special Reference to American Indians*. Seattle: University of Washington, 1988.

For ordering information, phone (206) 543-7155. This manual provides succinct information about FAS, focusing on older children and adolescents with special reference to America's First Peoples. (It is an older book but still has pertinent information.)

Videos

Cardinal, Gil. *David with FAS: A Story of Fetal Alcohol Syndrome*. 1996. Kanata Productions in co-production with the National Film Board of Canada and the CBC. NFB 1-800-267-7710.

David's condition went undiagnosed for the first 18 years of his life, causing confusion, anger, and pain for both David and his adoptive family.

Caring Together. 1996. Native Physicians Association in Canada, 103 1785 Alta Vista Drive, Ottawa, ON K1G 3Y6, Phone (613) 521-6582.

This is a video about caring and pregnancy for community caregivers who provide preconceptual and prenatal health information to Aboriginal people. There is an accompanying discussion guide.

Fetal Alcohol Syndrome and Effect: Stories of Help and Hope. 1994.

Hazelden 15251 Pleasant Valley Road, Box 176 Center City, MN 55012-176. This video presents a balanced view of the medical and social consequences of FAS and FAE. Excellent for women in treatment, addiction professionals, and community education programs, the video is centered on current work being done with children affected by FAS and their families. It provides a factual definition of FAS and FAE, explains how children are diagnosed, and most importantly, vividly illustrates the positive prognosis possible for FAS-affected children.

Helping Families-Helping Children. 1997. Yellowknife Films, for Yellowknife Association for Community Living, P.O. Box 981, Yellowknife, NT X1A 2N7 Phone 403-920-2644.

This video describes what FAS is, how it is diagnosed and how it affects the child who has it. A case for early intervention is made. Specific suggestions are given on how to educate these children, how to make abstract ideas seem real, and how to discipline.

Preventable Tragedy Fetal Alcohol Syndrome / Effects. 1991. NCA/Long Beach Area Council on Alcoholism and Other Drug Dependencies, 836 Atlantic Avenue, Long Beach, CA 90813.

This video shows interviews with birth and adoptive mothers of FAS/FAE victims. Parents talk about their expectations for their children and how they deal with them.

Rakel, Bob. *Family Practice Update: Fetal Alcohol Syndrome*. 1992. Lifetime Television, NY, NY.

This is a video with three parts from Lifetime Television's Family Practice Update. Dr. Bob Rakel has Dr. Ken Jones, Dr. Ann Streissguth, and Dr. Larry Culpepper discussing FAS, recognition of it, managing pregnancies, children and debunking myths.

A Series about FAS Program (3 parts), 1991: 1: *What Is FAS?*, 2: *Preventing FAS*, and 3: *Living with FAS*. Ministry of Health, 5th Floor, 1515 Blanshard Street, Victoria, B.C. V8W 3C8.

Wherever alcohol is abused, children are born with FAS. This video, designed for families,

educators and health professionals, examines the cause, treatment, and prevention of alcohol related birth defects.

What's Wrong with My Child? 1991. Marlin Motion Pictures Ltd., 211 Watline Avenue, Mississauga, ON L4Z 1P3.

This 20/20 segment introduces researchers Dr. Sterling Clarren and Ann Streissguth. Clarren notes the alcohol consumed by a pregnant woman reaches the brain of the fetus which is developing continually during pregnancy.

Informative Newsletters

About FASE: A Publication of the FAS/E Support Network of B.C. Quarterly. \$30/year. (604) 525-5069; fax (604) 521-1958; email: fasnet@istar.ca

F.A.S. Times: Fetal Alcohol Syndrome/Family Resource Institute Newsletter. Quarterly. US\$20 (family) or US\$30 (professional). FAS/FAE, P.O. Box 2525, Lynnwood, WA 98036, U.S.A.

Iceberg: an Educational Newsletter for People Concerned about Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effects (FAE). Quarterly. Includes Canadian information. Seattle, Washington. \$12 Can (family) or \$25 Can (professional). P.O. Box 95597, Seattle, WA 98145-2597, U.S.A. (206) 827-1773

Society of Special Needs Adoptive Parents Newsletter. Quarterly. \$25 (family) or \$35 (group/society). Provides the latest information for parents, professionals and others interested in special needs and adoption issues, including FAS. SNAP, 1150-409 Granville Street, Vancouver, BC V6C 1T2. (604) 687-3114; fax (604) 687-3364, e-mail: snap@snap.bc.ca

Internet

The *FASlink* listserv, maintained by the Canadian Centre on Substance Abuse in Ottawa, is an electronic support group and forum for the discussion of issues and concerns related to FAS. To join, send an e-mail to manager@list.ccsa.ca with the message "join faslink." Those who do not have the time or energy to read a large number of e-mail messages each day may subscribe to a digest version. Contact CCSA for details at (613) 235-4048 or toll-free 1-800-559-4514, or by e-mail: kpalmmer@ccsa.ca

The Canadian Centre on Substance Abuse also provides information on FAS on the World Wide Web: <http://www.ccsa.fasgen.htm>

Organizations

This is a list of FAS-related organizations and agencies providing services to British Columbians. Agencies with a national mandate are noted first, followed by a listing of services within the province. This is not intended to be an exhaustive list. We have included central agencies who will be able to refer you to more specific resources in your area.

National

FAS/FAE Information Service

Canadian Centre on Substance Abuse

75 Albert Street, Suite 300

Ottawa, ON K1P 5E7

tel: 1-800-559-4514; or (613) 235-4048, ext. 223, fax (613) 235-8101

email: fas@ccsa.ca; <http://www.ccsa.ca/fasgen.htm>

CCSA maintains the data-base of FAS/FAE support groups and contacts for all of Canada, which is available both on the INTERNET and in book form. *Faslink*—an electronic listserv for discussion of FAS/FAE issues—is also available. *See section on INTERNET resources.*

Adoption Council of Canada

180 Argyle Ave., #329

Ottawa, ON K2P 1B7

tel: (613) 235-1566; fax: (613) 235-1728

email: acc@adoption.ca; <http://www.adoption.ca>

Aboriginal Nurses Association of Canada

Marilyn Van Bibber

192 Bank Street

Ottawa, ON K2P 1W8

tel: (613) 236-3373; fax: (613) 236-3599

e-mail: info@anac.on.ca

Motherisk Program

Division of Clinical Pharmacology and Toxicology

Hospital for Sick Children

555 University Avenue

Toronto, ON M5G 1X8

tel: 1-877-327-4636

Bilingual service offered to callers throughout Canada. This toll-free information line provides information on the possible risks of consuming alcohol and drugs during pregnancy. Wherever possible, referrals are provided to services in the caller's home region.

Health Units

Local health units throughout Canada have resources and educational materials on the subject of FAS/FAE and on healthy pregnancies. Check your local phone directory for a health unit in your community.

Canadian Association for Community Living

Kinsmen Building
York University
4700 Keele Street
Toronto, ON M3J 1P3
tel: (416) 661-9611

The Canadian Association for Community Living is a federation of local associations across Canada. There are 90 associations in B.C. that serve individuals with mental disabilities and their families. The Association as a whole lobbies, educates with and for individuals to ensure opportunities, access, justice and rights in all areas of their lives. There are a number of local organizations throughout B.C. which have included work with individuals affected by FAS as part of their mandate.

Contact for B.C.:

B.C. Association for Community Living

#300 - 30 East 6th Avenue
Vancouver, B.C. V5T 4P4
tel: (604) 875-1119; fax: (604) 875-6744
e-mail: info@bcacl.org

British Columbia

Provincial FAS Prevention Coordinator

Women's Health Centre
5th Floor Rm E501
4500 Oak Street
Vancouver, B.C. V6H 3N1
tel: (604) 875-3599; fax: (604) 875-2039

The coordinator provides an information and referral service for the public on how to access information, resources, expertise and services related to FAS/E. The coordinator also helps with networking among health, education, justice and social service agencies and provides support to community groups addressing FAS issues. The position is fully funded by the Ministry for Children and Families.

Society of Special Needs Adoptive Parents (SNAP)

#1150 - 409 Granville Street
Vancouver, BC V6C 1T2
tel: (604) 687-3114; toll free in B.C.: 1-800-663-7627; fax: (604) 687-3364
e-mail: snap@snap.bc.ca; web site: <http://www.snap.bc.ca>

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-to-one contact resource parents throughout B.C. The Society operates a toll-free (in B.C.) telephone contact line and publishes a quarterly newsletter, as well as publishing booklets such as this one! SNAP also maintains a large resource library of books, periodicals, reports, audio tapes and videos on adoption and special needs-related issues.

BCANDS Resource Centre

1179 Kosapsum Crescent

Victoria, B.C. V9A 7K7

Toll Free: 1-888-815-5511

tel: (250) 381-7303; fax: (250) 381-7312

Resources are available to First Nations parents, groups and educators. There are videos, kits, manuals, displays and brochures dealing with FAS and the effects of alcohol on pregnancy.

B.C. FAS Resource Society

Sunny Hill Health Centre for Children

3644 Slocan Street

Vancouver, B.C. V5M 3E8

Project Office:

#302 11965 Fraser Street

Maple Ridge, B.C. V2X 8H7

tel: (604) 465-5211; fax: (604) 465-8204

The B.C. FAS Resource Society encourages the provision of information, support and services to families, professionals and the broader community around prevention, intervention and treatment issues relating to alcohol and other drug related developmental disabilities including FAS/E. Publications include: B.C. FAS Resource Society Newsletter; information pamphlets; FAS Community Action Guide: Youth in the Criminal Justice System; Identifying FAS and Other Alcohol Related Neurodevelopmental Disabilities; and a series of videos about FAS: What's FAS?; Prevention of FAS; and Living and Learning with FAS.

FAS/E Support Network of B.C.

Suite 187 151 10090 152nd Street

Surrey, B.C. V3R 8XA

tel: (604) 589-1854; fax: (604) 589-8438

e-mail: fasnet@istar.ca

The FAS/E Support Network, a parent-based group, provides information, support, consultation and advocacy services for individuals, families, professionals and the broader community around prevention, intervention and treatment issues pertaining to alcohol related birth defects caused by alcohol use during pregnancy. Included in the services are the WARMLINE and FAS support groups and publications

Vancouver Aboriginal Friendship Centre Society

1607 East Hastings Street

Vancouver, B.C. V5L 1S7

tel: (604) 251-4844; fax: (604) 251-1986

The Vancouver Aboriginal Friendship Centre Society's Fetal Alcohol Syndrome Program offers the following services: support services for children, youth, parents, elders, professionals; support groups for individuals diagnosed with FAS/E assessment, A/D counselling, residential treatment, and family violence; FAS/E outreach services for women who drank alcohol and took other drugs during pregnancy; information about pregnancy and liaison between VAFCS and the Aboriginal community; and FAS Workshops.

YWCA Crabtree Corner FAS/NAS Prevention Project

101 East Cordova Street
Vancouver, B.C. V6A 1K7

tel: (604) 689-2808; fax: (604) 689-5463

YWCA Crabtree Corner FAS/NAS Prevention Project offers FAS/NAS educational workshops, a resource lending library, a peer support group for moms with children with FAS/NAS and information and crisis counselling. Crabtree Corner has published posters and pamphlets, as well as three guides.

Fetal Alcohol and Drug Effects Resource Coalition

Regional Coordinator

Box 1249

Vanderhoof, BC V0J 3A0

tel: (250) 567-9205; fax: (250) 567-3939

Contacts for the eight sites:

Burns Lake (250) 692-1722

Fraser Lake (250) 699-8386

Vanderhoof (250) 576-9205

Fort St. James (250) 996-7645

Prince George (250) 561-2689

Quesnel (250) 992-8347

Williams Lake (250) 392-4481

100 Mile House (250) 395-5500

Each site delivers services required to meet local needs. Services may include direct support for at-risk prenatal and postnatal women through counselling, referrals, education and advocacy; work with caregivers, parents or foster parents of affected children or with preschool children themselves; and information and education about fetal alcohol and drug effects presented to school children, school staff, partner agencies, community groups and the general public.

Prevention Source B.C.

2730 Commercial Drive, Suite 210

Vancouver, B.C. V5N 5P4

tel: (604) 874-8452; toll free: 1-800-663-1880; fax: (604) 874-9348

e-mail: info@preventionsource.bc.ca

Prevention Source provides a toll-free information service for residents of the province seeking information about prevention contacts, organizations, programs, materials and research in the area of substance misuse. The Centre also has a collection of prevention resource materials for on-site use. Included in this collection are a variety of FAS and NAS resource materials.

Substance Exposure Resource Team

Sunny Hill Centre for Children's Health, B.C. Children and Women's Hospital

3644 Slocan Street

Vancouver, B.C. V5M 3E8

tel: (604) 453-8300, Local 8221; fax: (604) 453-8301

web: <http://www.cw.bc.ca>

Sunny Hill provides in patient and outpatient service to children (birth to 19) and their families where questions have arisen around the possible impact of prenatal exposure to alcohol and/or other drugs. Service may take the form of consultation and initial linking to available

community resources, diagnosis and developmental assessment, medical and social support to inpatient infants experiencing withdrawals. Community education is a vital component to all of Sunny Hill's clinical outreach.

Federation of Invisible Disabilities

1818 Belmont Avenue
Victoria, B.C. V8R 3Z2
tel: (250) 595-3569; fax: (250) 370-9309
e-mail: noise@islandnet.com

The Federation of Invisible Disabilities establishes a collective and united organization to create and direct change on behalf of and with children, youth and adults with invisible disabilities. The federation promotes awareness and public education regarding invisible disabilities, and provides information and support to parents and caregivers.

Family Support Institute

Suite 300, 30 East 6th Avenue
Vancouver, B.C. V5T 4P4
tel: (604) 875-1119; fax: (604) 875-6744
e-mail: info@bcacl.org

Family Support Institute provides information, training and province-wide networking to assist families and their communities to build upon and share strengths.

NISHA Family and Children's Services Society

Vancouver Region
#201 - 2830 Grandview Highway
Vancouver, B.C. V5M 2C9
tel: (604) 412-7950; fax: (604) 412-7951
e-mail: mailbox@nisha.org

NISHA Family and Children Services offers a variety of homes, programs and services for children, youth and families.

Learning Disabilities Association of B.C.

Provincial Office
1524 Fort Street
Victoria, B.C. V8S 5J2
tel: (250) 370-9513; fax: (250) 370-9421
e-mail: Ida-svi@commercial.net

The Learning Disabilities Association advances the education and general well-being of children and adults who have learning disabilities through the provision of information, referrals and support. The Association operates a resource centre where books, tapes and films may be borrowed. Speakers are available on request. The Learning Disabilities Association has 17 local chapters. Chapters with offices are in:

Vancouver	873-9511
Vernon	542-5033
South Vancouver Island	386-9511
Williams Lake	392-7801

Hours are from 9:00 am to 4:00 pm, Monday to Friday.

Kindale Developmental Association

Box 94

Armstrong, B.C. V0E 1B0

tel: (250) 546-3005; fax: (250) 546-3035

e-mail: kindale@mindlink.bc.ca

Kindale Developmental Association is a non-profit society which has been serving persons with mental and physical disabilities in the North Okanagan. The Society offers residential and a broad range of day programming to both children and adults.

Office of the Child, Youth and Family Advocate

Box 6, Suite 600, 595 Howe Street

Vancouver, B.C. V6C 2T5

tel: (604) 775-3203; toll-free: 1-800-476-3933; TTY (604) 775-3680; fax: (604) 775-3205

e-mail: info@advokids.org

web: www.advokids.org

The Office of the Child, Youth and Family Advocate has staff who help children and youth and their families when they feel they're not getting the services they need from the provincial government.

After Hours Foster Families Support Line Program

This service is designed to support foster parents who are dealing with difficult child behaviour issues by providing immediate support and expertise outside of regular Ministry for Children and Families office hours.

The After Hours Foster Families Support Line is staffed by professional caregivers with experience in a therapeutic foster care setting and/or a child and youth care residential setting. The staff provide professional consultation and support related to living with and managing difficult behaviour of children and youth in the Ministry's care, including difficult behaviour presented by children affected by FAS.

Call toll-free: 1-888-495-4440.

Hours of operation are Monday to Friday, 4:00 pm to 12:45 am, statutory Holidays and Weekends, 8:00 am to 12:45 am.

B.C. Federation for Foster Parents Association

3680 East Hastings, #301

Vancouver, B.C. V5K 2A9

tel: (604) 660-7696 or toll-free (in B.C.): 1-800-663-9999

Federation of Aboriginal Foster Parents Association

300-3680 East Hastings Street

Vancouver, B.C. V5K 2A9

tel: (604) 291-7091; fax: (604) 291-7098

e-mail: fafp@direct.ca

web: <http://mypage.direct.ca/f/fafp>

The Federation of Aboriginal Foster Parents is a non-profit organization run by and for Aboriginal caregivers throughout B.C. The Federation works in partnership with the B.C. Federation of Foster Parent Associations to provide support and training to Aboriginal caregivers and non-Aboriginal people caring for Aboriginal children in a way that respects Aboriginal culture and traditions.

Infant Development Program of British Columbia

2765 Osoyoos Crescent

Vancouver, B.C. V6T 1X7

tel: (604) 822-4014; fax: (604) 822-9556

e-mail: infantdv@unixg.ubc.ca

Infant Development Programs in B.C. provide home visits and group experiences for families with children aged birth through three at risk for, or living with, a developmental challenge. For families with a child with FAS or where a parent has FAS, information and support is given to the family that will promote the child's development and strengthen family capacity. (Member, B.C. Association for Child Development & Rehabilitation.)

FAS/NAS Early Intervention Consultant

Aurora Centre, B.C. Children & Women's Hospital

4500 Oak Street, 5th Floor

Vancouver, B.C. V6H 3N1

tel: (604) 875-2017; fax: (604) 875-2039

e-mail: jamos@cw.bc.ca

The early intervention consultant works with health and social service providers towards the provision of improved early intervention approaches with women at risk; develops and supports policy work regarding appropriate and accessible treatment options for women using alcohol and other drugs during pregnancy; and gathers and disseminates information on effective early intervention strategies for women who are pregnant and using substances.

Bibliography

- Aase, Jon M. (1994). "Clinical recognition of FAS: Difficulties of detection and diagnosis" *Alcohol Drug and Research World*, 18 (1), 5-9.
- Alberta Alcohol and Drug Abuse Commission. (1996). *Fetal Alcohol Syndrome and Other Alcohol-related Birth Defects* (2nd ed.). Edmonton: Author.
- Astley, S. J., & Clarren, S. K. (1995). A Fetal Alcohol Syndrome screening tool. *Alcoholism: Clinical and Experimental Research*, 19(6), 1565-1571.
- Bakley, S. & Whitney, M.F. (1995). Establishing and maintaining connections. In K. D. Lewis (Ed.), *Infants and Children with Prenatal Alcohol and Drug Exposure: a Guide to Identification and Intervention* (pp. 258-271). North Branch, MN: Sunrise River Press.
- Blaine, K. (1994, summer). Management interventions for the young child prenatally exposed to drugs and alcohol. *FAS Times*, 5-7.
- British Columbia. Ministry of Education, Skills and Training, Special Programs Branch. (1996). *Teaching Students with Fetal Alcohol Syndrome / Effects: A Resource Guide for Teachers*. Victoria: Author.
- Clarren, S. (1996). Rationale and development for a network of clinics for diagnosis and prevention of FAS. In *Coming Together to Meet the Challenges of FAS / NAS: Identifying Issues and Finding Solutions: Conference Syllabus* (pp.87-100). Vancouver: Sunny Hill Health Centre for Children & Continuing Education in the Health Sciences, University of British Columbia.
- Copeland, B., & Rutman, D. (1996, October). *Young Adults with Fetal Alcohol Syndrome or Fetal Alcohol Effects: Experiences, Needs and Support Strategies*. Victoria: School of Social Work, University of Victoria.
- Davis, D. (1991). *Reaching Out to Children with FAS: A Handbook for Teachers, Counselors and Parents Who Work With Children Affected by Fetal Alcohol Syndrome and Fetal Alcohol Effects*. West Nyack, NY: Center for Applied Research in Education.
- George, A. (1993). *Guide for Parents, Teachers and Others Caring for Children with FAS / FAE and NAS*. Vancouver: Vancouver YWCA Crabtree Corner, 1993.
- Gerring, L. (1993). *Children with Fetal Alcohol Syndrome: A Handbook for Caregivers*. St. Paul, MN: Human Service Associates.
- Health Canada. (1996, October). *Joint Statement: Prevention of Fetal Alcohol Syndrome (FAS) Fetal Alcohol Effects (FAE) in Canada* (Cat.: H39-348/1996E). Ottawa: Author.
- Kim, S. (1994). *Managing the Challenges of Fetal Alcohol Syndrome: A Handbook for Caregivers*. San Francisco: The Clearinghouse for Drug Exposed Children.

- Lutke, J. (1993). Parental advocacy for alcohol-affected children. In J. Kleinfield and S. Wescott (Eds.), *Fantastic Anton Succeeds!* (pp. 71-95.) Fairbanks, AK: University of Alaska Press.
- Malbin, D. (1996). When good techniques don't work: trying differently rather than harder. In *Coming Together to Meet the Challenges of FAS/NAS: Identifying Issues and Finding Solutions: Conference Syllabus* (pp. 115-137). Vancouver: Sunny Hill Health Centre for Children & Continuing Education in the Health Sciences, University of British Columbia.
- Mattson, S. N., & Riley, E. P. (1997). Neurobehavioral and neuroanatomical effects of heavy prenatal exposure to alcohol. In A. Streissguth & J. Kanter (Eds.), *The Challenge of Fetal Alcohol Syndrome: Overcoming Secondary Disabilities* (pp. 3-14). Seattle: University of Washington Press.
- Morse, B. (1993). Information processing: Identifying the behavioral disorders of Fetal Alcohol Syndrome. In J. Kleinfield and S. Wescott (Eds.), *Fantastic Anton Succeeds!* (pp. 23-36.) Fairbanks: University of Alaska Press, 1993.
- Morse, B.A. & Weiner, L. (1993). *FAS: Parent and Children*. Brookline, MA: Fetal Alcohol Education Program, Boston University School of Medicine.
- Murphy, M. F. (1991). *Hope for the FAS/FAE Nowhere Child: An Educational Approach for Successes in the Classroom*. Bethel, AK: Lower Kuskokwim School District.
- Normand, C. L., & Rutman, D. (1996, March). *Caring for Children with Fetal Alcohol Syndrome*. Victoria: School of Social Work, University of Victoria.
- Rathbun, A. (n.d.a). *Acceptance in Action*. (Available from A. Rathbun, M.A., A.T.R., 909 S.W. St. Clair, Portland, Oregon 97205).
- Rathbun, A. (n.d.b). *Common Reactions to Receiving a Diagnosis*. (Available from A. Rathbun, M.A., A.T.R., 909 S.W. St. Clair, Portland, Oregon 97205).
- Rathbun, A. (n.d.c). *Patterns of Conditions in Children*. (Available from A. Rathbun, M.A., A.T.R., 909 S.W. St. Clair, Portland, Oregon 97205).
- Rathbun, A. (n.d.d). *Psychosocial Tasks: Coping After Diagnosis*. (Available from A. Rathbun, M.A., A.T.R., 909 S.W. St. Clair, Portland, Oregon 97205).
- Rathbun, A. (n.d.e). *Talking About FAS/FAE with Children*. (Available from A. Rathbun, M.A., A.T.R., 909 S.W. St. Clair, Portland, Oregon 97205).
- Rutman, D., & Normand, C. L. (1996, May). *Working with Families Affected by Fetal Alcohol Syndrome/Effects*. Victoria: School of Social Work, University of Victoria.
- Slinn, J. (1994). *FAS/FAE: a Practical Guide for Parents*. Anchorage, AK: Parents.
- Sparks, S. (1993). *Children of Prenatal Substance Abuse*. San Diego: Singular Publishing Group.
-

- Stratton, K., Howe, C., & Battaglia, F. (1996). *Fetal Alcohol Syndrome: Diagnosis, Epidemiology, Prevention, and Treatment*. Washington: National Academy Press.
- Streissguth, A., Barr, H., Kogan, J., & Bookstein, F. (1997). Primary and secondary disabilities in Fetal Alcohol Syndrome. In A. Streissguth & J. Kanter (Eds.), *The Challenge of Fetal Alcohol Syndrome: Overcoming Secondary Disabilities* (pp. 25-39). Seattle: University of Washington Press.
- Streissguth, A. P. (1997). *Fetal Alcohol Syndrome: a Guide for Families and Communities*. Baltimore: Paul H. Brookes Publishing Co.
- Streissguth, A. P., Aase, J. M., Clarren, S. K., Randels, S. P., LaDue, R. A., & Smith, D. F. (1991). Fetal Alcohol Syndrome in adolescents and adults. *JAMA* 265 (15), 1961-1967.
- Streissguth, A.P., Barr, H.M., Kogan, J., & Bookstein, F.L. (1996). *Understanding the Occurrence of Secondary Disabilities in Clients with Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effects (FAE): Final Report to the Centers for Disease Control and Prevention (CDC) on Grant No. R04/CCR008515* (Tech. Report No. 96-06). Seattle, University of Washington, Fetal Alcohol and Drug Unit.
- Streissguth, A. P., Bookstein, F. L., Sampson, P. D., & Barr, H. M. (1993). *The Enduring Effects of Prenatal Alcohol Exposure on Child Development: Birth through seven years, a partial least squares solution*. Ann Arbor: University of Michigan Press.
- Streissguth, A. P., LaDue, R. A., & Randels, S. P. (1988). *A Manual on Adolescence and Adults with Fetal Alcohol Syndrome with Special Reference to American Indians* (2nd ed.). Seattle: University of Washington.
- Streissguth, A. P., & Little, R. E. (1994). Alcohol: Pregnancy and the Fetal Alcohol Syndrome. *Krock Foundation Slide Curriculum on Alcoholism, Unit 9: Alcohol and Pregnancy*. Timonium, MD: Milner-Fenwick.
- Tanner-Halverson, P. (1991a). *Strategies for Parents of FAS/FAE*. Sells, AZ: Indian Oasis School District.
- Tanner-Halverson, P. (1991b). *Survival Skills for Parents of FAS/FAE*. Sells, AZ: Indian Oasis School District.
- Wegmann, M., Colfax, L., Gray, M., & Reed, B. (1995). *Assessment and Resource Guide for FAS/FAE: Fetal Alcohol Syndrome/Fetal Alcohol Effect* (revised ed.). Port Angeles, WA: Pen Print Inc.
- Weiner, L., & Morse, B.A. (1994). Intervention and the child with FAS. *Alcohol and Health Research World*, 18 (1), 67-72.

Acknowledgements

Grateful acknowledgement is made to the following authors and publishers for permission to reprint:

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Quotes from an adoptive parent, Ken, Luke's Mom, Nigel, and Bev, excerpted from back issues of *The Society of Special Needs Adoptive Parents Newsletter*, copyright © 1994, 1997, The Society of Special Needs Adoptive Parents (SNAP).

Facial Characteristics diagram from Streissguth and Little, "Alcohol: Pregnancy and the Fetal Alcohol Syndrome," *Krock Foundation Slide Curriculum on Alcoholism, Unit 9: Alcohol and Pregnancy*. Timonium, MD: Milner-Fenwick, 1994. Reprinted by permission of Dr. Ann Streissguth, University of Washington Fetal Alcohol and Drug Unit.

Seven Common Misconceptions about FAS/FAE by Dr. Ann Streissguth, from Streissguth, A.P. (1997). *Fetal Alcohol Syndrome: A Guide for Families and Communities* (306pp). Baltimore: Paul H. Brookes Publishing Co. Reprinted by permission of the author.

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Appendix

Diagnostic Criteria for Fetal Alcohol Syndrome (FAS) and Alcohol-Related Effects, as recommended by the Institute of Medicine (IOM), 1996. For further details and analysis, see Stratton, K., Howe, C., & Battaglia, F. (1996), *Fetal Alcohol Syndrome: Diagnosis, Epidemiology, Prevention, and Treatment*.

Fetal Alcohol Syndrome

1. FAS with confirmed maternal alcohol exposure^a

- A. Confirmed maternal alcohol exposure^a
- 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:
 - 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

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^a
- 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
- 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 behaviour 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,^{a,b} 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 behaviour 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
-

^a 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 behaviour while drinking, or alcohol-related medical problems such as hepatic disease.

^b 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.

ISBN 0-9698617-5-3