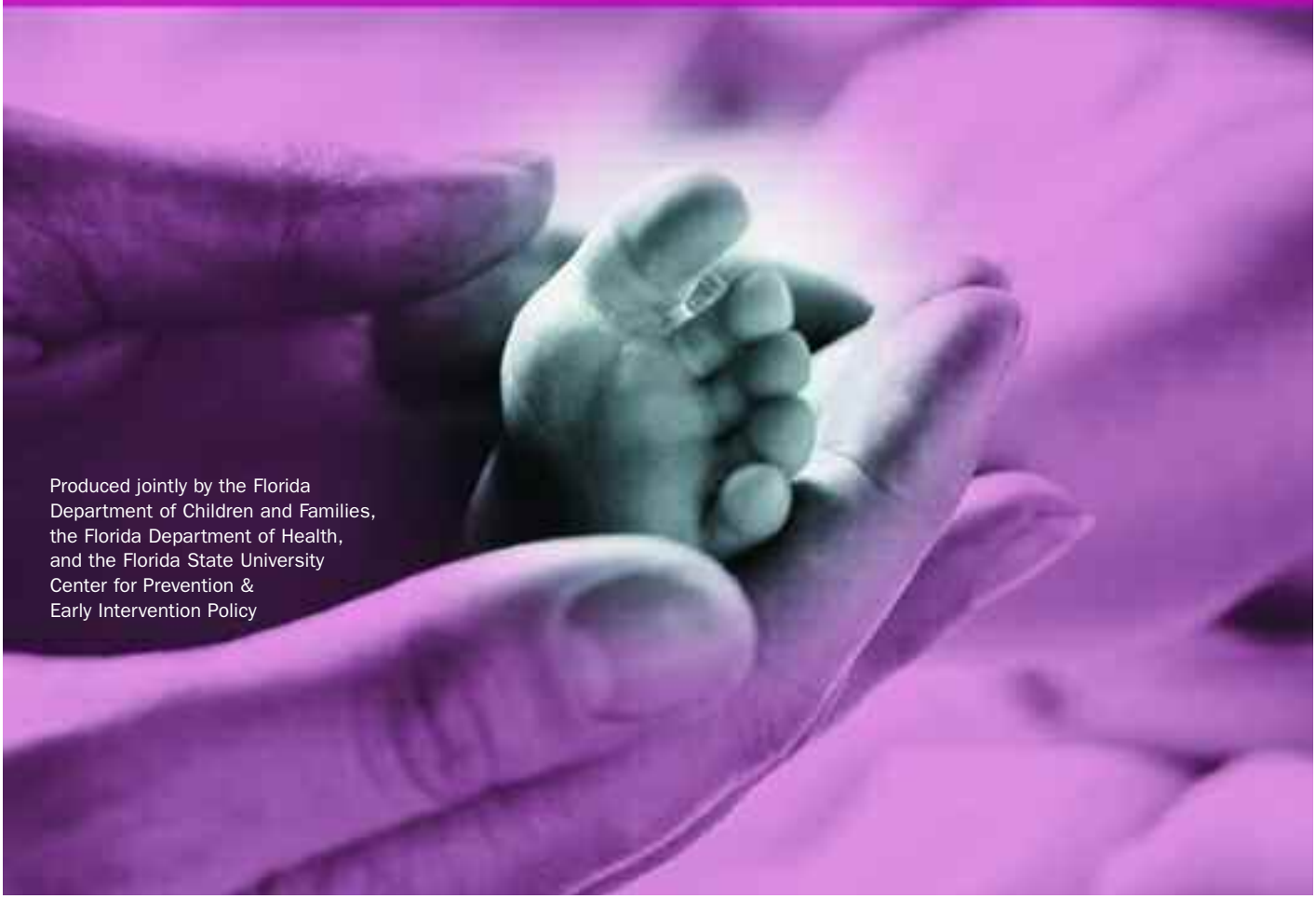
FETAL ALCOHOL SPECTRUM DISORDERS

florida resource guide



Produced jointly by the Florida Department of Children and Families, the Florida Department of Health, and the Florida State University Center for Prevention & Early Intervention Policy

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Fetal Alcohol Syndrom & Other Effects of Prenatal Alcohol Exposure

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The Florida State University Center for Prevention & Early Intervention Policy

Preface

On behalf of the Florida Fetal Alcohol Spectrum Disorders Interagency Action Group, we are pleased to present this resource guide. The guide summarizes key information from the body of knowledge about this topic.

The guide was prepared with a desire that it will be useful to individuals and families who are living with the results of fetal alcohol effects. Our purpose also was to provide a resource for professionals who seek to prevent fetal alcohol exposure and to offer interventions to assist affected individuals and families.

Florida's Fetal Alcohol Spectrum Disorders Interagency Action Group requested development of this guide and provided recommendations related to its content. The Florida Department of Health, Maternal and Child Health Program, led coordination of the FASD action group since it first convened in 2000. Its purpose is to develop and facilitate implementation of a plan and strategies to improve prevention, intervention, and support related to Fetal Alcohol Syndrome and Fetal Alcohol Effects. The action group includes committed state agencies, statewide organizations, the Florida Governor's Office, local service providers, advocates, and families who have fetal alcohol affected members. Key staff from the Departments of Health and of Children and Families who represented the action group to organize the project and serve as a review and editorial group, and the graphic artists, are identified in the Acknowledgements on page 2 of this guide.

We gratefully acknowledge the contributions of the many researchers and practitioners whose works are quoted throughout this guide. Among these, we offer special appreciation to: Larry Burd, Ph. D., Associate Professor at the University of North Dakota, Director of the North Dakota Fetal Alcohol Syndrome Center, who generously allowed Florida to include his Fetal Alcohol Screening Materials; Ann Streissguth, Professor, Department of Psychiatry and Behavioral Sciences at the University of Washington School of Medicine, whose exemplary research and publications are frequently quoted in the guide; Susan Astley, Associate Professor of Epidemiology/ Pediatrics, Director of the Washington State FAS Diagnostic & Prevention Network, University of Washington, who graciously allowed Florida to include her Fetal Alcohol Syndrome Facial Photographic Analysis Software materials; and Ed Riley, Ph.D., Center for Behavioral Teratology, Department of Psychology at San Diego State University who generously allowed Florida to use his research in this guide.

— Atrica Warr, M.Ed.

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JEB BUSH
GOVERNOR OF THE STATE OF FLORIDA

Fetal Alcohol Syndrome Awareness Day

WHEREAS, children are the most important resource in the great state of Florida; and

WHEREAS, Fetal Alcohol Syndrome is the leading cause of mental retardation in Florida, the United States, and all of western civilization; and

WHEREAS, as many as 1 in every 100 individuals in these United States may be adversely affected by prenatal exposure to alcohol; and

WHEREAS, Fetal Alcohol Syndrome and Effects are a root cause of numerous social disorders, including learning disabilities, juvenile delinquency, school drop-outs, homelessness, unemployment, mental illness, and crime; and

WHEREAS, economists estimate that each individual with Fetal Alcohol Syndrome and Effects will cost the U.S. taxpayer nearly $2 million in his or her lifetime; and

WHEREAS, people around the world will be observing the fourth International FAS Day on September 9,2002, in order that on the ninth day of the ninth month of the year, the world will remember that during the nine months of pregnancy a woman should abstain from alcohol; and

WHEREAS, Fetal Alcohol Syndrome and Effects are one hundred percent preventable if women do not drink during pregnancy;

NOW, THEREFORE, I, Jeb Bush, Governor of the state of Florida, do hereby extend greetings and best wishes to all observing **Fetal Alcohol Syndrome Awareness Day** September 9, 2002.

IN WITNESS WHEREOF, I have hereunto set my hand and caused the Great Seal of the state of Florida to be affixed at Tallahassee, the Capital, this 5th day of September in the year of our Lord two thousand two.

GOVERNOR

Introduction

The result of prenatal exposure to alcohol ranges from Fetal Alcohol Syndrome (FAS), the leading cause of mental retardation, to other fetal alcohol effects, which can cause lifelong disruptions in cognitive, linguistic, and social development. Florida's health care, education, juvenile and adult justice systems face significant challenges in addressing the needs of individuals with FAS and Fetal Alcohol Effects (FAE) and their families.

Families of children with FAS/FAE must deal with a multitude of issues touching every facet of their lives. In addition to addressing the immedicate physical, educational, and financial need of their child, families must also identify long-range strategies to ensure these needs are met throughout the lifetime of the child. Estimates of the total lifetime cost of caring for a typical child with FAS range from $1.4 million (Streissguth, Aase, Clarren, Randels, LaDue, & Smith 1991) to $3 million (Fetal Alcohol Support Network of Toronto & Peel 2001). Contributing to this cost is health care, special education, psychotherapy and counseling, welfare, crime, and the justice system.

The emotional toll on families should not be underestimated. For natural birth parents, recognizing that their child's mental retardation, birth defects, and/or neurodevelopment disorders are a result of maternal prenatal alcohol consumption is very difficult to face. For adoptive or foster parents, discovering that their child suffers from FAS/FAE after years of trying to understand his cognitive and behavioral problems results in feelings of frustration and isolation.

Health care costs associated with FAS are staggering. The Tenth Special Report to the U.S. Congress on Alcohol and Health estimated these costs to be $2.8 billion in 1998. Expenditures include care for low birth weight babies, surgical corrections of FAS related birth defects, heart defects, auditory defects, and moderate to severe mental retardation

Teachers face unique challenges in working with children with Fetal Alcohol Effects. Absent the characteristic facial abnormalities, many children are not diagnosed with FAE until they reach elementary school. Even then, classroom teachers may not have the tools or information to correctly identify the cause of cognitive or behavioral problems in a student. Best educational practices require children with special needs to be taught behaviors that help them succeed in school. This requires the development and implementation of an appropriate

Many things we need can wait; the child cannot. Now is the time his bones are being formed, his blood is being made, his mind is being developed. To him, we cannot say, tomorrow. His name is today.

— Gabriella Mistral, Chilean poet

educational plan. Despite the best efforts of general and special educators, parents often feel school personnel or programs do not understand or address the unique needs of children with FASD.

The number of juvenile and adult offenders with FASD currently incarcerated or under supervision is unknown. According to one study, 23% of individuals affected by prenatal alcohol exposure have been confined to a mental hospital, 15% to a drug treatment program, and 35% to a correctional system (Streissguth, 1996). In 2002 the cost of incarceration ranged from $17,570 per year for an adult offender (Florida Department of Corrections) to $180,00 for full completion of a program for a juvenile offender (Florida Department of Juvenile Justice).

Florida spends an estimated $78,918,000 annually to provide special education and juvenile justice services to children 5-18 years affected by FAS and FAE. This amounts to an estimated $914,183 spent per day for these services (www.online-clinic.com/calculator.php).

This resource guide provides important information to help families and health care professionals understand FASD. **Section One** defines FAS as well as other alcohol related effects and explains the latest terminology. **Section Two** explains how and when alcohol consumption affects fetal development. **Section Three** gives ten important facts about FAS that range from prevalence to causes and seven common myths. **Section Four** explains in detail the four criteria used to diagnose FAS and highlights two diagnostic tools used to identify individuals with FAS. **Section Five** describes the effects of FASD and provides cognitive, behavioral, educational, and health care intervention strategies for those working with individuals with FASD. **Section Six** outlines Florida's efforts in the prevention of FASD and compares several screening instruments currently used to identify women at risk for prenatal alcohol consumption. The **Resource Section** provides a comprehensive, but by no means all-inclusive, list of FASD resources.

The information provided in this resource guide is based on the research and literature currently available. It is our hope that it will provide the foundation for further dialogue and exploration into the prevention and early intervention of FASD.

SECTION 1

Overview of Fetal Alcohol Spectrum Disorders

Over the last several years the vocabulary used to describe individuals prenatally exposed to alcohol has evolved. Fetal Alcohol Syndrome was first identified in France in 1968 (Lemoine, et al) and in the U.S. in 1973 (Jones, et al). However, it was David Smith, the eminent scholar, who named the birth defect Fetal Alcohol Syndrome. Beginning in 1978, the term Fetal Alcohol Effects has been used to describe conditions that are presumed to be caused by prenatal alcohol exposure, but do not follow the exact configuration of the characteristics that uniquely identify FAS. In 1996, the Institute of Medicine proposed using the term Alcohol Related Neurodevelopmental Disorder (ARND) and Alcohol Related Birth Defects (ARBD) to describe conditions in which there is a history of maternal alcohol exposure and an outcome validated by clinical or animal research to be associated with that exposure (Stratton, Howe, & Battaglia, 1996). In addition, the term Fetal Alcohol Spectrum Disorders (FASD) has emerged to describe a spectrum or range of clinical conditions associated with prenatal alcohol exposure. Three diagnostic terms are used to describe this range of effects. FAS is used for those with full facial abnormalities, which include short palpebral fissures (eye slits), thin upper lip, shortened upturned nose, flattened, smooth wide philtrum, and flat midface. Partial Fetal Alcohol Syndrome (PFAS) is used to describe those without all the facial abnormalities, and ARND to describe those with little or no facial abnormalities. For the purposes of this resource manual FAS, FASD, PFAS, FAE, ARND, and ARBD will be used as they appear in the research supporting the information presented.

It is essential that we reach a level of public knowledge that will fuel tremendous change – change of a magnitude we have only now begun to appreciate.

– Anne Streissguth, 1997

Courtesy of Ann Streissguth

Fig. 1 Growing up with FAS

Fetal Alcohol Syndrome

Fetal Alcohol Syndrome (FAS) is a constellation of physical, cognitive, and behavioral abnormalities caused by prenatal exposure to alcohol (Jones, Smith, Ulleland, & Streissguth, 1973). FAS is defined by four criteria: prenatal alcohol consumption, characteristic facial abnormalities, growth retardation, and brain damage that results in intellectual difficulties or behavior problems.

FAS is highly individualized. Some babies are born with severe physical anomalies and mental retardation; others are only slightly affected (Streissguth, 1997). In addition to the abnormal facial features, pre and postnatal growth abnormalities, and mental retardation that define the condition, approximately 80 percent of children with FAS display behavior problems. As many as 50 percent of affected children also exhibit poor coordination, attention-deficit hyperactivity disorder, decreased fatty tissue, and identifiable facial anomalies such as cleft palate, and abnormal smallness of jaw. Cardiac defects, hermangiomas (biologically active birthmarks) and eye or ear abnormalities are also common (American Academy of Pediatrics, 2000).

Like most birth defects, FAS is a lifelong condition. While the most easily recognizable, growth and facial features are not really the essence of FAS, they are simply early markers that, in combination with Central Nervous System (CNS) effects, embody the collection of features that characterize the syndrome. The real long-term disability of FAS is the CNS dysfunction that is critical in the diagnosis of the older individual, for whom the growth and facial features may be less noticeable (Streissguth, 1997).

Evidence of possible CNS abnormalities includes:

- Head circumference below the third percentile
- Developmental delays
- Poor impulse control
- Inconsistent knowledge base
- Difficulty grasping abstract concepts
- Speech/language disorders
- Problems with perception, sensory integration, and tactile defensiveness
- Hyperactivity
- Learning disabilities
- Distractibility

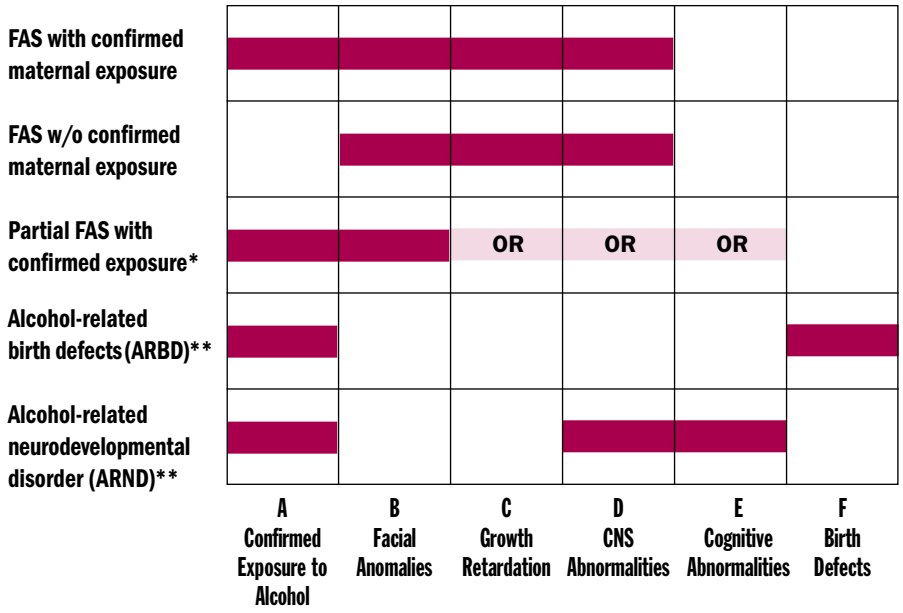
See Section 4, Diagnosis of FAS, for further information.

Other Effects of Prenatal Alcohol Exposure

Exposure to alcohol while in utero does not always result in a child having FAS. Some children who are exposed have no lasting effects; others have partial manifestations of the disorder, most frequently CNS damage (Streissguth, 1997).

Children with Fetal Alcohol Effects (FAE) may present with cognitive, behavioral, and psychological dysfunction that can cause lifelong disabilities. Abnormal cognitive functioning manifests in a variety of domains, including mathematical deficiency, difficulty with time and space, cause and effect, comprehension, and memory deficits. Further, children with FAE may demonstrate poor attention and concentration skills, impaired judgment, hyperactivity and impulsivity. Conduct problems such as lying, stubbornness, stealing, and oppositional behavior are also present in some children with FAE (Streissguth, 1997).

Fig. 2 Diagnostic Classification of FAS & Alcohol-Related Effects



*Partial FAS with confirmed exposure means there is confirmed exposure to alcohol, facial anomalies, and either C, D, or E, as indicated above.

**Alcohol-related effects indicate clinical conditions in which there is a history of maternal alcohol exposure, and where clinical or animal research has linked maternal alcohol ingestion to an observed outcome. There are two categories, alcohol-related neurodevelopmental disorder and alcohol-related birth defects, which may co-occur. If both diagnoses are present, then both diagnoses should be rendered.

Adapted from Stratton, Howe, & Battaglia, 1996.

While Fetal Alcohol Effects does not include the full battery of physical symptoms seen in children with FAS, neither is it considered a less severe form of FAS. To the contrary, since they lack outward signs, and consequently are not perceived as having brain damage, children affected by FAE often have more problematic experiences in school and as adults.

— Streissguth, 1997

Prevelance

The reported prevalence rates of FAS vary widely depending on the population studied and the intensity of case ascertainment. While an absolute rate of prevalence of FAS is not known, results of studies using different methods and data sources show rates for the United States that range from 3 to 22 cases per 10,000 births (CDC, Fetal alcohol Syndrome Surveillance Network, 2002). Prevelance rates for FAE are even more difficult to ascertain, however, one estimate is 100 cases per 10,000 births. **To calculate estimates of FAS in your area go to the Prevalence and Cost Calculator http://www.online-clinic.com/Content/Materials/calculator.asp**

On any given day in the United States…

10,657 babies are born
3,890,000/yr: US Census Bureau

1 of these babies is HIV positive.
5/100,000: Center for Disease Control and Prevention

3 of these babies are born with Muscular Dystrophy.
1 in 3,200: Muscular Dystrophy Association

4 of these babies are born with Spina Bifida.
3.2/10,000: Center for disease Control and Prevention

10 of these babies are born with Down Syndrome.
1/1,000: Center for Disease Control

20 of these babies are born with Fetal Alcohol Syndrome.
19.5 per 10,000: Natl Org. of Fetal Alcohol Syndrome

100 of these babies are born with Alcohol Related Neurodevelopmental Disorder.
1/100: Teratology 1997 Nov: 56(5): 317-26

The comprehensive lifetime cost of just one baby with FAS could be as much as $4 million.
FAS Community Resource Center

The cost to American taxpayers for Fetal Alcohol Syndrome is estimated to be $5 million a day.
$1.9 billion/year: National Institute on Drugs and Alcohol

As noted by the Institute of Medicine's 1996 Report to Congress on FAS: "These incidence figures are offered not as established facts but to emphasize the magnitude of a problem that has serious implications — for the individual and for society."

From the Executive Summary of the IOM Report.
Revised September 24, 1999
FAS Community Resource Center~http://www.come-over.to/FASCRC

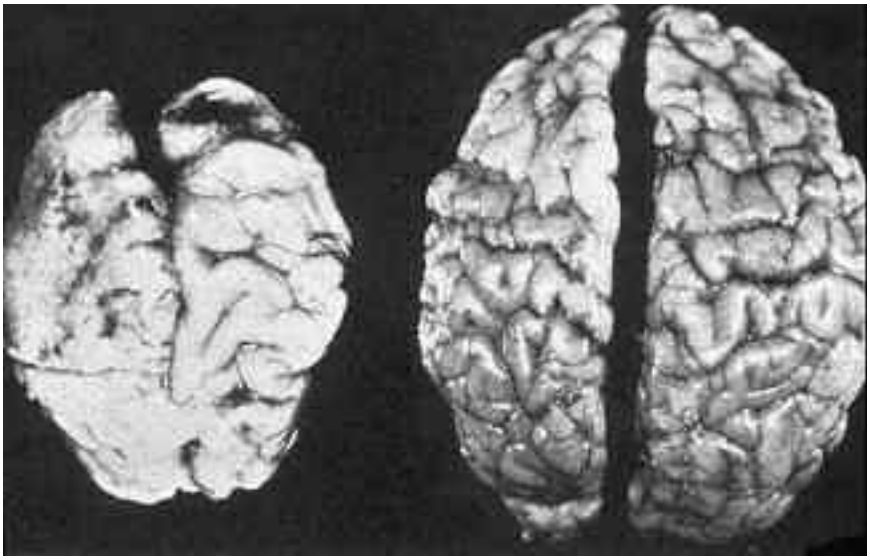
For additional information check: **www.acbr.com/fas/poster**

SECTION 2

The Effect of Alcohol Consumption on Fetal Development

The placenta does not protect the developing fetus from the negative affects of alcohol exposure. Ethanol (the kind of alcohol in beverages) crosses the placenta freely. When a pregnant woman consumes alcohol, her blood alcohol levels and that of her fetus are approximately equal within minutes of consumption (Streissguth & Little, 1994).

Fig. 3 Comparison of Normal Infant Brain and Brain of Infant Prenatally Exposed to Alcohol



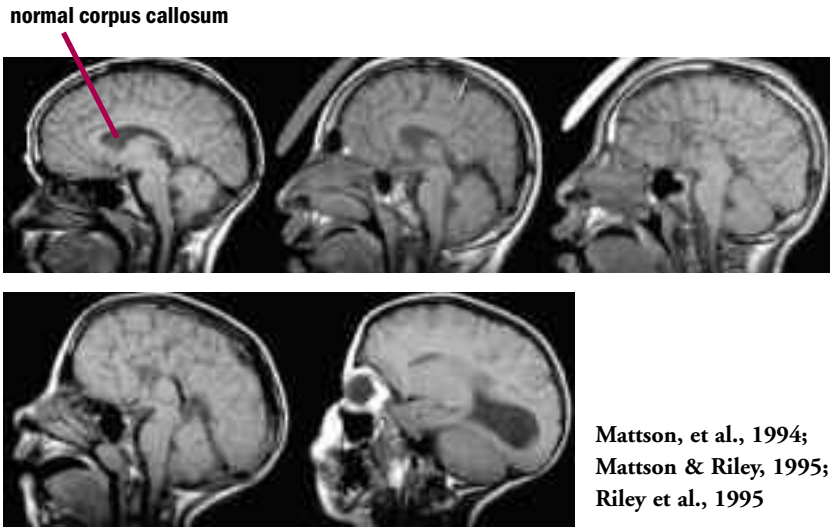
Clarren 1986

As a fetus develops, cells destined to become the brain and nervous system attach to each other with the help of cell adhesion molecules. A recent laboratory study by Wilkemeyer, Menkari, Spong, & Charness (2002) revealed that ethanol interferes with adhesion molecules and hinders crucial cell-to-cell attachments. Prenatal alcohol exposure can disrupt the normal proliferation and migration of brain cells and produce structural deviations in the brain development.

Alcohol is a neurobehavioral teratogen, an agent that can cause defects in the structure and function of the developing central nervous system in humans.

– Olson, Morse & Huffine

Fig. 4 Corpus callosum abnormalities



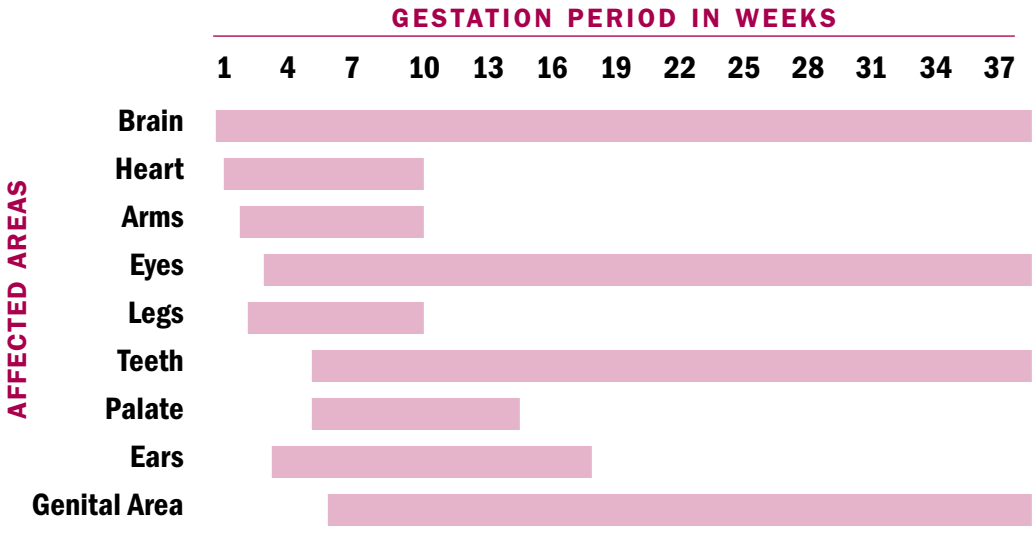
Mattson, et al., 1994; Mattson & Riley, 1995; Riley et al., 1995

The corpus callosum is the connective tissue that unites the left and right hemispheres of the brain. An abnormality in the corpus callosum of the brain is more common in children with FAS (approximately 6%) than in the general population (0.1%). While most children with FAS do have a corpus callosum, it may be reduced in size. The top left image in **Fig 4** is a control or normal brain. The other images are from children with FAS. In the top middle the corpus callosum is present, but is very thin at the posterior section of the brain. In the upper right the corpus callosum is essentially missing. The bottom two pictures are from a nine-year-old girl with FAS. She has agenesis (partial or complete absence) of the corpus callosum and the large dark area in the back of her brain above the cerebellum is essentially an empty space (Riley et al, 1995).

Prenatal alcohol exposure can also disrupt the electrophysiology and neurochemical balance of the brain, so that messages are not transmitted as efficiently or as accurately as they should be. In some children with FASD, the wiring of the brain's message system is dysfunctional, causing message receptors to be faulty.

In addition to brain damage, the developing fetus is negatively affected by alcohol exposure in a variety of ways. The table in Fig. 5 below indicates which areas of the developing fetus are affected during different stages of the gestation period.

Fig. 5 Areas of Developing Fetus Affected During Pregnancy by Prenatal Alcohol Exposure



For additional information check: www.chem-tox.com/pregnancy/alcohol.htm

SECTION 3

FAS: Fact and Fiction

10 Facts about Fetal Alcohol Syndrome

- Fetal Alcohol Syndrome is the leading known cause of mental retardation in western civilization (NIAAA, Eighth Special Report NIH Publication No. 94-3699).
- Of all the substances of abuse, including heroin, cocaine and marijuana, alcohol produces by far the most serious neurobehavioral effects in the fetus, resulting in permanent disorders of memory function, impulse control and judgment (Institute of Medicine Report to Congress, 1996).
- Over 50% of women of childbearing age drink alcohol (American Medical Association). And only 39% of women of childbearing age know what FAS is (National Institute of Health).
- Approximately 20% of women continue to drink after learning they are pregnant (Institute of Medicine Report to Congress, 1996).
- The incidence of binge and frequent drinking during pregnancy has not declined in recent years (Alcohol Use Among Women of Childbearing Age – United States, 1991-1999, Center for Disease Control).
- Women at highest risk of drinking during pregnancy include those who smoke, who are single, who are in college or have a college degree, and women in households with annual incomes over $50, 000 (Obstetrics and Gynecology, 1998, v92, p187-192).
- Each year in the US between 35,000 and 50,000 babies are born with Alcohol Related Neurodevelopmental Disorders (ARND) (March of Dimes).
- ARND affects one out of one hundred babies in North America, making alcohol the leading cause of brain damage (Teratology, 1997, v56n5, p317-326).
- Among children with FAS and ARND up to age 15, the social maturation process seems to be stunted at the level of a six-year-old child (Alcohol Clinical Exp Research, 1998, v22 n2).
- Fewer than 10% of individuals with FAS or ARND are able to successfully live and work independently (Center for Disease Control and Prevention study by Streissguth, A., Barr, H., Kogan, J., & Bookstein, F., 1996).

There is no safe level of alcohol consumption during pregnancy.

Even one drink risks the health of an unborn baby.

Pregnant?
Don't Drink.
Period.

— American Academy of Pediatrics, Fetal Alcohol Syndrome: 10 Things You Need to Know.

Seven Myths of FAS/FAE

Myth #1 – 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 found, only 25% of 178 individuals with the full FAS were classified as having mental retardation by an IQ score below 70 (Streissguth, Barr, Kogan, & Bookstein, 1996). 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 (Clarren & Astley, 1997). Only the most severely affected children — those with clear microcephaly and other physical malformations — are easily detected at birth (Darby, Streissguth, & Smith, 1981).

Myth #2 – 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 behavior 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.

Myth #3 – 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.

Myth #4 – 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.

Myth #5 – 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.

Myth #6 – It is useless to diagnose FAS/FAE because there is no "real" treatment approach. This attitude isn't taken toward any other incurable disease (e.g., childhood autism). Why should it be invoked for FAS/FAE? Any family is in a better position to a 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 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.

Myth #7 – 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.

From: Fetal Alcohol Syndrome: A Guide for Families and Communities
Reprinted with permission by Ann Streissguth, Ph.D.

SECTION 4

Diagnosis of FAS

There is general agreement across the literature that there are four specific criteria related to the diagnosis of FAS:

1. **Confirmed maternal alcohol consumption during the pregnancy**
2. **Growth deficiency, pre or postnatally, for height or weight, or both**
3. **Specific pattern of anomalies including a characteristic face with short palpebral fissures (eye slits), flat midface, flattened philtrum and thin upper lip**
4. **Central nervous system dysfunction, such as developmental delays, difficulty grasping abstract concepts, and speech/language disorders**

Mother's Profile

The first criterion related to the diagnosis of FAS is confirmed maternal alcohol consumption during pregnancy. Several studies provide insight into the women at risk for prenatal alcohol consumption.

In January 2001, Dr. Richard Hopkins, Florida Department of Health, Epidemiology, analyzed data from a random sample of live births with an over sampling of teens, African Americans, and those women with a low birth weight baby. Using the Pregnancy Risk Assessment Monitoring System (PRAMS), mothers were asked about the three month period prior to pregnancy and the last three months of pregnancy.

Early diagnosis can help prevent secondary disabilities such as mental health problems, dropping out of school, trouble with the law and substance abuse.

— Fetal Alcohol Syndrome Diagnostic & Prevention Network

We have never met a woman who drank through her pregnancy to hurt her baby. I don't think she exists.

– Clarren, S. 2002

Responses to the PRAMS survey were as follows:

- Women 20 years and older with higher education drank more than younger, less educated women
- 85 to 90% of young women reported that their doctor talked with them about the effects of alcohol on their baby, while only 70% of women 35 years and older reported such a discussion
- 70% of heavy drinkers versus 90% of light drinkers reported that their doctor had talked with them about drinking
- 10% of women reported continuing drinking and no reduction in drinking
- Heavier smokers were more likely to use alcohol

In a recent study of 80 birth mothers of children with FAS (Astely, Bailey, Talbot, & Clarren, 2000):

- 23.8% had foster parents
- 17.5% lived in group home
- 35% had been in a juvenile detention center
- 22.5% were involved with Child Protective Services as a child
- 80% had birth children who had been in foster care or Child Protective Services
- 57.5% were sexually abused as a child
- 46.2% were physically abused as a child
- 51.3% were sexually abused as an adult
- 85% were physically abused as an adult
- 86.3% were emotionally abused as an adult
- 95% were sexually and/or physically abused at some time

Studies of maternal alcohol consumption consistently report that women who have one child, and continue to drink, have progressively more severely fetal alcohol affected children with subsequent pregnancies (May, Hymbaugh, Aase, & Samet, 1983; Davis & Lipson, 1984; Abel, 1988).

Fig. 6 Major maternal risk factors associated with Fetal Alcohol Syndrome and alcohol-related birth defects

Factor	Reference(s)
Age: >25 years	Abel and Sokol 1987; May et al. 1983
Number of children: >3	Abel 1988; Abel and Sokol 1987; Davis and Lipsitt 1964; Larkin and Sokol 1996
Separated, divorced, or never married	Gehshan 1995; Hilton 1987; Wilsnack et al. 1997
High blood alcohol concentration	Chang et al. 1996; Day et al. 1993; Godel et al. 1992
Binge drinking	Chang et al. 1996; Day et al. 1993; Godel et al. 1992
Long history of drinking	May et al. 1983; Sokol et al. 1980
Heavy drinking by male partner	Wilsnack and Beckman 1984; Wilsnack et al. 1991
Heavy drinking by any family member	Abel 1988
Culture tolerant of heavy drinking	May et al. 1982; Robinson et al. 1987
Low socioeconomic status	Abel 1995; Abma and Mott 1991; Bingol et al. 1987; Sokol et al. 1986
Work in male-dominated occupation	Gehshan 1995; Wilsnack and Wilsnack 1982; Wilsnack et al. 1997
Unemployment	Gehshan 1995; Wilsnack and Wilsnack 1982; Wilsnack et al. 1991
Social transience	May et al. 1983; Streissguth et al. 1985
Low self-esteem	Kaskutas 1996
Loss of children to foster or adoptive care due to neglect, abuse, or abandonment	Halbock et al. 1995; May et al. 1982; Streissguth et al. 1986
Sexual dysfunction	Wilsnack et al. 1991
Use of multiple substances	Day et al. 1993; Godel et al. 1992; Serrus et al. 1991
Cigarette smoking	Day et al. 1993; Godel et al. 1992; Serrus et al. 1991

U.S. Dept. of Health and Human Services 10th Special Report to the U.S. Congress on Alcohol and Health, June 2000.

Fig. 7 reflects data obtained from the 1999 and 2000 National Household Surveys on Drug Abuse.

Fig. 7 Percentages of females aged 15 to 44 reporting past month use of alcohol, by pregnancy status and age: 1999 and 2000

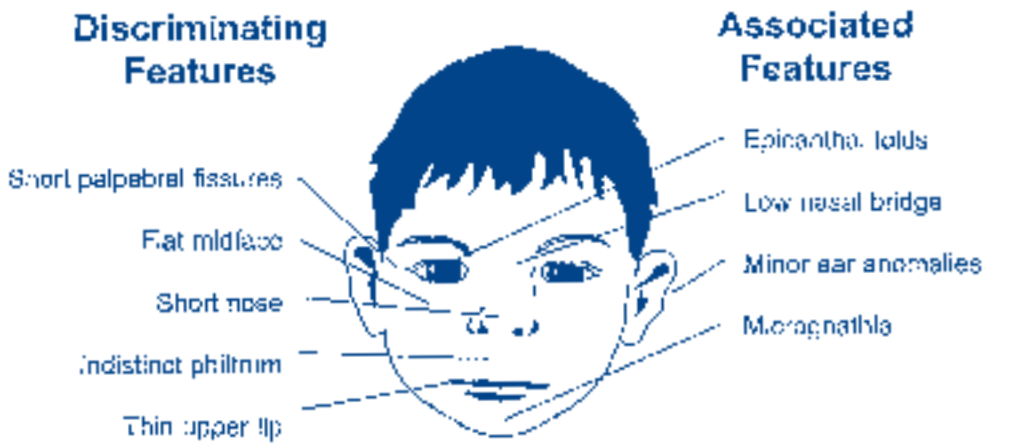
	15 to 17		18 to 25		26 to 44	
Past Month Use	Pregnant	Non-pregnant	Pregnant	Non-pregnant	Pregnant	Non-pregnant
Alcohol	9.6	25.1	10.1	53.5	14.0	50.2
Binge Alcohol Use*	7.0	15.4	4.6	28.6	3.1	17.1
Heavy Alcohol Use*	2.0	3.3	0.9	7.5	0.5	3.0

Physical and Neurodevelopmental Characteristics

Children with FAS possess certain characteristics in common, as well as a variety of effects that affect each child differently. However, all children with FAS possess facial abnormalities, most easily recognizable from ages two through 10; growth retardation that manifests itself in below average height throughout the lifetime and below average weight until adolescence; and central nervous system dysfunction.

Facial features characteristic of FAS include epicanthal folds, short palpebral fissures (eye slits), thin upper lip, shortened upturned nose, flattened, smooth wide philtrum, and flat midface.

Fig. 8 Facial Features Associated with FAS



Source: Streissguth and Little, 1994

Facial features particularly characteristic of a child with Fetal Alcohol Syndrome (FAS). Discriminating features (i.e., those considered definitive signs of FAS) are shown on the left side of the illustration; characteristics listed on the right side are associated with FAS but are not sufficient to determine the presence of the syndrome. Microcephaly (small head circumference) is not a facial feature per se, but a central nervous system characteristic. (Palpebral fissures – eye opening; philtrum – groove between nose and upper lip; epicanthal folds – skin folds covering inner corner of the eye; micrognathia – abnormal smallness of the jaws.)

from National Institutes of Health Publication No. 99-4368

Growth retardation associated with children with FAS includes low birth weight for gestational age, decelerating weight not caused by poor nutrition, and disproportionately low weight to height.

Equally serious characteristics of FAS are the invisible symptoms of neurological damage including mental retardation, attention and memory deficits, hyperactivity, poor problem solving skills, difficulty learning from consequences, poor judgment, immature behavior, poor impulse control, and difficulty with abstract concepts such as space, time, and money.

CNS abnormalities associated with FAS include decreased cranial size at birth, structural brain abnormalities, impaired fine motor skills, neurosensory hearing loss, poor tandem gait, and poor eye-hand coordination.

Brain damage associated with FAS may include poor habituation (unable to filter out stimulus), poor self-regulation, impulsivity, attention deficits, slow central nervous system processing speed, arithmetic disability, poor capacity for abstraction or metacognition, deficits in higher level receptive and expressive language, poor impulse control, memory problems, disorientation in time and space, poor judgment, and difficulty with self-reflection. Children with FAS who have IQ scores in the normal range may still have specific cognitive or neuropsychological impairments or problems with adaptive behaviors that do not register on IQ tests scores.

Birth defects associated with FAS may include cardiac, skeletal, renal, ocular, and auditory dysfunction.

Diagnosis of FAE

Unfortunately, there are no biochemical tests or physical markers to determine if a child has FAE. Symptoms may be unrecognizable at birth and may be misdiagnosed as difficulties resulting from a difficult delivery or other prenatal stressor. Further, the characteristics of children with FAE can vary. Often children with alcohol related, organically based brain problems are never given a diagnosis of FAE. Failure to diagnose children with FAE occurs because many health care professionals, teachers, and parents are not knowledgeable enough about FAE to recognize the symptoms for what they are. The cognitive, behavioral, and language manifestations of alcohol's effects are often attributed to disabilities such as attention deficit or general developmental delays.

Diagnostic Tools

Two screening tools specifically designed to diagnose FAS have been developed in recent years. The first tool, the FAS Screen, helps to determine children who are at high or low risk for FAS. (See pages 24-27.)

The second tool, the FAS Facial Photographic Analysis Software, uses the latest in technological advances to identify children with FAS. (See pages 28-30.)

The FAS Screen

This screening instrument, developed by Dr. Larry Burd is designed for community-wide use to determine children who are at high or low risk for FAS. This tool can be used in both population based settings, such a public schools, and in clinical or institutional settings.

The FAS SCREEN

A Rapid Screening Tool Designed for Community-Wide Use to Identify Children Who Are At High Risk for Fetal Alcohol Syndrome, Fetal Alcohol Effect or Alcohol Related Neurodevelopmental Disabilities

by
Larry Burd, Ph.D.
Director, North Dakota Fetal Alcohol Syndrome Center
701-780-2477
www.online-clinic.com

Fetal Alcohol Syndrome (FAS) is the best-known manifestation of prenatal alcohol exposure during pregnancy. However, for every case of FAS it is reported that there are six to eight times as many children and adults who have less complete forms of the disorder (Burd 1998). Nearly all syndromes have many more mild than severe cases. The diagnostic term for these other and much more frequent manifestations of prenatal alcohol exposure have been called fetal alcohol effect (FAE) or more recently alcohol related neurodevelopmental disability (ARNDD).

This tool was developed to be the first step in the process of identification of cases of FAS and FAE-ARNDD. The first step in this process is the identification of people who are at increased risk for FAS or FAE-ARNDD. This tool is designed to provide institutions, agencies and care providers a rapid and inexpensive method of screening for FAS, FAE, or ARNDD. The tool takes about ten to fifteen minutes to administer and can be used with the ARNDD Screen which focuses primarily on the behavioral features of these disorders. Many agencies or clinics use both tools when screening.

The FAS SCREEN can be used with children from three years of age through seventeen years of age. This screening tool uses physical features to identify children and adults who are at increased risk to have FAS or FAE-ARNDD. The tool is not a diagnostic tool and as a result does not produce a diagnosis of FAS or FAE-ARNDD. Rather the tool identifies two groups after screening, the first are people who have scores below 20. People with scores below 20 are at very low risk to have FAS, FAE-ARNDD. The second group will be people who have screening scores of 20 or above. People in this group are at much increased risk to have FAS, FAE-ARNDD and need to be referred for an evaluation to determine if they have FAS, FAE-ARNDD or another developmental disorder.

When screening complete the form beginning at the top. Remember this is a screening tool and no single item is critical. For some items the screener may have to use judgement to complete the item. When this occurs just use your best judgement and then move on. When the screening is complete total up the screening score. A score of 20 or above is considered a positive screening score and would result in a referral for further assessment.

On the following two pages the specific diagnostic criteria for the screening tool are presented. The last page is the screening form.

Used with permission. Larry Burd, Ph.D.

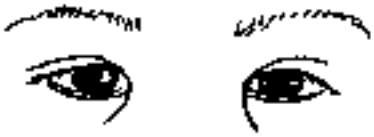
The FAS Screen p.2

CHARACTERISTICS

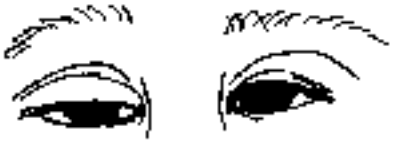
Each criteria from the screening form is demonstrated with a line drawing.

1. Ears stick out *(Protruding Auricles)*

2. Skin folds near inner eyes *(Epicanthic folds)*



3. Drooping of eyelids *(Ptosis)*



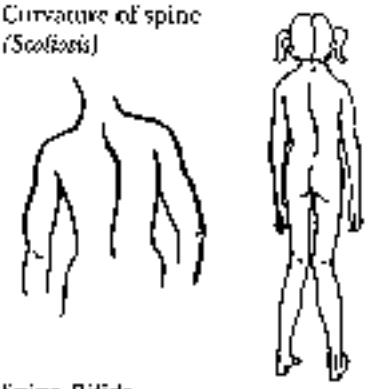
4. Cross eyes, one or both *(Strabismus)*

5. Flat mid-face/cheeks *(Hypoplastic maxilla)*
6. Flat, low nose between eyes *(Low nasal bridge)*
7. Upturned nose
8. Groove between lip and nose absent or shallow *(Flat philtrum)*
9. Thin upper lip

10. Cleft lip or cleft of roof of mouth *(present or repaired)*

11. Short, broad neck

19. Curvature of spine *(Scoliosis)*



13. Spina bifida *(History of neural tube defect)*

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The FAS Screen p.3

14. Fingers, elbows
(limited joint mobility)

15. Permanently curved, small fingers, especially pinkies
(Clinodactyly)

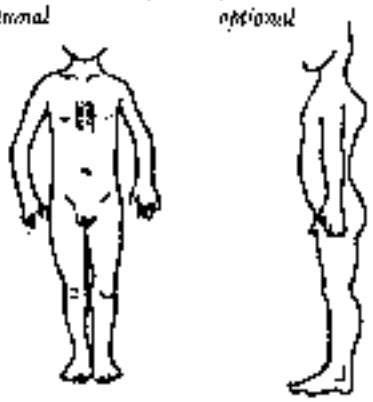
16. Deep or accentuated palmar creases

17. Small nails, nail beds *(Hypoplasia nails)*

18. Tremulous, poor finger agility
(Fine motor dysfunction)

19. Sunken chest
(Pectus excavatum)
optional

20. Chest sticks out
(Pectus carinatum)
optional



21. History of heart murmur or any heart defect

22. Raised red birthmark
(Capillary hemangioma)

23. Greater than normal body hair; hair also on forehead and back
(Hirsutism)

Used with permission. Larry Burd, Ph.D.

The FAS Screen p.4

FAS SCREEN FORM

Name _____ DOB___/___/___ AGE _____ SEX (circle one) F M DATE OF EXAM / /

CHILD'S RACE (circle one)					
1) white	HEIGHT	INCHES	<5%	Y___ N___	10
2) NA	WEIGHT	POUNDS	<5%	Y___ N___	10
3) other	HEAD CIR_____	CM	<5%	Y___ N___	10

HEAD AND FACE	EARS STICK OUT (Protruding Auricles)	Y___ N___	4
	SKIN FOLDS NEAR INNER EYE (Epicanthal Folds)	Y___ N___	5
	DROOPING OF EYELIDS (Ptosis)	Y___ N___	4
	CROSS-EYES, ONE OR BOTH EYES (Strabismus)	Y___ N___	5
	FLAT MIDFACE/CHEEKS (Hypoplastic Maxilla)	Y___ N___	7
	FLAT/LOW NOSE BETWEEN EYES (Low Nasal Bridge)	Y___ N___	2
	UPTURNED NOSE	Y___ N___	5
	GROOVE BETWEEN LIP & NOSE ABSENT OR SHALLOW (Flat Philtrum)	Y___ N___	5
	THIN UPPER LIP	Y___ N___	4
	CLEFT LIP OR CLEFT IN ROOF OF MOUTH (present or repaired)	Y___ N___	4
NECK AND BACK	SHORT, BROAD NECK	Y___ N___	4
	CURVATURE OF THE SPINE (Scoliosis)	Y___ N___	2
	SPINA BIFIDA (History of Neural Tube Defect)	Y___ N___	4
ARMS AND HANDS	FINGERS, ELBOWS (Limited Joint Mobility)	Y___ N___	4
	PERMANENTLY CURVED, SMALL FINGERS, ESPECIALLY PINKIES (Clinodactyly)	Y___ N___	1
	DEEP OR ACCENTUATED PALMAR CREASES	Y___ N___	4
	SMALL NAILS/NAIL BEDS) (Hypoplastic Nails)	Y___ N___	1
	TREMULOUS, POOR FINGER ACILITY (Fine Motor Dysfunction)	Y___ N___	1
CHEST	SUNKEN CHEST (Pectus Excavatum) } OPTIONAL	Y___ N___	3
	CHEST STICKS OUT (Pectus Carinatum) } OPTIONAL	Y___ N___	3
	HISTORY OF HEART MURMUR OR ANY HEART DEFECT	Y___ N___	4
SKIN	RAISED RED BIRTHMARKS (Capillary Hemangiomas)	Y___ N___	4
	GREATER THAN NORMAL BODY HAIR. HAIR ALSO ON FOREHEAD AND BACK (Hirsutism)	Y___ N___	1
DEVELOPMENT	MILD TO MODERATE MENTAL RETARDATION (IQ < 70)	Y___ N___	10
	SPEECH AND LANGUAGE DELAYS	Y___ N___	2
	HEARING PROBLEMS	Y___ N___	1
	VISION PROBLEMS	Y___ N___	1
	ATTENTION CONCENTRATION PROBLEMS	Y___ N___	2
	HYPERACTIVITY	Y___ N___	5

COMMENTS

TOTAL SCORE_____
Refer if 20 or above

For additional forms or information on FAS, FAE or ARNDD contact:
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Grand Forks, ND 58201
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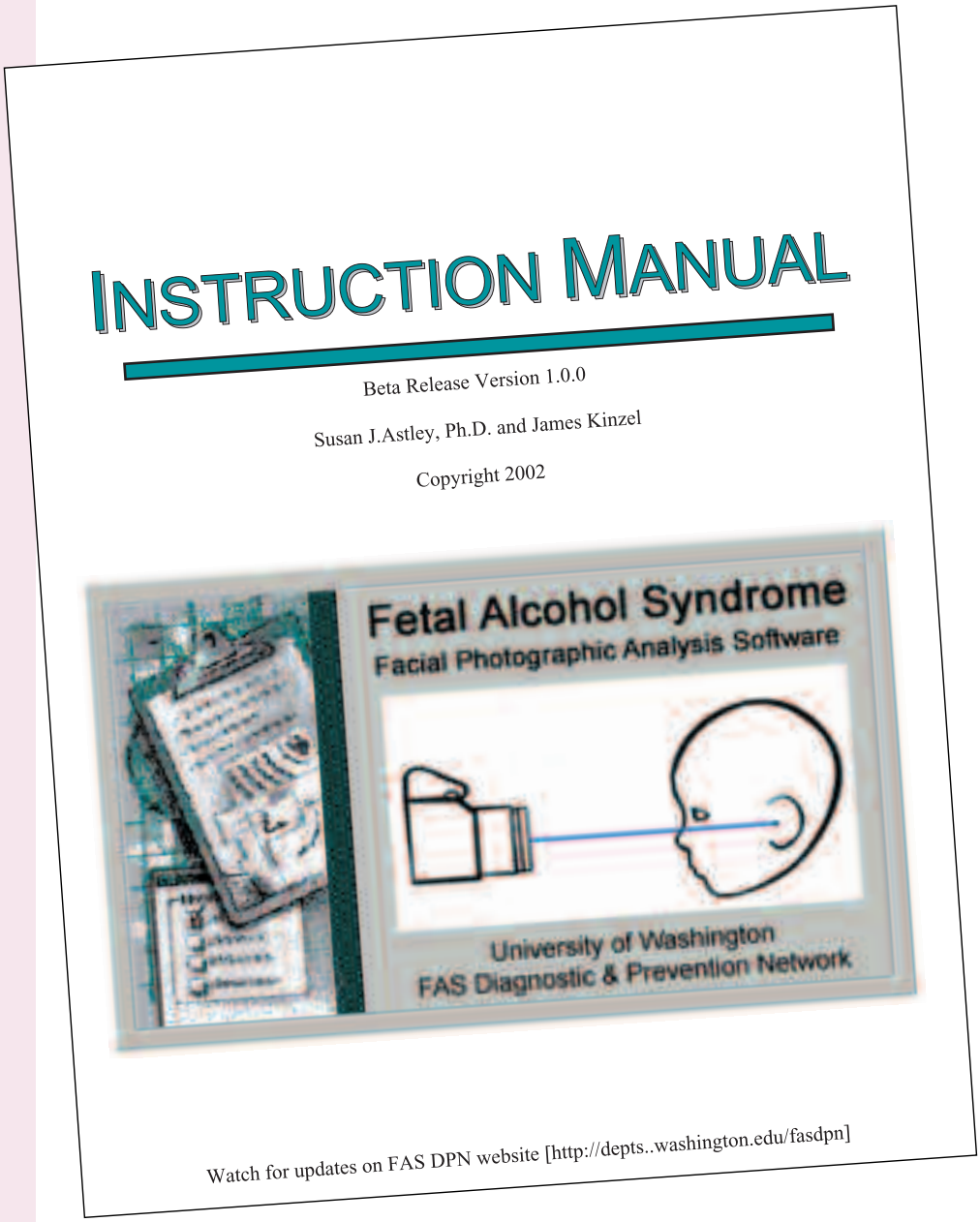
FAS Diagnostic Software

The FAS Facial Photographic Analysis Software developed by Susan Astley, Ph.D. and James Kinzel measures the magnitude of expression of the key features of FAS by analyzing an imported digital photograph. This software is designed for use by healthcare and research professionals, and will be available for general distribution in the near future. More information regarding the FAS Facial Photographic Analysis Software can be found at http://depts.washington.edu/fasdpn/software.htm


INSTRUCTION MANUAL

Beta Release Version 1.0.0

Susan J.Astley, Ph.D. and James Kinzel

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Watch for updates on FAS DPN website [http://depts..washington.edu/fasdpn]

PART I. INTRODUCTION

What is Fetal alcohol syndrome (FAS)?

Fetal alcohol syndrome (FAS) is a permanent birth defect syndrome caused by maternal consumption of alcohol during pregnancy. The syndrome has been broadly characterized by pre- and/or postnatal growth deficiency, a characteristic set of minor facial anomalies, central nervous system damage/dysfunction and prenatal alcohol exposure (Jones and Smith, 1973; Clarren and Smith, 1978; Smith, 1979; Rosett, 1980; Sokol and Clarren, 1989; Stratton *et al.*, 1996). Although these characterizations do provide guidance, they are not sufficiently specific to assure diagnostic accuracy and precision. In 1997, a new more objective and comprehensive, case-defined method for diagnosing the full spectrum of outcomes in individuals with prenatal alcohol exposure was created called the 4-Digit Diagnostic Code (Astley & Clarren, 1997, 1999, 2000; Astley et al., 1999).

The FAS 4-Digit Diagnostic Code

The four digits of the diagnostic code reflect the magnitude of expression of four key diagnostic features of FAS in the following order: (1) growth deficiency, (2) the FAS facial phenotype, (3) brain damage/dysfunction, and (4) gestational alcohol exposure (Figure 1). The 4-Digit Diagnostic Code is generated by first recording key clinical data on the standardized FAS Diagnostic Evaluation Form and following specific case-definitions to generate each digit.

4-Digit Diagnostic Code Grid

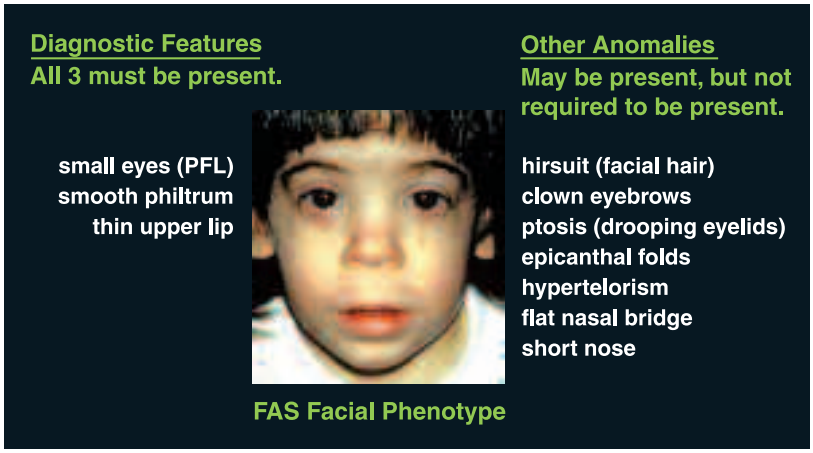
				3	2	4	4		
significant	severe	definite	(4)		X	X	X	(4)	high risk
moderate	moderate	probable	(3)	X				(3)	some risk
mild	mild	possible	(2)					(2)	unknown
none	absent	unlikely	(1)					(1)	no risk
Growth Deficiency	**FAS Facial Phenotype**	**Brain Damage**		Growth	Face	Brain	Alcohol		**Prenatal Alcohol**

The magnitude of expression of each feature is ranked independently on a 4-point Likert scale with 1 reflecting complete absence of the FAS feature and 4 reflecting a strong "classic" presence of the FAS feature. Each Likert rank is specifically case-defined. The 4-Digit Diagnostic Code can be used to diagnose individuals of all ages. The 4-Digit Diagnostic Code has been used effectively for diagnosis, screening and surveillance efforts in the Washington State FAS Diagnostic & Prevention Network of clinics since 1997.

Facial Features of FAS

The most specific feature of FAS is the facial phenotype. The FAS facial phenotype is characterized by the presence of all three of the following minor anomalies:

1. **Palpebral fissure lengths** (PFL) two or more standard deviations below the norm.
2. **A smooth philtrum** defined as a Rank 4 or Rank 5 on the 5-point Likert Scale depicted on the FAS DPN Lip-Philtrum Pictorial Guide (Astley & Clarren, 1999, 2000).
3. **A thin upper lip** defined as a Rank 4 or Rank 5 on the 5-point Likert Scale depicted on the FAS DPN Lip-Philtrum Pictorial Guide (Astley & Clarren, 1999, 2000).



Lip-Philtrum Guide

This diagnostic case definition for the FAS facial phenotype is based on the original definition reported by Smith (1979) and clinical research by Astley & Clarren (1996, 2000).

Other facial anomalies may be present. The presence of other anomalies should be recorded, but should not be used in lieu of any of the three diagnostic features (small palpebral fissures, smooth philtrum, thin upper lip) of the FAS facial phenotype.

FAS Facial Analysis Software

This software was developed for use by health care and medical research professionals. Computerized image analysis has been used effectively to measure and rank the magnitude of expression of the FAS facial phenotype on thousands of individuals evaluated in the FAS DPN clinics (Astley & Clarren, 2000). This software was developed to provide healthcare professionals with a user-friendly, inexpensive, objective method for analyzing facial photographs obtained in a clinical or research setting.

Discussing the Diagnosis with a Child

Some parents and caretakers are hesitant to discuss the diagnosis with their child. By school age, children with FASD usually recognize that they are not like other children. They may have suffered teasing, frustration, and humiliation in the classroom or on the playground. Self-esteem may be bruised by the time the diagnosis is made.

Having a medical diagnosis is often a relief to children with FASD. A diagnosis provides a reason for their problems. They understand it is not their fault. The child can begin to understand that their mother did not intentionally hurt them by drinking during her pregnancy. Parents may also feel a sense of relief. A diagnosis provides a medical reason for their child's behavior. Parents can understand that behaviors may not be intentional or due to poor parenting skills.

Common Misdiagnoses of FAS/FAE

FAS is not a psychiatric diagnosis and is therefore often not recognized by mental health professionals. The symptoms of individuals with FAS/FAE are similar to that of many mental health diagnoses and the possibility of prenatal alcohol exposure causing some of the symptoms is often not considered.

Some of the more common misdiagnoses or co-occurrences for a person with FAS/FAE are:

- Attention Deficit/Hyperactivity Disorder
- Bipolar I Disorder
- Bipolar II Disorder
- Major Depressive Disorder
- Posttraumatic Stress Disorder
- Obsessive-Compulsive Disorder
- Generalized Anxiety Disorder
- Oppositional Defiant Disorder
- Conduct Disorder
- Alcohol Dependence
- Alcohol Abuse
- Mild, Moderate, or Severe Mental Retardation
- Antisocial Personality Disorder
- Borderline Personality Disorder

Dubovsky, 2002

For additional information check: **www.uchsc.edu/ahec/fas/facts/index.htm**

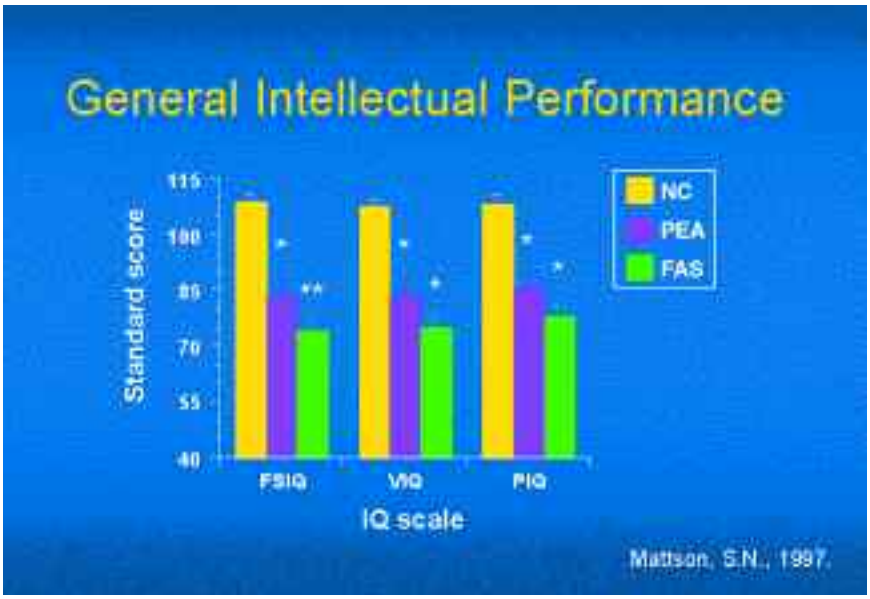
SECTION 5

Effects of Prenatal Alcohol Exposure and Intervention Strategies

Prenatal alcohol exposure may affect individuals in several ways with a considerable amount of variability in the levels of behavioral, psychological, and cognitive deficits (Werner & Morse, 1994).

In Fig. 9, when the mean IQ performances of children with FAS were compared to children exposed to high amounts of alcohol prenatally but did not have the FAS facial features (PEA) children and a normal control group (NC), both of the groups of alcohol exposed children displayed significant deficits in overall IQ measures as well as deficits on most of the subtest scores (Mattson, Riley, Gramling, Delis, & Jones, 1997).

Fig. 9 Comparison of Intellectual Performance



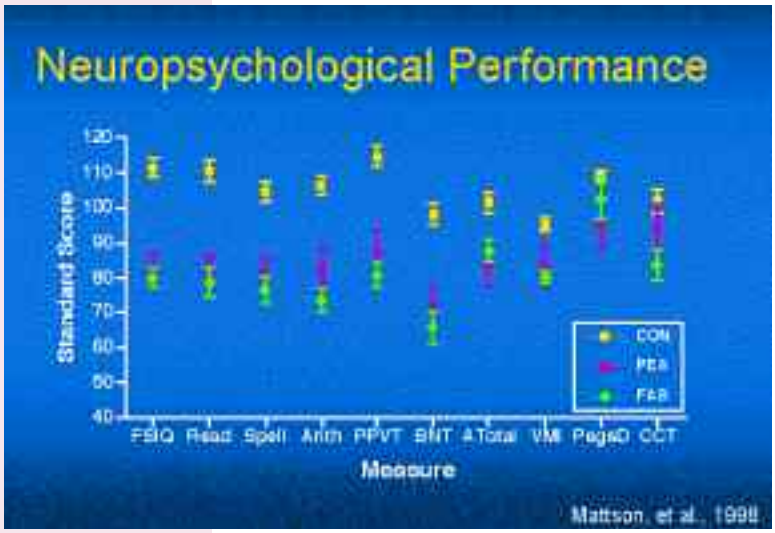
There have been over a dozen retrospective studies of children with FAS (total N = 269). Overall, these studies, such as the Seattle studies or studies out of Germany, reported an overall mean IQ of 72.26 (range of means = 47.4-98.2). The data presented here were collected in San Diego, CA, as part of a project at the Center for Behavioral Teratology.

Used with permission. Mattson, S.N., 1997.

In comparison with their peers, people with FAS/FAE seem to have more and more difficulties as they grow older, rather than more and more competencies.

– Streissguth, 1997

Fig. 10 Neuropsychological Tests



Used with permission. Matson, S.N., 1998.

The graph in Fig. 10 represents findings from a study of a broad range of neuropsychological tests such as the Wide Range Achievement Test, the Peabody Picture Vocabulary Test, the Boston Naming Test, the Visual-Motor Integration Test, the Grooved Pegboard Test, and the Children's Category Test.

Children with FAS or PEA (without FAS facial features) showed deficits in comparison to the control group (CON), although there is some indication that the nonverbal measures (those on the right side) are not as impaired as the verbal and academic measures. These findings indicated that children with FAS and those with PEA are similarly impaired (Mattson, Riley, Gramling, Delis, & Jones, 1998).

Secondary Disabilities

The best possible outcomes for an individual with FASD begin with early diagnosis and intervention which can reduce: disrupted schooling, trouble with the criminal justice system, confinement or incarceration, inappropriate sexual behavior, alcohol and drug problems, dependent living, and problems with employment because the organic problems of the child will be recognized from an early age (Streissguth, 1996).

Without early diagnosis and intervention, children with FASD develop a range of secondary disabilities — disabilities that the individual is not born with, and which could be ameliorated with appropriate interventions (Streissguth, et al, 1996).

Ninety percent of individuals with FASD suffer with Mental Health problems, 60% have a disrupted school experience, 60% have trouble with the law, 58% are confined to a correctional system, drug treatment program, or mental health facility, over 50% have inappropriate sexual behavior, and 45% have drug or alcohol problems.

Importance of Early Intervention

Early Intervention is a critical element in determining the prognosis for a child with FASD. The earlier in the child's life that medical, clinical and educational interventions can be provided, the better the outcome. Stable, structured, nurturing environments are necessary to support the child's growth and development. Special needs pre-school programs that are center-based and enroll parent and child can provide the most enriched experience. During the early years, the focus of treatment should be on establishing healthy parent/child relationships, motor and language development and sensory processing development. Medical and nutritional needs should be monitored as well.

Therapeutic Interventions must focus on all areas of development. Frequently, the child's behavior becomes the target, without consideration of the child's degree of sensory, emotional and social levels of development. Although a clear plan for addressing behavior is necessary, the focus must be on meeting the child's needs. Many times the disorganized, aggressive or self-abusive behavior the chid is presenting, stems from an under-aroused or over-aroused central nervous system (CNS). Children with FASD have difficulty taking in sensory information, integrating, organizing and processing it and then developing an appropriate social response. Some sensory channels (auditory, tactile) may be overly-responsive to input (sensory defensiveness), while others (vestibular, olfactory, gustatory) may be under-responsive to input. Sensory processing deficits can result in poor modulation of arousal and alertness resulting in emotional instability/ability, hyperactivity, behavioral disorganization and learning problems. An evaluation by an Occupational Therapist who has knowledge and experience in treating sensory processing issues can be very beneficial. "Sensory diets" can be initiated between home/school which can assist with normalizing sensory processing. Another treatment intervention that may prove beneficial for these children is Auditory Integration Training (AIT).

Emotional and social development can be enhanced by labeling feeling states of the child or others. Model expression of feelings for the child and help them find safe ways to express their anger and frustration (hitting pillow, punching bag, etc.) Role play and mediate social situations so the outcome is positive. If the social situation is increasing the arousal level of the child, remove him/her from the situation before negative behavior occurs. Reinforce all positive behavior. Do not take it for granted. It is extremely difficult for these children to meet adult's expectations. Adapting the environment, the task or your expectation will help these children experience a greater degree of success.

Psychotropic medication may be necessary and should be considered a critical component of the treatment plan. Some FASD children present with a significant degree of impulsivity, hyperactivity, oppositional behavior and sleep disorders. Medication can often assist with these symptoms. The age the child can start medication and the type of medication necessary will depend upon the individual child's history and presentation. The child's pediatrician, a child psychiatrist, or neurologist can assess medication needs.

Parents are often overwhelmed with the enormous job of caring for these children. Parent education and support, as well as respite services for families, is essential to maintaining positive parent/child relationships and stability in the home setting. These services must be available to foster and adoptive parents as well as the natural parent.

Ten Survival Tips for Parents of Children with Fetal Alcohol and Drug Exposure

1. Don't sweat the small stuff. Choose one or two critical behaviors at a time to work on.
2. Be firm, yet flexible. Rigidity can increase oppositional behavior. Remember they are not willfully trying to make you exhausted or crazy.
3. Allow yourself to grieve the loss of a "whole" person.
4. Don't expect them to act the same as every other child. They aren't like children who don't have brain damage.
5. Keep the mood positive. Give five times more praise to every one correction.
6. Don't hurry them. Defiant behavior increases when under pressure.
7. Don't take them places where they are likely to have problems. These are most often church, restaurants, malls, new and unfamiliar places, and events with high numbers of people and noise.
8. Do something fun with them every day. Encourage their sense of humor and yours.
9. Advocate for their needs. It will make you feel better about them and yourself.
10. Do something for yourself every day. A good warm bubble bath with soft music is a great way to end a stressful day.

Source: Kathryn Shea, C.S.W. www.taconic.net/seminars/fas01.html

Effects and Interventions for Infants and Toddlers

In general, children with FAS often display sensory processing disorders. They can range from mild to quite severe and are a result of the damaging effects of alcohol on the developing nervous system during pregnancy. These neuropsychological effects can be present throughout the child's life and cause significant problems in all domains of development. Cognitive and language delays are often apparent. Behavioral problems are also frequently a result of sensory processing dysfunction. Regulatory problems are seen very early in infancy due to the inability of the nervous system to screen out incoming stimuli and to modulate it. As a result, these babies are often very difficult to care for, and may cry inconsolably and have difficulty feeding. Children with FAS who experience nurturing and responsive caregiving environments, who are identified early, and receive appropriate sensory integration therapy and relationship-based intervention can be helped to learn self regulation and adaptive responses. The residual effects of FAS can be greatly reduced and the developmental outcome greatly improved with early identification and treatment, especially occupational therapy and speech therapy.

As a child with FASD matures, the effects of prenatal alcohol exposure present new challenges and opportunities for interventions. A spectrum of difficulties appears throughout the live of an individual with FASD, but there are some commonly seen problems and effective ways of dealing with them at different stages of development. Tactile and auditory defensiveness and the resulting negative responses by the child can be misinterpreted as acting out or bad behavior. Understanding the underlying problems, treating the sensory processing difficulties, and modifying the environment are critical components of effectively dealing with children with FAS at all ages and stages of development.

Infants with FAS may display jitteriness, seizures, tremors, weak suck, unpredictable and disrupted sleep/wake cycles, poor state regulation, decreased vigorous bodily activity, low hearing threshold, failure to thrive, poor ability to filter out stimulus, or hyperextension of the body with arched back.

For the caregiver of an infant with FASD the following early intervention strategies will help to ease the baby's fragile sensory system into the world:

- Protect the baby from being overwhelmed by stimuli.
- Be vigilante for cues that the baby is overstimulated (i.e., looking away or hiccupping).

The cornerstone of intervention with alcohol-exposed infants is discovering their tolerance for interactions"

— Harwood & Kleinfeld, 2002

Part C is a federal entitlement program for children age birth to three with a suspected delay or disability to receive screening, evaluation, and services needed regardless of income. Contact Children's Medical Services (www.cms-kids.com/ContactUs/CMS contacts.pdf) for more information.

- Provide an environment that feels safe and reduces the defensive responses to incoming stimuli. Babies with FAS may need to be swaddled or soothed by dim lighting and may be most receptive to new stimuli (textures, sounds) if they are introduced slowly over time.
- Some infants cannot tolerate eye contact and need to be held facing away. Do not force eye contact if the baby is showing defensive responses.
- Limit the number of caregivers who interact with the baby. This will promote the child's ability to learn the actions and understand the communication style of the primary caregiver.
- Promote attachment and bonding with sensitive caregiving by primary caregivers. Infants with FAS are at risk for attachment problems.
- Maintain a calm and quiet environment.
- Limit the number & type of objects hanging from the ceiling or walls.
- Use calm colors on the walls, such as pastel blue, light green, or pale yellow; avoid orange or bright red.
- Learn to read the child's cues so that he does not go over the edge … children can be very difficult to calm and soothe when they "lose it."
- Pacifiers can help a child self soothe.

Toddlers with FAS can be quite delightful. They are small, almost elf-like in appearance, and have an enthusiasm for new experiences. It is during this period that caregivers can teach important skills needed to ensure maximum success.

The following early intervention strategies will help caregivers of toddlers with FASD:

- Maintain a calm and quiet environment.
- Limit the number and type of objects hanging from the ceiling or walls.
- Use calm colors on the walls.
- Assist children in staying focused.
- Define spaces for play and eating.
- Provide routine quiet activities to aid a child in predicting events and staying organized.
- Establish rules for putting away items to help with transition and closure.
- Sing jingles about specific activities to facilitate a child's ability to remember what to do next.

At this stage of development, children generally begin to get a sense of limits, to establish a foundation for being organized and developing good self-esteem.

— Harwood & Kleinfeld, 2002

- Focus on cause and effect activities.
- Point out how things are related.
- Create habits of organization.
- Provide language stimulation activities: talk to the child, read stories in a calm voice.
- Set limits, but in a caring way that takes into account the child's sensory processing problems.

Effects and Interventions for Preschoolers

Preschoolers with FASD may display hyperactivity, poor eye-hand coordination, poor balance, poor tandem gait, central auditory dysfunction, delayed language, or mental retardation.

Preschoolers with FASD may not immediately grasp the meaning of a word or phrase they just heard. While they may appear to be listening, they may understand only a fraction of what is said to them (Malbin 1993).

Caregivers can employ the following strategies to ensure that preschoolers with FASD gain the most from a learning environment:

- Maintain a calm and quiet environment.
- Transitions can be very difficult for young children with FASD. They need time to adapt since they don't cope will with change.
- Limit the number and type of objects hanging from the ceiling or walls.
- Use calm colors on the walls.
- Have children repeat requests or directions.
- Model the behavior.
- Have the child act out the request or directions.
- Be prepared to repeat directions or requests; a problem for many children is their inability to consistently performs skills they once did with ease.
- Don't confuse inability to repeat a skill with unwillingness.
- Be aware of the self-esteem of the child; be willing to reteach, redirect, and repeat without demeaning or devaluing.

Effects and Interventions for Early School Age Children

Early school age children with FASD may display attention impairments, learning disabilities, arithmetic disabilities, specific cognitive disabilities, deficits in higher order receptive and expressive language, or poor muscle control. These children may have temper

Teachers must be aware that the type of brain damage that children with FAS/FAE have often leaves them unable to repeat a skill they once did with ease.

— Harwood & Kleinfeld, 2002

tantrums, may be easily influenced, have difficulty in predicting or understanding consequences, and have poor comprehension of social rules.

Strategies that teachers and caregivers can employ to help facilitate academic achievement for school age children with FASD:

- Maintain a calm and quiet environment.
- Limit the number and type of objects hanging from the ceiling or walls.
- Use calm colors on the walls.
- Use headphones for quiet times (this helps those with poor habituation).
- Keep rules few and simple.
- Be consistent in your enforcement of the rules.
- Give cues for the ending and beginning of activities.
- Maintain a consistent, predictable routine from day to day.
- Take breaks from during the day for napping or moving around.
- Talk to the student using language appropriate for their level.
- Use music to teach vocabulary and to help remember processes.
- Encourage developmentally appropriate quality of speech.
- Facilitate the understanding of the concept of numbers, not just the memorization of numbers.
- Teach the number one first: one pencil, one cat, etc.
- Touch and count objects.
- Teach functional math – money, time, practical uses for addition and subtraction.
- Use books with simple, plain pictures.
- Read aloud to children.
- Use sensory stimulation to teach concepts: to teach the color orange, wear orange clothes, paint with orange paint, use orange paper.
- Foster independence in school work and in play.
- Provide choices and encourage decision making.
- Teach daily living skills.
- Encourage positive self-talk.
- Teach child to prepare for the next day before going to bed.
- Establish routines.
- Break activities down into small pieces.

Adapted from Fantastic Antone Succeeds! Edited by Judith Kleinfeld and Soibhan Wescott

Part B is a federal entitlement program for children age 3-21 with a suspected delay or disability to receive screening, evaluation, and services needed regardless of income. Contact your local school board or Florida Diagnostic & Learning Resources System (FDLRS) for more information.

Effects and Interventions with Adolescents ages 13-18

Older school age and adolescent children with FASD may display memory impairments, difficulty with judgment, difficulty with abstract reasoning, or poor adaptive functioning. These children may give an appearance of capability without actual abilities, have difficulty separating fact from fiction, display low motivation or low self-esteem.

Teenagers with FASD may display problem behaviors such as lying or stealing. They may display poor judgment and have difficulty with peer relationships. Alcohol and drug abuse may occur and there is a greater risk for depression and suicide.

Some intervention strategies for this age group:

- Create a structured environment which includes limited choices.
- Establish clear and set routines.
- Provide supervision.
- Use simple directions when giving instructions.
- Break tasks into small steps.
- Use lists.
- Teach a new skill in the setting in which it will be used.

Effects and Interventions with Young Adults

Young adults with FASD may continue to have learning difficulties, memory impairments, difficulty with judgment, difficulty with reasoning, or inappropriate social skills.

Some young adults with FASD continue to need supervision and support. Help may be needed to perform household tasks. Independent living may not be possible and special living arrangements may be needed.

Intervention strategies for young adults:

- Teach the tasks of daily living.
- Maintain routines which do not vary from day to day.
- Use lists.
- Supervise money management.
- Provide support and guidance.
- Teach coping skills for stress management.

The Children's Research Triangle has developed "Cause and Consequence," an interactive CD-ROM guide educators and parents can use on a daily basis as they deal with the long-term impact of prenatal drug exposure on the child's behavior and learning. For more information go to http://www.childstudy.org/crt/products/software.php.

For additional information check: **www.cdc.gov/ncbddd/fas/fasask.htm**

One of the most debilitating effects of prenatal alcohol exposure involves the development and use of social communication. Social communication enables people to influence 'day-to-day' events in their lives.

— Coggins, Friet, & Morgan 1997

Health Care Interventions

Health care professionals can work with families to:

- Develop a personal and family medical history.
- Develop a plan of care.
- Develop an understanding of FASD and how to manage the condition.
- Create an environment that meets the needs of a child with FASD.
- Foster healthy coping skills for the child and the family.
- Foster self-esteem in the child.
- Plan for educational needs, including post-secondary education, and career and employment.
- Plan for transition to the adult health care system.

Strategies for Developing Social Skills

Individuals with FASD often display maladaptive behaviors thus creating stress on families. In a study of 54 adolescents and adults with FAS and FAE, 77% had poor concentration and attention, 62% were shown to withdraw, 57% were too impulsive, 53% were overly dependent, 53% were teasers or bullies, and 51% exhibited extreme anxiety (Streissguth & O'Malley, 2000).

To mitigate maladaptive behaviors in children with FASD:

- Set and enforce limits.
- Provide a variety of rewards.
- Repeat consequences of behaviors.
- Praise appropriate behaviors.
- Redirect inappropriate behavior.
- Intervene early.
- Don't expect children to "act their age" — it may not be possible.

Advocate Strategies

Successful advocate strategies to avoid confrontation can range from specific interventions to address cognitive impairments and overload to coping with the emotions generated. Often subtle warnings may be necessary to help child avoid activities that will over stimulate. Using inconspicuous modes of communication, a look, or a touch helps children to "save face" while maintaining control and avoiding trouble (Streissguth, 1997).

Fig. 11 Behavioral and emotional consequences of fetal alcohol-associated brain damage and advocate strategies

Brain damage	Dysfunctional behavior	Consequences	Emotion	Advocate strategies
Poor habituation	Drawn to stimulation Emotional overload Shuts down discriminations Behaves erratically	Disappoints people Gets criticized	Defensive	Decrease stimulation Teach techniques to reduce stimulation Teach techniques to inhibit behaviors
Poor self-regulation	Out of control behavior Acts without thinking	Gets into trouble	Confused	Reduce settings that induce out-of-control behavior Teach techniques to stay in control
Impulsivity	Quick to anger	Gets punished	Feels picked on	Teach to think before acting Anger management strategies Reward withholding response
Attention deficits	Distracted/easily distractible	Incomplete goals	Disappointment Frustration	Reduce distractions Reward paying attention
Slow central nervous system processing speed	Fails to grasp meaning and main deadlines	Object of derision Lack of success	Feels dumb Low self-esteem	Give more time Lower expectations Reward success
Arithmetic disability	Cannot handle money	Bounces financial Assigned a payee	Resentful	Develop cell-date systems Encourage rigid adherence to rules
Difficulty abstracting	Does not understand consequences Does not generalize learning to new situations	Tries hard and fails	Disappointment Frustration	Provide increased structure Vivacity goals Provide alternative satisfactions
Perseveration	Does same things over and over	Misses the rewards	Confusion Frustration	Teach goal oriented behaviors with concrete examples Find other behaviors to reward
Memory problems	Does not learn from experience	Makes same mistakes repeatedly	Confusion Frustration	Teach/develop memory aids Develop rigid routines
Disorientation in time and space	Misses appointments Misperceives social cues	Disappoints people Unpredictable	Feels ridiculed Lonely	Develop coping strategies Have friends be a part of the solution
Poor judgment	Trusts anybody Behaves irrationally	Easily victimized Easily scapegoated	Confused, hurt Low self-esteem	Develop coping strategies Reduce expectations Develop other sources of self-esteem
Difficulty with self-relaxation	Cannot express needs	Does not get help Fails to have needs met	Feels a failure Feels dissatisfied	Provide verbal feedback for expressed feelings Reward clear need expression

Used with permission. Streissguth, A. (1997). Fetal alcohol syndrome: A guide for families and communities. Baltimore, MD: Paul H. Brookes.

Early identification and intervention can:

- Stabilize the home, improve parenting, and prevent subsequent FAS births
- Structure environments to enhance development
- Coordinate care and provide for smooth transitions from infancy, toddlerhood, and school
- Promote preventative parenting techniques focused on problem solving rather than control
- Identify child's strengths, inclinations, and interests

Absence of early identification can result in:

- Poor bonding, failure to thrive, withdrawal
- Possible physical and emotional issues, abuse, neglect
- Early removal from home, multiple residences
- Early inconsistent memory, poor sequencing, hyperactivity
- Developmental delay
- Early school failure
- Functioning at levels lower than indicated by testing
- Misinterpretation of behaviors resulting in punishment rather than support
- Academically non-competitive by the fourth grade, when called upon to use higher cognitive process
- Social isolation
- Early first use of drugs and other behavior problems such as shoplifting, aggression
- Sexual victimization/acting out
- Inability to manage money or time
- Inability to maintain employment
- Narrow repertoire of behaviors
- Unstable relations with significant others

Source: Diane B. Malbin, M.S.W.
FAS Resource Coalition

SECTION 6

Prevention

Seems so simple. Fetal Alcohol Spectrum Disorders could be completely eliminated just by convincing women not to drink during pregnancy. Easier said than done.

Estimated Prevalence

- 2040 Florida infants are born with FAS or FAE each year.
- 156,582 Floridians of all ages are affected with FAS or FAE.
- Florida spends an estimated $78,918,000 yearly providing special education and juvenile justice services to children 5-18 years old affected by FAS or FAE.
- This amounts to an estimated $914,183 spent per day.

Source: www.online-clinic.com/calculator.php

According to the Centers for Disease Control and Prevention

- One in eight women of childbearing age (18 to 44 years old) reported, "risk drinking" (seven or more drinks per week, or five or more drinks on any one occasion).
- One of every 29 women who knows that she is pregnant reports risk drinking
- Birth defects associated with prenatal alcohol exposure can occur in the first three to eight weeks of pregnancy, before a woman even knows that she is pregnant.

Current Strategies

Current strategies to prevent FAS have been delineated into three components by The Committee to Study Fetal Alcohol Syndrome of the Institute to Medicine of the National Academy of Sciences. They include universal, selective, and indicated prevention methods (Stratton, Howe, & Battaglia 1996).

Universal prevention methods attempt to educate the general public about the risks of drinking alcohol during pregnancy. This method reaches a broad audience, but is geared toward pregnant women and women of childbearing age. Universal prevention methods include public service announcements, articles in newspapers and popular magazines, pamphlets distributed in health care settings, billboards, and alcoholic beverage warning labels.

There should be no doubt. It is **alcohol,** not the other associated risk factors; it is **alcohol,** not the other drugs, legal or illegal, that the mother might also be taking; it is **alcohol** that causes FAS and the other effects of prenatal alcohol exposure described in this book. If women did not drink alcohol during pregnancy, no more children would be born with FAS/FAE.

– Anne Streissguth, 1997

Current Strategies, continued

The cadre of universal prevention methods have been somewhat effective in increasing the general public's knowledge about the dangers of drinking while pregnant. Studies on awareness of the alcohol beverage warning label showed an increase in awareness over time. And, a larger proportion of the public is knowledgeable about the relationship between drinking during pregnancy and FAS (Hankin, 2002).

Selective prevention methods target women of childbearing age who drink alcohol. Screening all women who are pregnant for alcohol use is one example of a selective prevention method.

An example of selective prevention is the CDC's project CHOICES. This project is working to prevent FASD by educating women about the risk of prenatal alcohol exposure before they become pregnant.

Indicated prevention methods are directed at high-risk women, including women have previously delivered an infant with FAS or FAE. Indicated prevention methods have shown substantial progress in preventing prenatal alcohol exposure. The following studies demonstrate the effectiveness of indicated prevention methods.

In a study of 42 women who reported drinking while pregnant, 34 showed a significant reduction in alcohol consumption two months after receiving either written information about the risks related to drinking during pregnancy or a one-hour motivational interview focusing on the health of the participants' unborn babies (Handmaker, Miller, & Manicke, 1999).

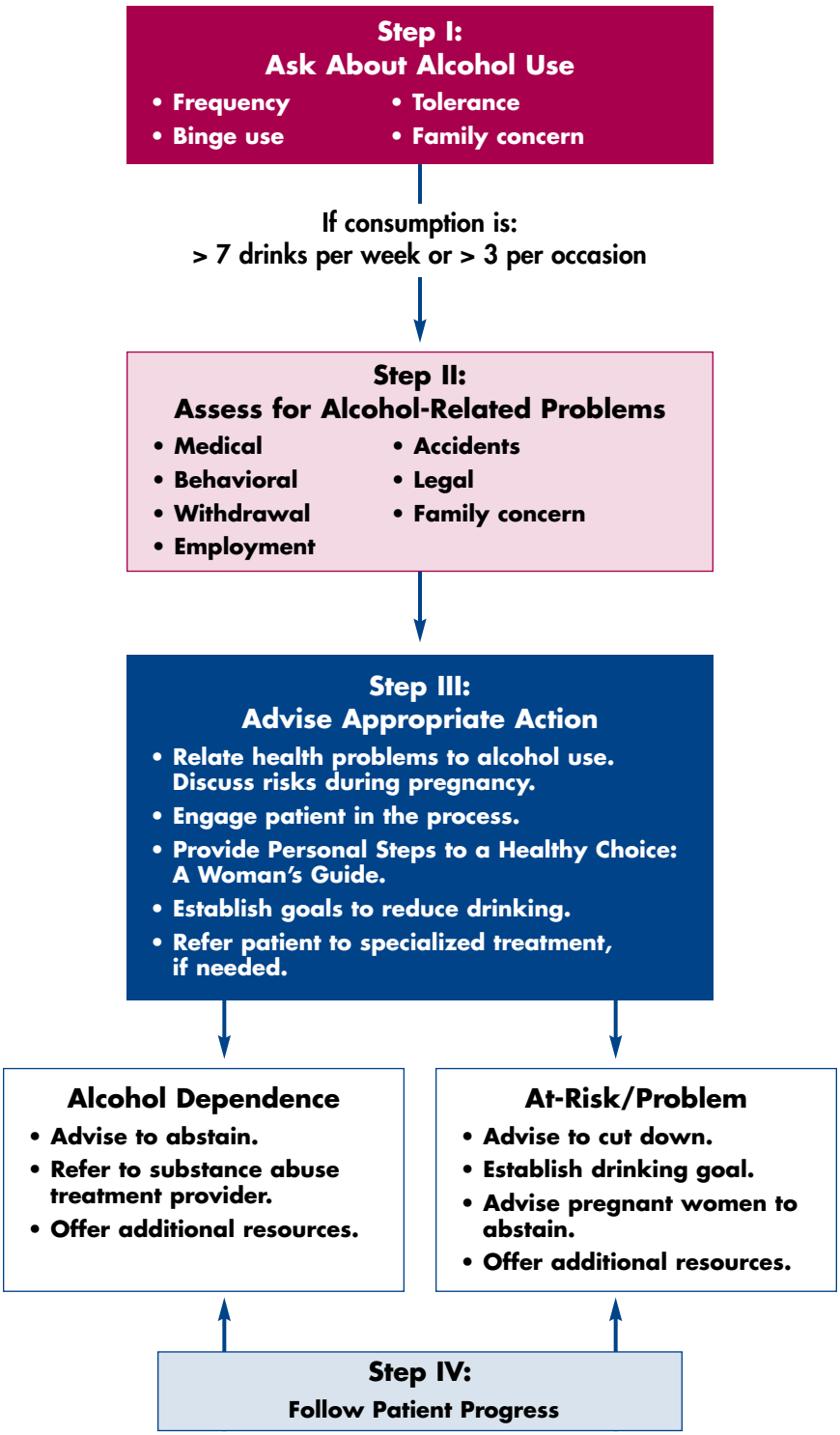
In another study, 123 pregnant women received a brief intervention after a comprehensive alcohol assessment was completed shortly after initiating prenatal care. Seventy-seven percent of the women chose abstinence during pregnancy as their goal during the brief intervention; twenty-three percent did not choose to be abstinent for various reasons (Chang, Goetz, Wilkins-Haug, & Berman, 2000).

Through a local referendum, a community in Alaska prohibited the possession of alcohol in an attempt to reduce prenatal alcohol exposure. The self-reported alcohol use among pregnant women during the initial six-month period of the alcohol ban (November 1994 through March 1995) was compared with that of a similar group of women prior to the ban. During the first five months of the ban, alcohol abuse during pregnancy dropped significantly from 42% to 9% (Bowerman, 1997).

For more information on the CDC's project CHOICES:
www.cdc.gov/ncbddd/fas/choices.htm

Identification of At-Risk Drinking Women

Fig. 12 Identification and Treatment of Women Who Drink Above Recommended Limits



from National Institutes of Health Publication No. 99-4368

Even women who do not normally utilize health care will get medical care and prenatal care when they are pregnant. Unfortunately, not all health care professionals capitalize on the fact that during pregnancy women can be highly motivated to stop drinking for the sake of their unborn child.

Screening for Women at Risk for Drinking During Pregnancy

Screening women for alcohol problems can be easily incorporated into routine clinical care through the use of health questionnaires or questions administered by support staff or the clinician. Ideal opportunities for screening include routine well women care, treatment of acute problems, pregnancy or pre-pregnancy counseling.

Since women expect their health care providers to ask them about their health habits, inquiring about type and level of drinking is timely and appropriate. Women will, for the most part, welcome prevention activities that will improve their quality of life and that of their baby. Primary care physicians have a unique opportunity to identify and treat women who are using alcohol above recommended limits.

A variety of screening instruments are available that can assist in identifying women at risk for drinking during pregnancy and can be further used to facilitate a discussion of the negative effects of prenatal alcohol exposure. (See Fig. 13.)

Florida's Fetal Alcohol Syndrome Initiatives

Florida's initiatives to reduce the incidence and impact of Fetal Alcohol Syndrome are housed in many programs. Often theses activities are collaborative efforts involving several agencies. Some of the many activities are listed below.

Department of Health

- All health care providers receiving state or federal funding are required to educate women of child bearing age about the dangers of using alcohol or other drugs during pregnancy, assess substance abuse history, and make appropriate referrals and follow up on referrals.
- Lake County Citizens for Alcohol Warning Labels worked with the Bureau of Professional Regulation to advise all alcoholic beverage sales outlets of the availability of posters warning of the danger of drinking during pregnancy. To obtain call (850) 488-3638.
- The Family Health Hotline provides education about the danger of using alcohol and other drugs during pregnancy and links those unable to access treatment services with those services. Call 800-451-2229 (451-BABY).

Fig. 13 Comparison of Screening Instruments to Identify Women at Risk for Drinking During Pregnancy

INSTRUMENT	FEATURES	STRENGTHS	CONCERNS
CAGE **C**ut down **A**nnoyed **G**uilty **E**ye opener	4 Questions. Not specifically designed for screening pregnant women, has served as a source of items for questionnaires designed to screen for risk drinking during pregnancy	Asses lifetime rather than current alcohol related problems	Does not identify heavy drinkers who have not experienced alcohol related problems. More effective in screening men than women
***T-ACE** **T**olerance-**A**nnoyed **C**ut down **E**ye opener	4 Questions. One question regarding how many drinks to feel high, and three questions from the CAGE	Developed for use in obstetric-gynecological practice. More sensitive to risk drinking than the CAGE	
***TWEAK** **T**olerance **W**orry **E**ye Opener **A**mnesia **C**ut-down	5 Questions. Combines questions from the MAST, CAGE, & T-ACE	More sensitive and less specific than the T-ACE. Out performs the MAST or CAGE	
MAST **M**ichigan **A**lcoholism **S**creening **T**est	25 Questions. Not specifically designed for screening pregnant women, has served as a source of items for questionnaires designed to screen for risk drinking during pregnancy		Does not identify heavy drinkers who have not experienced alcohol related problems. More effective in screening men than women
***AUDIT** **A**lcohol **U**se **D**isorder **I**dentification **T**est	10 Questions. Combines questions about alcohol use directly and on consequences of alcohol use	Its purpose is the early identification of harmful drinking rather than alcohol disorders such as alcohol abuse	Not been evaluated in obstetric populations. Longer and more complicated to score
***4 P's**	4 Questions. Questions about alcohol or drug use during current pregnancy, in her past, in her partner, and in her parents	Yes or No format Easy to administer and score	Potential lack of specificity and the possibility that women would answer direct questions about alcohol before questions about problems with alcohol
Modified 5P's	5 Questions. Questions about alcohol or drug use during this pregnancy, in her parents, in her partner, in her past, in her previous pregnancy *The 5 P's is an adaptation of the 4 P's.	Question about alcohol use during previous pregnancy may help to diagnose FAS in woman's other child(ren). One predictor of a FAS is being born to a mother with a child with FAS.	Potential lack of specificity and the possibility that women would answer direct questions about alcohol before questions about problems with alcohol
***TQDH** **T**en-**Q**uestion **D**rinking **H**istory	10 questions Focuses on type and amount of alcohol consumed.	Does not differentiate between beer, wine and liquor when determining at-risk drinking.	More than 4 drinks per week is considered risk drinking Best for women not yet pregnant

*Available at: www.ncemch.org/pubs/PDFs/SubAbuse.pdf
AUDIT: Saunders, J., Aasland, O., Babor, T., DeLaFuente, J., & Grant, M., 1993; 4P's: Ewing, H.; TACE: Sokol, R., Martier, S., & Ager, J., 1989; TWEAK: Russel, M., 1994; TQDH: Weiner, L., Rossett, H., & Edelin, K., 1982

Florida spends an estimated $78,918,000 annually to provide special education and juvenile justice services to children 5-18 years effected by FAS or ARBDND. This amounts to an estimated $914,183 spent per day for these services.

www.online-clinic.com/calculator.php

Florida's Fetal Alcohol Syndrome Initiatives

Department of Health, continued

- Substance abuse treatment programs and public health care facilities are required to give priority for services to pregnant, abusing women.
- Pregnant women using alcohol or other drugs are identified on Florida's Healthy Start Risk Screening Instrument, which is expected to be offered to all pregnant women.
- All pregnant women who are abusing alcohol or other drugs are eligible for Healthy Start care coordination services including home visiting, education, and support for abstinency efforts.
- All infants whose mother abused alcohol or other drugs during pregnancy and their families are eligible for Healthy Start care coordination services including home visiting, education on unique parenting needs of the child, support for abstinency efforts, and family planning education and support. Foster and adoptive families are eligible for these services also. For more information, contact your local Healthy Start coalition. Contact information available at: www.healthystartflorida.com/contact.htm or www.babies.org/
- Florida statute allows professional discretion in reporting to Florida's Abuse Hotline a child born prenatally exposed to alcohol. Florida's Abuse Hotline number is 1-800-96-Abuse.
- The Florida Birth Defects Registry includes Fetal Alcohol Syndrome. Call Jane Corriea at (850) 245-4444 ext. 2198. http://flbdr.hsc.usf.edu
- Children with Fetal Alcohol Syndrome receive needed services as identified. Services are available through Children's Medical Services, early intervention programs, schools, and health care providers.
- The Department of Health School Health Services program has 313 Comprehensive School Health Services Project schools in 47 counties that provide small group interventions and health education classes on pregnancy prevention, HIV/STD prevention, and alcohol, tobacco and other drug abuse prevention. Pregnant students are referred to pre-natal care, Healthy Start, and school district Teenage Pregnancy Programs. Students that give birth are provided with case management and support services that enable the majority of them to return to school and graduate. For more information about Comprehensive schools or other school health services, call (850) 245-4445 or log on to the School Health Services website at: http://www9.myflorida.com/Family/school/index.html

Department of Children and Families

- Center for Substance Abuse Prevention – Prevention Works! Training is available for nurses and others through the Internet at http://www.fadaa.org/events/training/prevention.html
- Ongoing substance abuse prevention activities target school age children through school health and other prevention programs.
- There are universal, selective, and indicated substance abuse prevention activities throughout Florida.

The Healthy Families Florida Program is administered by the Ounce of Prevention. It is a voluntary home visiting program that helps parents during the most important learning years of a child's life, from birth to five years. A home visitor works with families to learn what to expect as the baby grows and develops, how to stimulate the child's healthy growth and development, and how to cope and problem solve during stressful times. The home visitor can also help the family connect to other community services the family may need. For more information, go to: www.healthyfamiliesfla.org/

The Substance Abuse Program makes every effort possible to identify and encourage treatment entry for pregnant and postpartum substance abusing women in the State of Florida through its intervention/ outreach efforts. Pregnant women are given first priority status for admission and placement.

Programs for pregnant women and women with dependent children are offered: primary medical services for both the mother and dependent children; prenatal care and peri-natal care for effects of maternal substance abuse; pediatric health care for dependent children; postpartum care for mother and child; counseling for both the adult and the child on a range of needs; transportation, childcare, outreach services; and screening/testing/counseling for HIV & TB. Services may be provided directly by providers or by formal agreements with other service providers.

Through the **Family Safety Program** children who are placed in foster care receive a Comprehensive Behavioral Health Assessment. This process should assist in improving identification and interventions for foster care children with FASD.

The **Children's Mental Health Program** receives referrals through a single point of access and provides a range of children's mental health evaluation and treatment services. This program is also piloting Infant Mental Health prevention programs.

The Agency for Health Care Administration (AHCA)

AHCA administers Medicaid funding to provide diagnostic and medical care for individuals determined eligible for Medicaid. All Medicaid eligible children qualify for a well child evaluation that includes a behavioral health screen.

Reducing the Effects of Prenatal Substance Abuse in Florida

Florida provides a statewide systematic structure for reducing the impact of prenatal substance abuse.

Florida's system of care for families affected by prenatal drug abuse:

- Requires that all health care workers paid with state funds assess the tobacco, alcohol, and other drug use history of all the women of child bearing age for whom they provide care (64F-4, F.A.C.).
- Assures universal prenatal care for women in Florida (s. 383.011, F.S.).
- Provides a hotline to assist women having problems accessing prenatal care or alcohol and other drug abuse treatment. Call 800-451-2229 (451-BABY).
- Requires that communities develop a coordinated, transdiciplinary response to these families' needs (Letter of Agreement between the Department of Health and Department of Children and Families).
- Requires that all pregnant women will be screened for tobacco, alcohol, and other drug use. Women who use these drugs are offered Healthy Start care coordination and enhanced services.
- Offers families of children born prenatally drug exposed intensive care coordination services, home visiting, education on the unique parenting skills needed, links with needed services, and support for steps in drug abuse abstinence (s. 383.14, F.S., 64F-4, F.A.C., Healthy Start Standards and Guidelines, and the County Health Department Guidebook, Maternal Health Technical Assistance Guidelines).
- Provides, through the Regional Perinatal Intensive Care Centers, obstetrical services to women identified as having high-risk pregnancies and neonatal intensive care services to critically ill or low birth weight babies at designated centers in Florida.
- Offers smoking cessation programs for the pregnant woman and others in her home, and nicotine patches to other smokers in the home as part of the enhanced services.
- Requires drug treatment programs and county health departments receiving state or federal funds to give priority to pregnant and postpartum women and to accept the children with the mother when requested by the mother (64F-4, F.A.C.).

- Allows use of professional discretion in determining when to report to the abuse hotline a child born prenatally drug exposed; Call 800-352-2873 (FLABUSE) (s. 39.01(30)(g), F.S., 64F-4, F.A.C.).
- Provides, through Child Protective Teams, a multidisciplinary assessment and review of selected incidents of child abuse.
- Makes posters available through the Department of Business and Professional Regulation for display at points of sale for alcoholic beverages. The posters advise of the dangers of drinking alcohol and driving or drinking alcoholic beverages during pregnancy.

Centers for Disease Control and Prevention's efforts to prevent FASD:

- Project CHOICES (Changing High Risk Alcohol Use and Increasing Contraception Effectiveness Study) is a multi-site collaborative effort between CDC and three universities working to prevent FAS by educating women about the risk of prenatal alcohol exposure before they become pregnant.
- Epidemiological studies have identified selected community-based settings (i.e. jails, alcohol and drug treatment centers, primary care centers serving low income populations) for intervention targeting because they have higher proportions of women at risk for an alcohol exposed pregnancy.
- A clinical trial to test Project CHOICES' behavioral intervention among high-risk women in the settings described above. The project completion date is Fall, 2003.

Federal alcohol and drug abuse agencies efforts to prevent FASD:

National Institute on Alcohol and Alcoholism and the **National Institute on Drug Abuse** support a significant range of research and treatment interventions related to pregnant, postpartum, substance abusing women; alcohol prevention and treatment for all individuals including those with FASD.

For additional information check: **www.niaaa.nih.gov/publications/FASguides.htm**

Thousands of infants continue to be born with preventable birth defects due to prenatal alcohol exposure .

— Blume. S. 1996

Future Strategies to Prevent FASD

Educate the General Public

Public education is the cornerstone of all FAS prevention efforts (Streissguth, 1997). We must do a better job of communicating that FAS is public health issue of considerable magnitude.

- In a study of alcohol related issues in the national press (Lemmons, Vaeth, & Greenfeild, 1999), researchers found that of the 1,677 articles reviewed, only 23 dealt with alcohol and pregnancy.
- In a study of national network evening news broadcasts between 1977 and 1996 revealed that alcohol and pregnancy was the topic of a newscast a mere 36 times.

Educate Health Care Professionals

Early detection and identification of women at risk for alcohol consumption during pregnancy is a primary preventative strategy for reducing the incidence of FAS/FAE. However, only 20% of obstetrician-gynecologists surveyed in a recent study reported abstinence as the safest way to avoid FAS/FAE (Diekman, Floyd, DeCoufle, Schulkin, Ebrahim, & Sokol, 2000). Of even greater concern is the finding that 13% were unsure about the risk of alcohol consumption associated with FAS/FAE. Moreover, physicians graduating from medical school before 1973 were less likely than those graduating after 1989 to be sure of the risk of prenatal alcohol consumption and least likely to use a valid screening tool to identify women at risk.

In 2002, seventy-five family physicians in the Toronto area responded to a survey regarding the prevention and diagnosis of FAS. Only 60.8% reported counseling childbearing women in general on the use of alcohol. Even more troubling is that 25% reported that they did not counsel pregnant women on the use of alcohol (Nevin, Parshuram, Nulman, Koren, & Einarson, 2003).

When asking why so many physicians are not screening and counseling women on the dangers of prenatal alcohol exposure, one might look at a recent study of 81 obstetrical textbooks identified from a national listing service and local library shelves. Of these 81 textbooks only 14 (17%) contained a consistent recommendation that pregnant women should not drink alcohol. Further, of the 29 texts published after 1990, only 24% were in this category. Fifty-three percent of all 81 texts and 52% of texts published after 1990 contained a sentence condoning drinking at some level. The remaining texts (30%) contained no recommendations (Loop, & Nettelman, 2002).

Health care professionals are missing an important opportunity to educate and intervene with women at risk for drinking during pregnancy. Even women who do not normally utilize health care will get medical care and prenatal care when they are pregnant. Training and education for health care professionals must include information about the importance of capitalizing on the fact that during pregnancy women can be highly motivated to stop drinking for the sake of their unborn child.

Identify High Risk Birth Mothers and Intensify Prevention Programs

Children with FAS can be biomarkers. Several studies report that women who have had one child with FAS, and who continue to drink, have progressively more severely affected children with subsequent pregnancies (May et al., 1983; Davis & Lipson, 1984; Abel, 1988). Identifying high-risk birth mothers and targeting intervention strategies (diagnostic and treatment) could potentially provide a cost effective approach to FAS prevention. Focusing prevention efforts on this select and high-risk group of women could reduce the incidence of FAS births dramatically without overburdening the current healthcare and alcohol treatment system (Clarren & Astely, 1998).

While Florida devotes considerable resources to prevention and intervention services for individuals with FASD, continuing needs remain. To improve our capacity to ascertain true surveillance and identification of FASD, Florida must:

- Improve awareness of the dangers of alcohol consumption during pregnancy.
- Increase and enhance identification methods.
- Increase training of pediatricians in recognizing symptoms of FASD.
- Implement health-care provider training and education on FASD to improve knowledge about the effects of alcohol use during pregnancy, and improve referrals for needed services and prevention activities.
- Create capacity to review a sample of state's births for FAS.
- Augment training on FASD in medical schools.
- Increase identification of women at high risk for prenatal alcohol consumption.
- Continue and expand state capacity for staff resources to support work of the Fetal Alcohol Spectrum Disorders Interagency Action Group.

The Fetal Alcohol Spectrum Disorders Interagency Action Group Strategic Plan

Highlights

Priority Area 1: Prevention – How to Prevent Children from Being Born with FAS

- Increase professional awareness of FASD through video, print media, conferences, city buses, pharmacies, clinics, ABC stores, bathrooms, bars, and restaurants. Educate foster care and child protection workers and other professionals on signs of FASD.
- Increase teen awareness of FASD.
- Increase awareness of FASD in pregnant women.

Priority Area 2: Diagnosis

- Assess current educational level of FASD information among health professionals, educators, human services.
- Implement educational initiatives.
- Move toward a more active Birth Defects Registry.
- Increase information dissemination to health care professionals.
- Add alcohol consumption (prenatal) question to children's services intake forms for WIC, CMS, Foster Care, and EIP.
- Support Diagnostic/Evaluation Regional Centers.

Priority Area 3: Intervention

- Increase the number of professionals qualified to provide intervention to children and families affected by FASD.
- Improve the quality of treatment services available to children and adults with FASD.
- Increase access to treatment services.

Priority Area 4: Life Support/Extended Services

- Train professionals how to identify and assess FASD in young adults. This may include training for vocational rehabilitation (VR) counselors, high school counselors, school nurses and social workers, judges, and Department of Corrections personnel.
- Conduct literature review on effective intervention strategies for promoting positive outcomes for FASD adults.
- Advocate for specific inclusion of FASD in listing of eligibility criteria for VR, developmental disabilities, etc.
- Identify existing support services for young adults and older adults with FASD: work evaluation, job training, sheltered living, ongoing employment supervision, money/life management assistance, in-home respite/support.

Resources

BOOKS

Alcohol, Health and Research World, Special Focus: Alcohol-Related Birth Defects. Alcohol, Health and Research World; Vol. 18, No. 1, 1994; to order this special edition call (800) 553-6847. For more information on subscribing contact the U.S. Government Printing Office at (202) 783-3238.

The Best I Can Be: Living with Fetal Alcohol Syndrome or Effects. Kulp, L. & Kulp, J. Order at www.betterendings.org (763) 531-9548

The Broken Cord. Dorris, M., 1989, 300 pgs. Story by a father about his adopted son, Adam, who has fetal alcohol syndrome. Cost: $18.95 hard back; $9.95 paperback. Order from: Harper & Row, Publishers, 10 East 53rd St., New York, NY 10022.

Bruised Before Birth: Parenting Children Exposed to Parental Substance Abuse. Publication addresses the needs of children through adolescence. Cost: $14.95 plus $2.75 postage and handling. Order from: Family Resources, 1521 Foxhollow Rd., Greensboro, NC 27410.

Cheers, Here's to the Baby. LaFever, L. Story by a mother about her son who has FAS. Order from: FAS*FRI Publications, PO Box 2525, Lynnwood, WA.98036. Email at: vicky@fetalalcoholsyndrome.org

Children with Fetal Alcohol Syndrome. / A Handbook for Caregivers ($8.00 includes S/H) HAS, Publications, 336 N. Robert Street, #1520, Saint Paul, MN 55101. (800) 736-896

Children with Fetal Alcohol Syndrome: A Handbook for Parents and Teachers. 1998 Burd, L. Helps parents and teachers understand FAS. 1300 South Columbia Road, Grand Forks, ND 58202. 701-780-2477

Fantastic Antone Grows Up: Adolescents and Adults with Fetal Alcohol Syndrome. Kleinfeld, J.M., Wescott, S., & Morse, B. (Eds.). Order from: NOFAS, 1819 H Street NW, Suite 750, Washington, DC 20006 (202) 785-4585

Fantastic Antone Succeeds: Experience in Educating Children with FAS. Kleinfeld, J.M, Wescott, S. (Eds.) 1993, 361 pgs. ($23.50 softcover, $33.50 hardcover S/H incl.) NOFAS, 1819 H Street NW, Suite 750, Washington, DC 20006 (202) 785-4585

FAS and FAE and Education: The Art of Making a Difference. Berg, S. et al. 1997. The FAS and FAE Support Network of British Columbia, #151-10090, 152nd Street, Suite 187, Surrey, BC V3R 8X8. (604) 589-1854, Fax : (604) 589-8438. Email: fasnet@istar.ca.

FAS/FAE: A Practical Guide for Parents. 1994. Slinn, J. Based on experiences with his two FAS adopted children. Order from: Parents Resource Network, 540 West International Airport Road, Anchorage, AK 99518-1110, (907) 564- 7489.

FAS: Parent and Child: A Handbook. 1992. Morse, B.A, & Weiner, L. Fetal Alcohol Education Program, Boston University School of Medicine, 1975 Main Street, Concord, MA 01742. (978) 369-7713.

Fetal Alcohol Syndrome/Fetal Alcohol Effects Strategies for Professionals . 1993. Malbin,D. Hazelden. Educational Materials, Pleasant Valley Road, P.O. Box 176, Center City, MN, 55012-0176. (800) 328-9000

Fetal Alcohol Syndrome: A Guide for Families and Communities. 1997. Streissguth, Ann, Ph.D. Paul H. Brookes Publishing Company, P.O. Box 10624, Baltimore, MD 21285-0624. www.brookespublishing.com/store/books/streissguth-2835/index.htm

Fetal Alcohol Syndrome: The Impact on Children's Ability to Learn; National Health/Education Consortium Occasional Paper #10. Institute for Educational Leadership, 1001 Connecticut Ave. NW, #310, Washington, DC 20036 (202) 872-8450

Handle with Care: Helping children prenatally exposed to drugs and alcohol. Villarreal, S.F., Mckinney, L.E., Quackenbush, M., 1992, 200 pgs. ($17.95, soft cover) Sales Department, ETR Associates, P.O. Box 1830, Santa Cruz, CA 95061-1830; (800) 321-4407

Layman's Guide to Fetal Alcohol Syndrome and Fetal Alcohol Effects. 1995. Berg, S. et al. ($15.00) (604) 589-1854, Fax: (604) 589-8438, Email: fasnet@istar.ca

My Name is Amanda and I Have FAE — A Book for Young Children with FAS/E ($8.50) Is published by: FAS/E Support Network of B.C. (604) 589-1854, Email: fasnet@istar.ca

Our FAScination Journey: The Best We Can Be, Keys to Brain Potential Along the Path of Prenatal Brain Injury. Kulp, J. Order from: www.betterendings.org (763) 531-9548

Reaching Out to Children with FAS and FAE. 1992. Davis, D. Handbook for parents, teachers and others who live and work with children who have FAS/FAE. Available from: The Center for Applied Research in Education, West Nycak, NY 10995. Published in Seattle, WA.

Recognizing and Managing Children with Fetal Alcohol Syndrome/Fetal Alcohol Effects: A Guidebook. McCreight, B. ($16.50) Available from: CWLA, c/o CSSC, 130 Campus Drive, Edison, NJ 08818-7816, when ordering as for stock # 607-0. (800) 407-6273. www.cwla.org

So Your Child Has FAS and FAE – What You Need to Know. 1997. Berg, S., et al. The FAS and FAE Support Network of British Columbia, #151-10090, 152nd Street, Suite 187, Surrey, BC V3R 8X8. (604) 589-1854, Fax : (604) 589-8438. Email: fasnet@istar.ca

Trying Differently Not Harder. Malbin, D. Sequel to Fetal Alcohol Syndrom/Fetal Alcohol Effects Strategies for Professionals. Available only at Fascets Marketplace, (503) 621-1271

Women and Alcohol: Issues for Prevention. 1997. Thom, B. This literature review provides an overview of the factors influencing women's alcohol consumption and drinking patterns, it also examines issues dealing with prevention and early intervention and identifies areas for future research. ISBN 0752105205

VIDEOS

…and down will come baby. A new seventeen-minute video for teenagers, which examines the specific health risks to the unborn child exposed to cocaine, heroin, alcohol and tobacco. For ordering information write to: Scott Newman Center, 6255 Sunset Blvd, Suite 1906, Los Angeles, CA 90028, (800) 783-6396

A Challenge to Care. This video focuses on the pregnancy and postpartum stage of a pregnant substance abuser. Cost $275. Order from: Vida Health Communications, 6 Bigelow Street, Cambridge, MA 02139. Phone: (617) 864-4334, Fax: (617) 864-7862.

Alcohol and Pregnancy: Fetal Alcohol Syndrome and Fetal Alcohol Effects. A video showing how alcohol adversely affects the developing fetus and points out critical periods during pregnancy when the fetus is most vulnerable. Through candid interviews, it presents a realistic look at the daily struggles of the FAS/FAE child and his parents or caregivers. 20 minutes. Cost $295. To order, write: Aims Media, 9710 DeSoto Avenue, Chatsworth, CA 91311-4409; (800) 367-2467. Contact for free previews and rentals.

The Clinical Diagnosis of Fetal Alcohol Syndrome. A new video by Jon M. Aase, M.D., shows complete and never before seen information on the clinical diagnosis of FAS. The video can be purchased for the price of $150.00 + $9.00 for S/H from Flora & Company P.O. Box 8263 Albuquerque, NM 87198-8263 or by calling (505) 255-9988, 24 hours a day.

FAS. Includes interviews with noted experts Sterling Clarren, M.D., Diane Malbin, M.S.W., Antonio Rathbum, and others. 45 minutes. Cost $225, plus $6.00 for shipping and handling. Order from: Hazelden Educational Materials, Box 176, Center City, MN 55012.

Fetal Alcohol Syndrome and Effect: Stories of Hope and Help. Families and individuals affected by fetal alcohol exposure share their stories. Cost $225. Order from: Hazelden, P.O. Box 176, Pleasant Valley Road, Center City, MN 55012. (800) 329-9000.

Four Part Series on FAS. Provides information for caregivers about how to handle children with FAS as they get older. Cost: $345/tape. To order, write: Altschul Group Corporation, 1560 Sherman Ave., Suite 100, Evanston, IL 60201-9971; (800) 421-2363. Contact regarding free previews and rentals.

Straight From the Heart. A motivational film in which six women share their stories about addiction and recovery. Cost $275. Order from: Vida Health Communications, 6 Bigelow Street, Cambridge, MA 02139. Phone: (617) 864-4334, Fax: (617) 864-7862.

Training Tapes for Living with F.A.S. and F.A.E. The Early Years, The School Years and A Focus on Prevention explaining the cause of FAS and FAE, how to care for and better meet the needs of children with FAS/FAE. Each tape is 20 minutes long and costs $295. To order, write: Altschul Group Corporation, 1560 Sherman Avenue, Suite 100, Evanston, IL 60201-9971; (800) 421-2363. Contact regarding free previews and rentals.

Training Tapes of Living with F.A.S. and F.A.E. The Early Years, Birth through Age 12 and Independence, Ages 12 to Adult seek to assist those living with FAS/FAE and their families from soothing a fussy baby to adaptive living skills. Each tape is 32 minutes long and costs $295. To order, write: Altschul Group Corporation, 1560 Sherman Avenue, Suite 100, Evanston, IL 60201-9971

Women of Substance. A new one-hour documentary on the barriers pregnant and child caring women addicts encounter in their struggle towards sobriety. Call Video Action Fund for ordering information (202) 338-1094

Worth the Trip: Raising and Teaching Children with Fetal Alcohol Syndrome. About health, development, and learning style of a child with FAS. Cost $150. Order from: Vida Health Communications, 6 Bigelow Street, Cambridge, MA 02139. Phone: (617) 864-4334, Fax: (617) 864-7862.

SUPPORT GROUPS, AGENCIES and ORGANIZATIONS

Adoptive & Foster Moms Support Group (AM/FM)
Beaver Dam, WI
Sandy Yaroch
Email: syaroch@hotmail.com
(414) 885-6903

Adult Children of Alcoholics
PO Box 3216
Torrance, CA 90510
(310) 534-1815

Alcoholics Anonymous
P.O. Box 459, Grand Central Station
New York, NY 10163
(212) 870-3400
http://www.alcoholics-anonymous.org/econtent.html

Al-Anon
Al-Anon Family Group Headquarters
1600 Corporate Landing Parkway
Virginia Beach, VA 23454-5617
Phone: (888) 4AL-ANON
(757) 563-1600
Fax: (757) 563-1655
http://www.al-anon.alateen.org

American Medical Association
515 N. State St.
Chicago, IL 60610
(312) 464-5000

The Arc (a national organization on mental retardation)
500 East Border Street, Suite 300
Arlington, TX 76010
(800) 433-5255

The Association for Retarded Citizens of Florida
2898 Mahan Drive, Suite #1
Tallahassee, FL 32308
(850) 921-0460

Centers for Disease Control and Prevention
Division of Birth Defects and FAS Prevention Section
4770 Buford Hwy. NE (MS F15)
Atlanta, GA 30341-3724
(404) 488-7370

Center for Science in the Public Interest
Alcohol Policies Project
1875 Connecticut Ave. NW, #300
Washington, DC 20009
(202) 332-9110

Children of Alcoholics Foundation
555 Madison Avenue, 20th Floor
New York, NY 10022
(212) 754-0656
(800) 359-2623

Child Development Unit, Kids in Need Program
University of Colorado Health Sciences Center
Child Development Unit, B-140
The Children's Hospital
1056 East 19th Ave
Denver, CO 80218
(303) 861-6630

Families Anonymous (FA)
P.O. Box 3475
Culver City, CA 90231
Phone: (800) 736-9805

SUPPORT GROUPS, AGENCIES and ORGANIZATIONS, continued

Family Empowerment Network Support Group, (The FEN Pen Newsletter)
Georgiana Wilton
610 Langdon St., 519 Lowell Hall
Madison, WI 53703
(800) 462-5254

Fetal Alcohol Task Force
1016 East First Street Port
Angeles, WA 98362

Fetal Alcohol Education Program
Boston University School of Medicine
1975 Maine St.
Concord, MA 01742
(978) 369-7713

Fetal Alcohol and Drug Unit
University of Washington
180 Nickerson St., Suite 109
(206) 543-7155

FAS Family Resource Institute
P.O. Box 2525
Lynwood, WA 98036
(206) 778-4048
FAS Workshops; Adult and Teen Prevention Programs

Fetal Alcohol Syndrome Support Network (FASN)
Margaret Sprenger
Mississauga Coordinator
2266 Homelands Drive
Mississauga, ON L5K1G6
Phone/Fax – (905) 822-0733

Florida Alcohol and Drug Abuse
Association Resource Center, (850) 878-2196,
http://www.fadaa.org
Disseminates alcohol and other drug information.

Florida Department of Children and Families
1317 Winewood Blvd. Building 1, Room 202
Tallahassee, Florida 32399-0700
Phone: (850) 487-1111
Fax:(850) 922-2993

Florida Department of Health
4025 Esplanade Way
Tallahassee, Florida 32399-1723
Phone: (850) 245-4444

International F.A.S. Trainer
Contact Keith Wymer,
P.O. Box 312
Angel Fire, NM 87710
Email: kwc2@afweb.com

March of Dimes Birth Defects Foundation
1275 Mamaroneck Ave.
White Plains, NY 10605
(914) 428-7100

National Clearinghouse for Alcohol and Drug Abuse Information (NCADI)
P.O. Box 2345
Rockville, MD 20847-2345
(800) 729-6686

National Council on Alcoholism and Drug Dependence, Inc.
12 West 21 St.
New York, NY 10010
(212)-206-6770

National Institute on Alcohol Abuse and Alcoholism (NIAAA)
Wilco Bldg.
600 Executive Blvd.
Rockville, MD 20852
(301) 443-6370

National Indian Health Service Fetal Alcohol Syndrome Project
Headquarters West
5300 Homestead Rd. NE
Alburquerque, NM 87110
(505) 837-4228

National Organization on Fetal Alcohol Syndrome (NOFAS)
1815 H St., NW, Suite 1000
Washington, DC 20006
(202) 785-4585
(800) 66-NOFAS

National Council on Alcoholism and Drug Dependence (NCADD)
12 West 21 St.
New York, NY 10010

National Perinatal Information Center
One State Street, Suite 102
Providence, RI 02908

National Association for Native American Children of Alcoholics
1402 3rd Ave., Suite 1110
Seattle, WA 98101
(206) 467-7686
(800) 322-5601

National Black Alcoholism Council
285 Genesee St.
Utica, NY
(315) 798-8066

National Coalition for Hispanic Health and Human Services
1501 16th St. NW
Washington, DC 20036
(202) 387-5000

National Council on Disability
1331 F St., NW, Suite 1050
Washington, DC 20004-1107
(202) 272-2004

National Women's Resource Center for the Prevention and Treatment of Alcohol, Tobacco and other Drug Abuse and Mental Illness
200 N. Michigan Ave, Suite 300
Chicago, IL 60601
1-800-354-8824
(312) 541-1272

National Women's Health Network
1325 G St. NW,
Washington, DC 20005
(202) 347-1140

Parent to Parent, (800) 527-9552.
Organization serving as a support network for parents to children with disabilities in Florida.

Resource Center on Substance Abuse Prevention and Disability
1331 F St. NW, Suite 800
Washington, DC 20004
(202) 783-2900

SAMHSA National Clearinghouse for Alcohol & Drug Abuse Information
(800) 729-6686 Provides information packets, brochures, literature searches.

SNAP, (Society of Special Needs Adoptive Parents)
409 Granville Street, Suite 1150
Vancouver, BC V6C1T2, CANADA
(604) 687-3114

Support Group for Adoptive and Foster Parents
Contact: Ronnie Jacobs
Paramus, NJ
(201) 261-1450

Toughlove
P.O. Box 1069
Doylestown, PA 18901
Phone: (215) 348-7090
Fax: (215) 348-9874

Women for Sobriety
PO Box 618
Quakertown, PA 18951-0618
1-800-333-1606

NEWSLETTERS

Iceberg Newsletter
P.O. Box 95597
Seattle, WA 98145

Manitoba FAS News
CAP, Manitoba Medical Assn.
125 Sherbrook St.
Winnipeg, Manitoba, Canada R3c2B5,
Attn: D. Ridd
(204) 944-6360

F.A.S. Track
PO Box 3418
Peoria, IL 61612
(309) 691-3800

FANN – Fetal Alcohol Network Newsletter
158 Rosemont Avenue
Coatsville, PA 19320
Listing of National Support Groups
(610) 384-1133

F.A.S. Times
The Family Resource Institute
PO Box 2525
Lynnwood, WA 98036
(206) 531-2878
1-800-999-3429
Subscriptions available:
$15.00(family), $25.00 (Professional)

The Clearinghouse for Drug Exposed Children Newsletter
Division of Behavioral and Developmental Pediatrics
University of California, San Francisco
1350 7th Avenue, Room 101
San Francisco, CA 4143-1311
(415) 476-9691

Growing With FAS/FAE Newsletter,
contact Pamela Groves
7802 SE Taylor
Portland, OR 97215
(503) 254-8129

FAS/FAE Newsletter
c/o Mailbag
P.O. Box 74612
Fairbanks, AK 99707
Support Group, contact Gail Hales
(907) 456-2866

Notes from NOFAS
1819 H St, NW, Suite 750
Washington DC 20006
1-800-66-NOFAS

The FEN Pen
Family Empowerment Network
University of Wisconsin-Madison
521 Lowell Hall
610 Langdon Street
Madison, WI 53703-1195
(608) 262-6590 / 1-800-462-5254
Subscriptions available: $5.00 (Family), $10.00 (Professional)

SNAP (Society of Special Needs Adoptive Parents)
409 Granville Street, Suite 1150
Vancouver, BC V6C1T2, CANADA
(604) 687-3114
Subscription available:
$15.00 (Individual Membership), $20.00 (Family), $35.00 (Group/Society)

OTHER RESOURCES

Alcohol Research and Health has an ARBD Update, Vol. 23(3), 2001, entire volume is FAS related $20/year. Back issues are sometimes available. Write to: Superintendent of Documents, P.O. Box 371954, Pittsburgh, PA, 15250-7954. Call (202) 512-2250 processing code is #5746.

Alcohol, Pregnancy, and the Fetal Alcohol Syndrome. This new Slide-Lecture Unit from Project Cork of the Dartmouth Medical School contains seventy-nine full color slides, with accompanying text, covering the effects of maternal drinking on fetal development. The slide unit is available from Milner-Fenwick, Inc., 2125 Greenspring Drive, Timonium, MD 21093. To order call (800) 432-8433 or fax (410) 252-6316.

CSAP National Clearinghouse for Alcohol & Drug Abuse Information. Provides referrals, information packets according to need or topics of interest, literature search service or select from their 1,000 publications. (800) 729-6686.

CSAP National Resource Center for the Prevention of Perinatal Abuse of Alcohol and Other Drugs. For health professionals and educators interested in obtaining information. 9302 Lee Highway, Fairfax, VA 22301. (800) 354-8824.

Drug and Alcohol 24 Hour Hotline. 800-562-1240

Family Health Line. Provides education about the effects of drinking during pregnancy and helps link pregnant women with treatment services 800-451-2229.

FAS Information Packet South Dakota UAP Interdisciplinary Center for Disabilities, Early Childhood Research Program. 414 E Clark Street, Vermillion, SD 57069-2390 (800) 658-3080 or (605) 677-5311 ($3.00 for out-of-state).

FASERS of Florida – Fetal Alcohol Syndrome Education Service
Email: wishesthree@earthlink.net

FDA Drug Bulletin: Surgeon General's Advisory on Alcohol and Pregnancy. Information of importance to physicians and other health professionals. Vol 11(2), July, 1981.

Guidelines of Care for Children with Special Health Care Needs: Fetal Alcohol Syndrome and Fetal Alcohol Effects. Minnesota Department of Health 1999 Minnesota Children with Special Health Needs 85 East Seventh Place, P.O. Box 64882, St. Paul, MN 55164-0882. (651) 215-8956 (Voice or TDD) (800) 728-5420 (Voice or TDD)

Hazelden Hotline. A service of the Hazelden treatment program, helps people to overcome fears about talking to friends and relatives with addiction problems. Call 1-800-I-DO-CARE.

A Manual on Adolescents and Adults with FAS with Special Reference to American Indians. Indian Health Service FAS Project, 5300 Homestead Avenue NE, Albuquerque, NM 87109 (505) 837-4228 (free of charge).

Men Have Babies Too. Brochure developed by the March of Dimes examines the male's influence on the unborn baby. To order, call the March of Dimes National Office (914) 428-7100.

Office of Minority Health Resource Center. Conducts customized database searches, accessing information on health programs and organizations, as well as funding sources and articles. A printout will be mailed to you at no charge (800) 444-6472.

Preventing FAS and Other Alcohol-Related-Birth-Defects: Teachers and Student Manuals. The Arc National Headquarters, 500 East Border, Suite 300, Arlington, TX 76010, (817) 261-6003.

Prevention of perinatal substance use: Pregnant and Postpartum Women and Their Infants Demonstration.. 350 pages, 1993. Available free of cost. NMCHC inv. Code G031. Order from: National Maternal and Child Health Clearinghouse, 8201 Greensboro Drive, Suite 600, McLean, VA 22102, (703) 821-8955, ext: 254 or 265.

Training of Trainers Manual on FAS American Indian Family Healing Center. 1815 39th Avenue Oakland, CA 94601. (510) 534-2737 ($20.00).

When the Bough Breaks: Pregnancy and the Legacy of Addiction. New Sage Press 825 NE 20th Avenue #150, Portland, OR 97232, (503) 232-6794.

Working with FAS Children: A Handbook for Caregivers of FAS/FAE Children. Jean Cornish, Minnesota Services Associates, (612) 645-0688.

WEBSITES

Alcohol Exposure During Pregnancy. Links to Learning Disabilities, ADD and Behavior Disorders. Contains articles written by a graduate research team at the University of South Florida. These articles contain various environmental and chemical factors that can adversely effect a fetus.
www.chem-tox.com/pregnancy/alcohol.htm

AlcoholismHelp.com. A resource for people affected by alcoholism.
www.alcoholismhelp.com

The Arc. The national organization of and for people with mental retardation and related developmental disabilities and their families. (800) 433-5255
www.thearc.org/fetalalcohol.html

ARCH — National Respite Network and Resource Center. Access to Respite Care and Help (ARCH) helps families find respite care options for disabled children and adults in all 50 states. Call (800) 773-5433 or go online.
www.respitelocator.org

Canadian Center on Substance Abuse. Fetal Alcohol Spectrum Disorder Information Service. Includes an overview of FASD, recommended readings, and resources for professionals working with individuals with FASD and their families.
www.ccsa.ca/index.asp?ID=17

Center for Disease Control and Prevention. Posters, information on incidence of alcohol related birth defects and information about funded activities related to prenatal alcohol use.
www.cdc.gov/ncbddd/fas/

Children's Research Triangle. Ordering information for Dr. Chasnoff's articles and educational tools, including information on identifying and intervening with children with FAS. The site also includes information to use when adopting a child overseas.
www.childstudy.org/

Facts About Alcohol Use During Pregnancy.
http://TheArc.org/faqs/fas.html

WEBSITES, continued

Family Village. A global community for people with varying disabilities.
www.familyvillage.wisc.edu

FAS Bookshelf, Inc. Order videos and books for families living with FAS.
www.fasbookshelf.com/buyit.html

FAS Community Resource Center.
http://come-over.to/FASCRC

FAS Facial Photographic Analysis Software.
www.depts.washington.edu/fasdpn/software.html

FAS/E Support Network of British Columbia.
www.fetalalcohol.com

FASCETS — Fetal Alcohol Syndrome Consultation, Education, and Training Services, Inc.
www.fascets.org

FASD — The Partnership to Prevent Fetal Alcohol Spectrum Disorder. Unites communities nationwide in a public health response to prevent Fetal Alcohol Syndrome and alcohol-related birth defects. The Partnership aims to empower mothers to deliver healthy babies by encouraging women who are planning a pregnancy or already pregnant to avoid alcohol.
www.prevention.samhsa.gov/faspartners

FASlink. Fetal Alcohol Syndrome Information, Support & Communication Link. Includes information for families and health care professionals.
www.acbr.com/fas/

fasWorld. An international alliance of parents and professional working together to prevent FAS.
www.fasworld.com

Fetal Alcohol Syndrome/Effects. Created by Kathryn Shea, C.S.W. Rich source of information and inspiration for families of children with FAS.
www.taconic.net/seminars/fas01.html

Florida Alcohol and Drug Abuse Association Resource Center. Disseminates information about alcohol and other drugs to Floridians.
www.fadaa.org

Healthy Families Florida. Promoting Positive Parent Child Relationships.
www.healthyfamiliesfla.org/

HRSA (U.S. Dept. of Health & Human Services) **Information Center.** Downloadable Manual — Screening for Substance Abuse During Pregnancy: Improving Care, Improving Health.
www.ask.hrsa.gov/detail.cfm?id=MCHN092

Journal of FAS International.
www.motherisk.org/JFAS

Motherisk. Research findings related to the effects of alcohol on pregnancy.
www.motherisk.org/alcohol/index.php3

National Institute on Alcohol Abuse and Alcoholism. Includes several Fetal Alcohol Syndrome guides for health care providers.
www.niaaa.nih.gov/publications/publications.htm

National Institutes of Health, National Institute on Alcohol Abuse and Alcoholism.
www.niaaa.nih.gov/

National Organization on Fetal Alcohol Syndrome. Information about preventing, identifying and living with Fetal Alcohol Syndrome.
http://www.nofas.org/

NIDA — National Institute on Drug Abuse.
www.nida.nih.gov/NIDAHome.html

NOFAS — The National Organization on Fetal Alcohol Syndrome.
www.nofas.org/

Northeast Consultation and Training Center. Provides training and consultation on FAS issues.
www.taconic.net/seminars

Online Clinic. This is Dr. Larry Burd's site. Includes a presentation on Fetal Alcohol Syndrome and three tools to help you estimate the scope of the problem due to Fetal Alcohol Syndrome and related developmental disorders resulting from prenatal alcohol exposure in your community.
www.online-clinic.com/#

WEBSITES, continued

Post Adoptive Resources Project. Support for families who have adopted children with emotional/behavioral disabilities. Many of the disabilities are alcohol/drug related.
www.geocities.com/heartland/prairie/4786

Region 3 FAS Partnership. Creative FAS website for parents.
www.fas-region3.com/Daily.html

SAMHSA Fetal Alcohol Spectrum Disorders Center for Excellence. Provides information and resources about FASD.
www.fascenter.samhsa.gov

SAMHSA National Clearinghouse for Alcohol & Drug Abuse Information. Provides information packets, brochures, literature searches. Includes a treatment locator.
www.samhsa.gov/public/public.html

Screening for Mental Health, Inc. Includes information on screening for alcohol abuse.
www.mentalhealthscreening.org/

Screening for Substance Abuse During Pregnancy: Improving Care, Improving Health. Online copy of publication includes copies of recommended screening forms.
www.ncemch.org/pubs/PDFs/SubAbuse.pdf

Texas Fetal Alcohol Syndrome Consortium. Includes information about Texas's FAS prevention and education initiatives as well as links to other FAS sites.
www.main.org/texasfasc

U.S. Department of Health and Human Services, and SAMHSA's National Clearinghouse for Alcohol and Drug Information.
www.health.org

Writeslaw. Article entitled "Play Hearts, Not Poker," about working with and having an IEP written for special needs children.
www.wrightslaw.com/advoc/articles/iep.bollero.hearts.htm

In Spanish:

Publicaciones en Español. Texto completo accesible en linea. Provides online ordering of Spanish materials on Fetal Alcohol Syndrome.
www.niaaa.nih.gov/publications/brochures.htm#espanol

SIGNS

Department of Business and Professional Regulation (850) 488-3638 Provides alcohol warning signs for alcohol beverage licenses for posting on alcohol beverage coolers or at point of sale stating the risk of alcohol use if driving or pregnant.

References

Abel, E. (1988). Fetal alcohol syndrome in families. Neurotoxicology and TLanceeratology, 10, 12.

Astely, S., Bailey, D., Talbot, C., & Clarren, S. (2000). Fetal alcohol syndrome (FAS) primary prevention through FAS diagnosis II: A comprehensive profile of 80 birth mothers of children with FAS. Alcohol & Alcoholism, 35(5), 509-519.

Bowerman, R. (1997). The effect of community supported alcohol ban on prenatal alcohol and other substance abuse. American Journal of Public Health, 87(8), 1378-1379.

Blume, S. (1996). Preventing fetal alcohol syndrome: Where are we now? Addiction, 91(4), 473-475.

Centers for Disease Control. (2002). Fetal alcohol syndrome: Alaska, Arizona, Colorado, and New York, 1995–1997. MMWR, 51(20), 433-435.

Chang, G., Goetz, M., Wilkins-Haug, L., & Berman, S. (2000). A brief intervention for prenatal alcohol use: An in-depth look. Journal of Substance Abuse Treatment, 18, 365-369.

Clarren, S. (2002). Keynote address to the Yukon 2002, Prairie Northern Conference on fetal alcohol syndrome. Retrieved March 7, 2003, from www.come-over.to/FAS/Whitehorse/WhitehorseArticlesSC1.htm

Clarren, S. (1986). Neuropathology in fetal alcohol syndrome. In J.R. West (Ed.), Alcohol and Brain Development (pp.158-166). New York: Oxford University Press.

Clarren, S., & Astely, S. (1998). Identification of children with fetal alcohol syndrome and an opportunity for referral of their mothers for primary prevention: Washington, 1993-97. Morbidity and Mortality Weekly Report, 47, 861-864.

Coggins, T., Friet, T., & Morgan, T. (1997). Analyzing narrative productions in older school-age children and adolescents with fetal alcohol syndrome: An experimental tool for clinical applications. Clinical Linguistics and Phonetics, 12, 221-236.

Davis, A., & Lipson, A. (1984). Challenge in managing a family with fetal alcohol syndrome. Clinical Pediatrics, 23, 304.

Diekman, S., Floyd, R., Decoufle, P., Schulkin, J., Ebrahim, S., & Sokol, R. (2000). A survey of obstetrician-gynecologists on their patients' alcohol use during pregnancy. Obstetrics & Gynecology, 95(5), 756-763.

Dubovsky, D. (2002). Behavioral Health Care Education. MCP Hahnemann University. Philadelphia, PA.

Florida Department of Corrections. (2002). Florida Department of Corrections 2001-2002 Annual Report. Tallahassee, FL: Author.

Florida Department of Juvenile Justice. (2003). Program accountability measures report: A two-year analysis (Management Report #03-01). Tallahassee, FL: Author.

Handmaker, N., Miller, W., & Manicke, M. (1999). Findings of a pilot study of motivational interviewing with pregnant drinkers. Journal of the Study of Alcohol, 60(2), 285-87.

Hanwood, H, & Napolitano, D. (1985). Economic implications of the fetal alcohol syndrome. Alcohol Health and Research World, 10, 38-43.

Hankin, J. (2002). Fetal alcohol syndrome prevention research. Alcohol Research and Health, 26(1), 58-65.

Harwood, M., & Kleinfeld, J. (2002). Up front, in hope: The value of early intervention for children with fetal alcohol syndrome. Young Children, 86-90.

Hopkins, R. (2001). Alcohol use in Florida in adults and in relation to pregnancy, 1999. Tallahassee, FL: Florida Department of Health.

Jones, K., & Smith, D. (1973). Recognition of the fetal alcohol syndrome in early infancy. Lancet, 2(7836), 999-1001.

Jones, K., Smith, D., Ulleland, C., & Streissguth, A. (1973). Pattern of malformations in offspring of chronic alcoholic mothers. Lancet, 1, 1267-71.

Kellerman, C. (2000). The five million dollar baby: The economics of FAS. Retrieved February 15, 2001, from http://www.acbr.com/fas/index.htm

Kleinfeld, J.M., & Wescott, S. (Eds.). (1993). Fantastic Antone succeeds: Experience in educating children with FAS. Washington, DC: NOFAS.

Lemoine, P., Harousseau, H., Borteyru, J., & Menuet, J. (1968). Les enfants de parents alcooliques: Anomlies observees a proposos de 127 cas [Children of alcoholic parents: Abnormalities observed in 127 cases]. Quest Med, 21(6), 476-482.

Lemmons, P., Vaeth, P., & Greenfield, T. (1999). Coverage of beverage alcohol issues in the print media of the United States, 1985-1991. American Journal of Public Health, 89, 1555-60.

Loop, K., & Nettleman, M. (2002). Obstetrical textbooks: Recommendations about drinking and pregnancy. American Journal of Preventive Medicine, 23(2), 136-38.

Malbin, D. (1993). Fetal alcohol syndrome, fetal alcohol effects: Strategies for professionals. Center City, MN: Hazelden Educational Materials.

May, P., Hymbaugh, K., Aase, J., & Samet, J. (1983). Epidemiology of fetal alcohol syndrome among American Indians of the Southwest. Social Biology, 30, 374-87.

Mattson, S., Jernigan, T., & Riley, E. (1994). MRI and prenatal alcohol exposure. Alcohol Health & Research World, 18(1), 49-52.

Mattson, S., & Riley, E. (1995). Prenatal exposure to alcohol: What images reveal. Alcohol Health & Research World, 19(4), 273-277.

Mattson, S., Riley, E., Gramling, L., Delis, D., & Jones, K. (1997). Heavy prenatal alcohol exposure with or without physical features of fetal alcohol syndromeleads to IQdeficits. Journal of Pediatrics, 131 (5), 718-721.

Mattson, S., Riley, E., Gramling, L., Delis, D., & Jones, K. (1998). Neuropsychological comparison of alcohol-exposed children with or without physical features of fetal alcohol syndrome. Neuropsychology, 12(1), 146-153.

Nevin, A., Parshuram, C., Nulman, I., Koren, G., & Einarson, A. (2003). A survey of physician's knowledge regarding awareness of maternal alcohol use and the diagnosis of FAS. Family Practice, 3(1), 2.

Olson, H., Morse, B., & Huffine, C. (1998). Development and psychopathology: Fetal alcohol syndrome and related conditions. Seminars in Clinical Neuropsychiatry, 3(4), 262-84.

Riley, E., Mattson, S., Sowell, E., Jernigan, T., Sobel, D., & Jones, K. (1995). Abnormalities of the corpus callosum in children prenatally exposed to alcohol. Alcoholism: Clinical and Experimental Research, 19(5), 1198-1202.

Shea, K. (1999). Fetal Alcohol Syndrome/Effects. Retrieved April 22, 2004, from www.taconic.net/seminars/fas01.html

Substance Abuse and Mental Health Services Administration. (2001). Summary of findings from the 2000 National Household Survey on Drug Abuse (NHSDA Series: H-13, DHHS Publication No. SMA 01-3549). Rockville, MD: Author.

Stratton, K., Howe, C. & Battaglia, F. (Eds.). (1996). Fetal alcohol syndrome diagnosis, prevention and treatment. Washington, DC: National Academy Press.

Streissguth, A., & O'Malley, K. (2000). Neuropsychiatric implications and long-term consequences of fetal alcohol spectrum disorders. Seminars in Clinical Neuropsychiatry, 5(3), 177-90.

Streissguth, A. (1997). Fetal alcohol syndrome: A guide for families and communities. Baltimore, MD: Paul H. Brookes.

Streissguth, A., Aase, J., Clarren, S., Randels, S., LaDue, R, Smith, D. (1991). Fetal alcohol syndrome in adolescents and adults. JAMA, 265, 1961-1967.

Streissguth, A., Barr, H., Kogan, J., & Brookstein, F. (1996). Understanding the occurrence of secondary disabilities in clients with fetal alcohol syndrome (FAS) and fetal alcohol effects (FAE). Seattle, WA: Washington Publications Services.

Streissguth, A., & Little, R. (1994). Alcohol, pregnancy, and the fetal alcohol syndrome: Unit 5. Biomedical education: Alcohol use and its medical consequences (slide lecture series, 2nd ed.) Hanover, NH: Dartmouth Medical School Project Cork.

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), August, 1996, Seattle: University of Washington, Fetal Alcohol & Drug Unit, Tech. Rep. No. 96-06,

U.S. Department of Health and Human Services. (2000). The tenth special report to the U.S. congress on alcohol and health. Rockville, MD: Author.

Weiner, L., & Morse, B. (1994). Intervention and the child with FAS. Alcohol Health and Research World, 18(1), 67-72.

Wilkemeyer, M., Menkari, C., Spong, C., & Charness, M. (2002). Peptide antagonists of ethanol inhibition of L1 – mediated cell-cell adhesion. The Journal of Pharmacology and Experimental Therapeutics, 303(1), 110-116.