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MATERNAL CHILD HEALTH

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Fetal Alcohol Syndrome

Last Christmas I talked with a pregnant woman drinking a cup of spiked eggnog

"I've heard of fetal alcohol syndrome," she said. "You have to be an alcoholic and pregnant for your baby to be born with it. Besides, my Ob Gyn told me it is safe to drink alcohol during my pregnancy to relax, as long as I only drink occasionally."

Her comment startled me. I realized how little many women know about the dangers of drinking alcohol when pregnant. Indeed, one study found that although nearly two thirds of women had heard of fetal alcohol syndrome, 70 percent of them thought it meant an infant was born addicted to alcohol.

Fetal alcohol syndrome (FAS) is the most clinically recognizable form of a larger group of problems caused by prenatal alcohol consumption, termed fetal alcohol spectrum disorders (FASD), which also includes the more diagnostically elusive alcohol related neurodevelopmental disorder (ARND). Children with FAS have some tell-tale facial anomalies, growth deficiencies and various levels of brain damage, behavioral and learning problems result, and the consequences are generally lifelong. ARND describes a similar behavioral and cognitive syndrome without the characteristic facial abnormalities or growth deficiencies of FAS. With fewer physical clues, diagnosis of ARND is more complicated, only a doctor who is an expert in ARND can determine whether a child's behaviors or disabilities are alcohol related.

Each year, as many as 40,000 babies in the U.S. are born with FASD—as many as one out of every 100 births—costing the nation about four billion dollars. Neurological and learning challenges range from severe to mild, and symptoms often resemble those for attention deficit hyperactivity disorder (ADHD). Children with FASD also have lower IQ—although only 25 percent of children who have FAS have mental retardation (IQ of 69 or under). A recent Michigan study focused on the IQ of 300 children who were followed from before birth to more than seven and a half years of age. For every two additional drinks per day consumed by a mother while pregnant, the child's IQ dropped an average of three points. Children of mothers over the age of 30 who drank were most at risk of having a child with a lower IQ.

How Much Alcohol Is Safe to Drink When Pregnant?

While the medical literature has been clear for some time that there is no safe amount or period for alcohol consumption during pregnancy, some doctors have continued to suggest that limited use during later stages may not be harmful. Nevertheless, studies suggest even a single episode of consuming as little as two drinks may lead to loss of fetal brain cells (one drink = 12 ounces of beer, 5 ounces of wine or 1.5 ounces of hard liquor).

Recently, Surgeon General Richard Carmona urged national attention to the importance of complete abstinence during pregnancy. Said Dr. Carmona, "We must prevent all injury and illness that is preventable in society, and alcohol-related birth defects are completely preventable. We do not know what, if any, amount of alcohol is safe. When a pregnant woman drinks alcohol, so does her baby. Therefore, it's in the best interest for a pregnant woman to simply not drink alcohol." The Surgeon General also noted that despite public health advisories, significant numbers of women continue to drink during pregnancy. In a survey by the National Task Force on Fetal Alcohol Syndrome and Fetal Alcohol Effect, 10 percent of women aged 18 to 44 reported drinking during pregnancy, and two percent reported drinking in a binge fashion, with more than five drinks per episode.

The FASD syndromes are not hereditary, neuron damage and cell loss in the fetal brain occurs through the direct effects of alcohol as a toxin. Nevertheless, there seems to be a genetic predisposition to problem drinking, and how rapidly and completely a woman's body breaks down alcohol depends to some extent on genetics. Whether from genetic or other factors, the risks for FASD are increased in women older than 30 years and women with low socioeconomic status. How Can Parents and Teachers Help?

FASD cannot be cured, but early intervention helps improve children's learning and medical outcomes. Ideally children diagnosed or suspected of having FAS or ARND are referred to a multidisciplinary team including specialists such as a clinical geneticist, a developmental pediatrician, mental health professionals, social workers and educational specialists.

Treatment involves coordination of multiple community services. Social services can ensure a safe home environment and help parents learn what problems to expect and how to constructively respond to them, and special educational techniques may help children overcome learning problems.

Parents and teachers often struggle to understand the challenging or maladaptive behavior of children with FASD, and they need help learning effective management techniques for learning and behavior problems. The FAS Diagnostic and Prevention Network is currently evaluating an intervention model based on two complementary elements: 1) individualized, supportive behavioral consultation for parents and school staff of children with FAS/ARND and 2) a school-based social communication intervention provided directly to children with FAS/ARND that targets critical deficits in social communication and peer relations.

"Each child is as different as a tiny snowflake," says Bonnie Buxton, author of the book

Damaged Angels and adoptive mother of a child diagnosed with ARND. However, some core problems result from damage to the frontal lobe and deeper structures of the brain, and these problems continue into adulthood. Areas most affected include organizational skills, social interaction, memory, perception and coordination.

Kate's Story

Many children with FASD also experience sensory, developmental and medical problems. As an infant and toddler, Kate, who was later diagnosed with ARND, could not tolerate loud noises, bright lights or crowds. Her mother had to avoid these triggers so her daughter would not go into sensory overload. Kate could not even go to a grocery store without screaming. She also had developmental problems, such as delayed speech and difficulty learning how to roll over, crawl and walk. Learning the alphabet was a major hurdle, and she was never able to learn multiplication or cursive writing. But in terms of health, Kate was fortunate. Although she has a heart murmur and slight scoliosis, Kate had few medical problems beyond frequent earaches. (Ear infections are common in people who have FASD because the Eustachian tubes are poorly formed and the fluid does not drain out, leaving a perfect environment for infection.)

As Kate grew older, more difficulties arose. She had mood swings and rages and had trouble making and keeping friends. By the time she was nine years old, her impulses were so out of control that her doctor concluded she must have ADHD and prescribed Ritalin. The medication helped Kate with her impulse control and hyperactivity, but the other problems persisted. School became increasingly frustrating because she was unable to think abstractly. She also kept losing and forgetting things. Other children were progressing in school, and Kate knew that she could not keep up with them. Unfortunately, the origin of her problems was not known until she was 17 years old. Interventions are thought to be most successful when started before the age of six.

Now [illegible], Kate is the mother of two children who have FAS. Despite the knowledge that alcohol was the cause of many of her own problems, she lacked the judgment and ability to abstain from alcohol during her pregnancies. After numerous parenting difficulties, Kate moved with her two daughters into her mother's home.

Kate has held [illegible] jobs, but she has never lasted more than three months in a work situation. Her mother could not afford to support all of them, so she fought to get Social Security for Kate and the children. The process was complicated. Kate was applying for disability for mental health reasons, but FAS is [illegible]. Because neither FAS nor ARND is listed separately in the DSM-IV, the Diagnostic and Statistical Manual, Fourth Edition, [illegible] Kate's mother had to use her daughter's ADHD diagnosis [illegible] "If you don't have a code in the DSM, you don't exist," she explained.

Fetal alcohol syndrome

Laura Maria Deming

Definition

Fetal alcohol syndrome (FAS) is a group of birth (congenital) defects occurring in an infant as a result of maternal alcohol abuse during pregnancy.

Description

Fetal alcohol syndrome was first recognized and identified in 1968. It is currently the leading cause of mental retardation in western civilization, outranking Down Syndrome. In the United States, more than 5,000 infants are diagnosed each year. It is 100% preventable but has no cure.

Congenital effects associated with FAS include:

- Neurologic abnormalities: mental retardation (average I.Q. of 63), small head (microcephaly), problems with movement (motor retardation), poor muscle tone, and hearing disturbances.
- Facial abnormalities: small eyes and/or short eye openings (palpebral fissures), underdevelopment of the upper lip, and flattening of the upper lip ridges (flat philtrum).
- Growth disturbances: small size and weight with growth lag before and after birth.
- Behavioral disturbances: infant irritability, childhood hyperactivity, and attention deficit.
- Cardiac defects: heart murmur, which may subside by one year of age, and heart defects, including ventricular or atrial septal defect.

Causes & symptoms

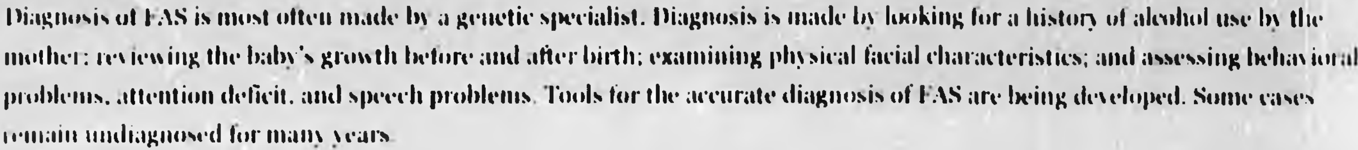
The cause of FAS is alcohol abuse during pregnancy. The exact amount of alcohol consumption causing FAS has not been identified; however, binge drinking is known to be very harmful. Drinking during the first trimester has been linked to congenital defects, while drinking in the last trimester is known to result in premature birth and low birth weight. FAS occurs among people of all social and economic backgrounds.

Infants born to women who drink heavily during pregnancy show the most signs of FAS. Infants born to heavy drinkers have a 50% risk of harmful effects, while infants of moderate drinkers are at a 10% risk. It is not uncommon for children to be diagnosed later in childhood when there is a noticeable lag in school performance, and possibly hyperactivity and attention deficit.

Children and adults of women with a history of alcohol abuse during pregnancy may display behavioral problems, thinking and reasoning (cognitive) deficits, and psychological and social disturbances without facial abnormalities or growth retardation. These individuals are frequently diagnosed with fetal alcohol effects (FAE).

Low birth weight and preterm delivery may be seen in infants of women who used alcohol in low to moderate amounts during pregnancy.

Diagnosis



Diagnosis of FAS is most often made by a genetic specialist. Diagnosis is made by looking for a history of alcohol use by the mother; reviewing the baby's growth before and after birth; examining physical facial characteristics; and assessing behavioral problems, attention deficit, and speech problems. Tools for the accurate diagnosis of FAS are being developed. Some cases remain undiagnosed for many years.

Treatment

Ideally, women planning to become pregnant should stop drinking several months before the pregnancy. Women who are pregnant should stop drinking as soon as possible in their pregnancy. The highest risk to the developing fetus is in the first trimester; however, heavy drinking at later stages of pregnancy can also cause serious harm. Discontinuing alcohol consumption even as late as the last trimester of pregnancy show improved outcomes for the infant. During the last trimester, the fetus normally has the greatest brain growth.

Fetal alcohol syndrome is completely preventable. The treatment of FAS is in response to symptoms. For example, cardiac defects can be treated surgically. Early diagnosis is essential for optimal treatment of behavioral related problems. Motor and speech issues may be addressed by developmental specialists including physical, speech, and occupational therapists. Problems with hearing and vision are followed up by medical specialists.

Prognosis

Prognosis depends on the degree of mental and neurological development, as well as the timing of diagnosis, and family and social support. Many children with FAS are placed in adoptive or foster homes by age five. Family support and interaction is crucial for promoting more positive outcomes. FAS is a life-long illness with no cure.

Follow up studies in a group of adolescents with an age of 18 showed that the average academic functioning was at a fourth-grade level. Deficits in arithmetic were common. Additionally, adolescents in the group studied displayed poor judgment and were easily distracted.

Prevention

FAS is completely preventable with the avoidance of alcohol during pregnancy. No one knows exactly how much alcohol is harmful. Ideally, women planning to conceive should stop drinking prior to becoming pregnant. Most specialists and researchers agree that the best prevention is complete abstinence of alcohol use during pregnancy.

Family and community education is necessary to prevent FAS. Obstetricians should get a complete history of maternal alcohol use and promote prenatal education. Although most obstetric providers ask about the use of alcohol in pregnancy, few probe in depth.

FAS is a public health issue. Currently, warnings are placed on the labels of alcoholic beverages, but research shows that alcoholics and heavy drinkers frequently ignore these warnings. Many states have made public education of alcohol use in pregnancy a priority.

Key Terms

Congenital

Present at birth.

Further Reading

For Your Information

Books

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Periodicals

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- Hanlin, J.R., et al. "Heeding the Alcohol Beverage Warning Label During Pregnancy: Multiparae vs. Nulliparae." *Journal of the Study of Alcohol* (March 1996): 171-177.
- Johnson, V.P., et al. "Fetal Alcohol Syndrome: Craniofacial and Central Nervous System Manifestations." *American Journal of Medical Genetics* (February 1996): 329-339.

Organizations

- March of Dimes. 1275 Mamaroneck Avenue, White Plains, NY 10605. (914) 428-7100.

Gale Encyclopedia of Medicine. Gale Research, 1999.

Fetal Alcohol Spectrum Disorders

Protective Factors for Children with FAS

Several positive factors have been identified that might help reduce secondary conditions that result from fetal alcohol syndrome (FAS). Some of these protective factors are:

Early Diagnosis - Children with FAS who are identified early have an improved prognosis. A child who is identified early in life can be placed in appropriate educational classes and given access to social services that can help the child and his or her family. In addition, early diagnosis helps families and school personnel understand why the child might act or react differently from other children in some situations.

Involvement in Special Education and Social Services - Children who receive special education geared towards their specific needs and learning style are more likely to achieve their developmental and educational potential. Children with FAS show a wide range of behaviors and severity of symptoms. Special education allows for individualized educational programs. In addition, families of children with FAS who receive social services, such as respite care or stress and behavioral management training, have more positive outcomes than families who do not receive such services.

Loving, Nurturing, and Stable Caretaking Environment - While all children benefit from a loving and stable home life, children with FAS can be particularly sensitive to disruptions, transient lifestyles, or harmful relationships compared to children who do not have FAS. Community and family support are needed to prevent secondary conditions in individuals with FAS.

Absence of Violence - Individuals with FAS who live in stable or non-abusive households or who do not become involved in youth violence are much less likely to develop secondary conditions than children who have been exposed to violence in their lives. Children with FAS need to learn and be taught other ways of showing their anger or frustration.

Source:

Streissguth, A.P., Barr, H.M., Kogan, J. & Bookstein, F. L., "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, (1996).

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Date: May 2, 2006
Content source: National Center on Birth Defects and Developmental Disabilities

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- Fact Sheets
- Materials
- CDC Activities
- National Task Force

Quick Links

Read about the Science Ambassador Program and available lesson plans on FAS for middle and high school classrooms

FAS Guidelines for Referral and Diagnosis
Click here to view or download the Guidelines. [PDF document]
Find out how to order copies

Surgeon General's Advisory on Alcohol Use in Pregnancy [PDF document]

MMWR Recommendations and Reports - Guidelines for Identifying and Referring Persons with Fetal Alcohol Syndrome

Report on alcohol consumption among women who are pregnant or who might become pregnant

Curricula Available

Contact Info

Fetal Alcohol Syndrome
NCBDDD, CDC
Mail-Stop E-86
1600 Clifton Road
Atlanta, GA 30333
1-800-CDC-INFO (232-4636)

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Kate has held numerous jobs, but she has never lasted more than three months in a work situation. Her mother could not afford to support all of them, so she sought to get Social Security for Kate and the children. The process was complicated. Kate was applying for disability for mental health reasons, but FAS is a medical diagnosis, not a specific psychiatric one. Because neither FAS nor ARND is listed separately in the DSM-IV (the Diagnostic and Statistical Manual [illegible]), Kate's mother had to use her daughter's ADHD diagnosis to help her qualify for Social Security. "If you don't have a [illegible] in the DSM, you don't exist," she explained.

Fetal Alcohol Spectrum Disorders

Fetal alcohol spectrum disorders (FASDs) can cause serious disabilities that last a lifetime. They can affect how a person looks, grows, learns, and acts. But, FASDs are 100% preventable—if a woman does not drink alcohol while she is pregnant.

- FASD is a term that describes the range of effects that can occur in a person whose mother drank alcohol while pregnant. These effects can include physical and mental disabilities and problems with behavior or learning. Often, a person has a mix of these problems. The term FASD is not intended for use as a clinical diagnosis.

- People with an FASD often have problems with learning, memory, attention span, problem solving, speech, and hearing. They are at very high risk for trouble in school, trouble with the law, alcohol and drug abuse, and mental health disorders.

- FASDs include fetal alcohol syndrome (FAS), which causes growth problems, abnormal facial features, and central nervous system problems. Children who do not have all of the symptoms of FAS can have another FASD. These children can have problems that are just as severe as those of children with FAS.

- It is not known exactly how many people have an FASD. Studies by the Centers for Disease Control and Prevention (CDC) have shown that 0.2 to 1.5 cases of FAS occur for every 1,000 live births in the United States. Other studies using different methods have estimated the rate of FAS at 0.5 to 2.0 cases per 1,000 live births. Scientists believe that there are at least four times as many cases of FASDs as FAS.

There is no known amount of alcohol use that is safe during pregnancy. There is no known time during pregnancy when alcohol use is safe.

- All drinks with alcohol can hurt an unborn baby. A 12-ounce can of beer has as much alcohol as a 4-ounce glass of wine or a 1-ounce shot of liquor. Some drinks, like malt beverages, wine coolers, and mixed drinks, have more alcohol than a 12-ounce can of beer.

- A woman should not drink any alcohol if she is pregnant or planning to get pregnant. If a woman could become pregnant, she should talk to her doctor and take steps to lower the chance of exposing her baby to alcohol.

- FASDs last a lifetime—there is no cure. But if children with an FASD are identified early, they can receive services to help increase their well-being.

- FASDs are 100% preventable—if a woman does not drink alcohol while she is pregnant.

LEGISLATIVE RESEARCH REPORT

FEBRUARY 21, 2008

REPORT NUMBER 08.165

EARLY DIAGNOSIS OF FETAL ALCOHOL SPECTRUM DISORDER

PREPARED FOR SENATOR BETTYE DAVIS

BY TIM SPENGLER, LEGISLATIVE ANALYST

You asked for information about Fetal Alcohol Spectrum Disorder (FASD). Specifically, you wished to know whether early diagnosis of FASD was important. Briefly, all our sources believe that early diagnosis is a key factor in enhancing the quality of the life of any child so affected.

Prenatal exposure to alcohol can cause a range of disorders collectively known as fetal alcohol spectrum disorder (FASD).[1] The term FASD is not a clinical diagnoses but rather an umbrella term describing the range of effects that can occur to a child whose mother consumed alcohol during pregnancy. These effects can be physical, mental, or behavioral and have lifelong implications. The term "spectrum" is used because each individual with FASD may have some or all of the aforementioned effects with varying degrees of severity.

Fetal alcohol syndrome (FAS) is the most well know diagnosis—and the most severe—within FASD. To be diagnosed with FAS, a wide range of testing is required including physical, psychological, speech and language tests. Symptoms and the extent of damage caused vary depending on factors such as the amount and kind of alcohol the mother drank, when the alcohol was consumed in the gestational period, and the genetic makeup of both mother and fetus. Fetal Alcohol Syndrome is characterized by abnormal facial features, growth deficiencies, and central nervous system problems. Other conditions that fall under FASD include fetal alcohol- effects (FAE), alcohol related neurodevelopment disorder (ARND) and alcohol-related birth defects (AEBD). All of these conditions are permanent and have no cure. However, all FASDs are also 100% preventable—if a woman does not drink alcohol during pregnancy.

Experts agree that early diagnosis of FASD is important for a variety of reasons. While the conditions are incurable, a child who is identified early can receive services and accommodations that can help him or her lead a more productive and rewarding life. All of the literature we surveyed and the professionals with whom we spoke stress that the earlier intervention occurs, the better the outcome. Diagnosis at birth is ideal but only occurs in cases where the mother acknowledges drinking during pregnancy or the child has extreme FAS facial features. According

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[1] Much of the information we gathered for this report came from the Center for Disease Control *www.cdc.gov/ncbddd/fas* and the Substance Abuse and Mental Health Services Administration *www.samhsa.gov*, as well as conversations with experts in the field and other literature.

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to our sources, children are often not initially diagnosed until they start school. Many children, however, especially those without distorted facial features, are never diagnosed with having FASD.

Dan Dubovsky, FASD Specialist for the federal Substance Abuse and Mental Health Services Administration (SAMHSA), emphasizes that FASDs, which often appear as oppositional or anti-social behavioral choices, are actually the result of brain damage.[2] As a result, children are negatively pigeon-holed as disruptive or lacking in intelligence. He stresses that being **misdiagnosed** is extremely counterproductive to the child, his or her family, and to their community. For parents, knowing their child (in many cases their adoptive or foster child) is affected by FASD can be of immeasurable importance. Although the challenges of raising a child with special needs remain, knowing that the behavior issues are due to a disorder—and not willful disobedience—is of obvious importance. When a child is accurately identified as having FASD, educational plans and services can be set in place appropriate for his or her needs.

Mr. Dubovsky was emphatic that early diagnosis is crucial—especially as a way to minimize the occurrence of **secondary disabilities**. Secondary disabilities include mental health problems, disrupted school experiences, trouble with the law, confinement, inappropriate sexual acting out, and substance abuse problems. He pointed us to a "groundbreaking" Center for Disease Control/ University of Washington study headed by Dr. Ann Streissguth that examines how individuals with FASD whose needs go unmet frequently develop one or more of these secondary conditions. One of the findings highlighted in the study is the importance of being diagnosed before the age of six. We include Dr. Steissguth's report as well as two brief overviews regarding the findings of her study as Attachment A. [3]

A SAMHSA publication, *Fetal Alcohol Spectrum Disorders, The Basics*, includes the following as some of the benefits of identification and treatment of FASD[4]

- Helps decrease anger and frustration for individuals, families, providers, and communities by helping them understand that negative behavior results from the disability and is not willful;
- Helps people with an FASD succeed by focusing on why they have trouble in certain programs; and
- Helps improve outcomes and helps prevent future births of children with alcohol related disorders.[5]

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[2] Dan Dubovsky can be reached at (866) 786-7327.

[3] The document *Understanding the Occurrence of Secondary Disabilities in Clients with Fetal Alcohol Syndrome and Fetal Alcohol Effects* is in less than stellar condition. We contacted the University of Washington and, while they do not have the report in an electronic format, they will send a hard copy which we will scan and make available. The Center for Disease Control's *Protective Factors for Children* with FAS is available at *www.cdc.gov/ncbddd/fas/protective.htm*. *Secondary Disabilities* from Alaska's FAS office is located at *www.state.ak.us/fas/info/secondaryDisablities.htm*.

[4] We include *Fetal Alcohol Spectrum Disorders, The Basics* as Attachment B.

[5] Dan Dubovsky stresses that a mother who remains unaware of her child's condition may drink during subsequent pregnancies possibly resulting in the birth of additional children afflicted with alcohol related disorders. However, if a diagnosis is made early, and the family educated about FASD, the mother may adjust her behavior and abstain from consuming alcohol during these pregnancies. Therefore early diagnosis can potentially lessen future FASD occurrences.

Dr. Eugene Hoyme, who spent years studying the effects of fetal alcohol syndrome at Stanford University, helped develop a diagnostic spectrum used with alcohol-exposed children. It looks at the whole child, from physical features to cognitive thinking and motor skills. Dr. Hoyme is currently studying ways to diagnose children at birth. He emphasizes that the earlier a child is identified with FASD, and the sooner he or she can receive help, the better the chance for a successful outcome.[6] Often FASD diagnoses are conducted as a team approach with physicians, speech and physical therapists, psychologists, and audiologists participating. Obviously, in some geographic areas, such teams are not available. In these cases, physicians, and other health professionals with proper training, are able to make a diagnosis on their own.

We spoke with Juneau pediatricians Joy Neyhart and Amy Dressel as well as Alaska's FAS program manager Diane Casto and Ric Iannolino, FASD Diagnostic Team Coordinator with Central Council Tlingit Haida Indian Tribes.[7] All these experts concur that early diagnosis of FASD is of paramount importance for children, families and providers. Additionally, Diane Casto points out that many children with FASD are not being raised by their birth mothers but reside with relatives, or in adoptive or foster homes. She asserts that it is vital that these caregivers have all information possible to best assist, and advocate for, the children relying on them. Dr. Neyhart notes that FASD children often have multiple placements within the foster care system as they can be very difficult to manage. This phenomenon is exacerbated when their condition is undiagnosed.

As mentioned, there is a continuum of multiple issues that children with FASD—and their families and providers—face. Interventions for children with FAS/FASD are sometimes non-specific, unsystematic and often lack scientific evaluation. In an effort to remedy this situation, The Center for Disease Control currently has a number of grantees working through a collaborative effort to identify, develop, and evaluate effective strategies for working with children with FASD and their families.[8] While there is no "one size fits all" strategy for helping these unfortunate children, all our sources agree that the earlier a child is accurately diagnosed, the better chance he or she has to lead the fullest life possible. As the State of Alaska's FAS website notes,

> With the right diagnosis, support and understanding, many individuals with FASD are living happy and full lives.

I hope you find this information to be useful. Please do not hesitate to contact us if you have questions or need additional information.

---

[6] *Diagnosing FASD is Tricky*, Minnesota Public Radio, *minnesota.publicradio.org/display/web/2007/09/05/fasd2*.

[7] Dr. Neyhart can be reached at (907) 463-1210, Dr Dressel at (907) 586-1542, Diane Casto at (907) 465-1188, and Ric Iannolino at (907) 463-7373.

[8] For information on the CDC's development of strategies program see *www.cdc.gov/ncbdd/fas/intervening*.

Don Burrell

From:	Marilyn Dodd [akafp@gci.net]
Sent:	Friday, February 29, 2008 2:44 PM
To:	Sen. Bettye Davis
Subject:	sb267
Attachments:	ATT00001.htm; sb267.doc

RECEIVED
MAR 0 3 2008

ATT00001.htm (4 KB)

sb267.doc (31 KB)

Maryann Foland, MD
President Elect, Alaska Academy of Family Physicians

Dear Senator Davis:

The Board of Directors of the Alaska Academy of Family Physicians represents over 365 primary care physicians who practice throughout Alaska. We oppose Senate Bill No. 267. This bill requires documentation in an infant's medical record any prenatal exposure to alcohol, but only with the mothers consent.

We believe this bill is unnecessary and has unintended legal consequences. Practitioners already have a statutory and ethical duty to report suspected alcohol or drug abuse affecting a child. The Medical Practice Act requires all pertinent information to be entered into a medical record. Furthermore, to restrict use of any information only for the purpose of providing medical diagnosis or treatment limits its use in any potential legal case. Since this would affect how evidence may be used, it may require a more wide-reaching change in court rules.

The benefits of early diagnosis and treatment for Fetal Alcohol Syndrome Disorder are undeniable. However, we do not believe this bill adds any encouragement to better document a medical history. It would not help with either early diagnosis or treatment. Therefore, we strongly urge that SB267 be defeated.

Sincerely,

Maryann Foland, M.D.
President Elect, AKAFP

Alaska Academy of Family Physicians

35555 Spur Highway #266, Soldotna, AK 99669 akafp@gci.net www.alaskaafp.org 907 258-2255 office 530 326-5612 fax

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President Elect, Alaska Academy of Family Physicians

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Sincerely,

Maryann Foland, M.D.
President Elect, AKAFP

Alaska State Medical Association

4107 Laurel Street • Anchorage, Alaska 99508 • (907) 562-0304 • (907) 561-2063 (fax)

March 3, 2008

Honorable Bettye Davis
State Senate
Chair, Senate Health, Education, and Social Services Committee
State Capitol, Room 30
Juneau, AK 99801-1182

Transmitted by email: Senator_Bettye_Davis@legis.ak.state.us

RE: SB 267 - Documentation of an Infant's Pre-natal Exposure to Alcohol

Dear Senator Davis:

The Alaska State Medical Association (ASMA) represents physicians statewide and is primarily concerned with the health of all Alaskans.

Notwithstanding your laudable intent to "assist with early FASD diagnosis's when applicable", ASMA feels that this bill, if passed as is, provides for unintended consequences that puts physicians in situations where they may violate other laws, put themselves at unwarranted risk in civil litigation, and impair their ability to be paid by health insurance companies. ASMA can not support SB267.

This statement is based on the comments and advice provided to ASMA by its legal counsel, Mr. Roger Holmes. Those comments are attached to the written testimony.

I am an internal medicine specialist who specializes in the treatment of diabetes and lipids. I do not specialize in the treatment of FASD. However, it is good medicine to include everything in the patient's medical chart that is relevant to the delivery of good medical care to the patient.

From a medical standpoint, it makes no sense to dictate what a physician might include in her or his medical record for an infant based on the consent of a mother who may indeed be impaired by alcohol abuse and/or addiction.

ASMA suggests that Alaska would be better served through legislation that furthers research and education to prevent, identify, and treat FASD.

ASMA urges you not to support SB267.

Sincerely,

By: J. Ross Tanner, DO, President
For: Alaska State Medical Association

cc: Senate Health, Education, and Social Services Committee members

BISS AND HOLMES
ATTORNEYS AT LAW
3948 CLAY PRODUCTS DRIVE
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TELEPHONE (907) 248-8013
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BURTON C. BISS, RETIRED
ROGER F. HOLMES

E-Mail rogerbh@gci.net

February 29, 2008

James J. Jordan
Executive Director
Alaska State Medical Association
4107 Laurel Street
Anchorage, Alaska 99508

Re: SB 267

Dear Mr. Jordan:

You have asked me to comment on the proposed language in AS 08.64.364 which states:

> (a) For the purpose of screening for fetal alcohol spectrum disorder, a person licensed under this chapter attending or making a postnatal examination of a mother and infant shall document the infant's prenatal exposure to alcohol in the infant's medical file, *if the mother provides her consent to the inclusion of the information in the infant's medical file.*
>
> (b) Information received under this section may not be used except for the purposes of providing medical diagnosis, treatment, or care.

The Sponsor's Statement indicates that the purpose of this statute is to mandate the inclusion of this information in an infant's chart to encourage early detection of FASD. However, the way the bill is written, it appears physicians *may not* include this information in the patient's chart unless the mother gives her consent. Were this to be the result of this bill, it would turn medicine upside down. The infant is the patient. The doctor has a moral, legal and ethical obligation to include anything and everything in the patient's medical chart which the physician feels is relevant regardless of receiving the permission of the patient or the patient's mother.

It is below the standard of care for a physician to fail to record in the chart all of the information pertinent to diagnosis and treatment. The failure to record something the physician feels is relevant subjects the physician to a claim of malpractice.[1] It also subjects the physician to discipline

---

[1] Sweet v. Sisters of Providence in Washington, 881 P.2d 304, 311 (Alaska, 1994) "In Patrick v. Sedwick, 391 P.2d 453, 457 (Alaska 1964), for example, the Alaska Supreme Court noted that "it was incumbent upon the appellee surgeon to have described accurately and fully in his report of the operation everything of consequence that he did and which his trained eye observed during the

including a possible loss of license as it is unprofessional conduct for a physician fail "to prepare and maintain accurate, complete, and legible records in accordance with generally accepted standards of practice for each patient...."[2] No physician could ethically or legally fail to include this information in an infant's chart regardless of the feelings of the mother.

Subsection (b) limits the use of FASD information in the chart to diagnosis, treatment and care of the patient. This too has unintended, impermissible and, most likely, unconstitutional consequences. It appears the information could not be used by the patient in a law suit against a school district, health care provider or other third party. Nor could the health care provider use that information in defense of a suit. Actually, as written, the health care provider could not even submit the record to Blue Cross in connection with getting paid for the care provided. Nor, if this record were made in a hospital emergency room, could it used as part of a peer review process.

There is a companion bill in the House - HB300. The House sponsor's statement says:

> The bill specifies that information related to a mother's use of alcohol can only be used for diagnostic and medical purposes, not as evidence against the woman's fitness or in an attempt to remove her custodial rights.

Since this bill purports to limit the evidence which can be used in a Court proceeding, it may need a two-thirds majority.[3]

Please call me if you have any questions.

Very truly yours,

BISS & HOLMES

Roger F. Holmes

---

operation.... If these requirements had been met the report would ... more likely ... have supplied sufficient facts to have permitted expert witnesses to testify on the question of negligence.'"

[2] 12 AAC 40. 967(9).

[3] I have not looked at the issue of the constitutionality of depriving a spouse or a child's guardian ad litem of the use of relevant information in a child custody dispute.

March 3, 2008

Senate Bill 267

Talking Points

- If medical providers were reporting prenatal alcohol exposure routinely we would not need this bill

- It is not illegal for women to drink during pregnancy in Alaska and children exposed to alcohol during pregnancy cannot be diagnosed for several years from the time of their birth.

- Witn respect to mandatory reporting of suspected alcohol abuse affecting a child by medical professionals per Title 47 Child Protection. It is our contention that this practice is reactive and counter to the intent of this piece of legislation. Senate Bill 267 provides a non-punitive, pro-active means for mothers to self report their prenatal alcohol use.

- As a coordinator of one of Alaska's diagnostic clinic my experience is that some mother have died or have lost custody of their children, relative may not be aware of their alcohol use during the specific nine months of a mother's pregnancy the result is many children and their families can not obtain a diagnosis.

- Children are diagnosed at the earliest in our clinic at 2 years of age children must be identified much early in order to mitigate some of the behavior and cognitive deficits long past the post natal reporting period that this bill provides for.

LEGAL SERVICES

DIVISION OF LEGAL AND RESEARCH SERVICES
LEGISLATIVE AFFAIRS AGENCY
STATE OF ALASKA

(907) 465-3867 or 465-2450
FAX (907) 465-2029
Mail Stop 3101

State Capitol
Juneau, Alaska 99801-1182
Deliveries to: 129 6th St., Rm. 329

M E M O R A N D U M March 3, 2008

SUBJECT: Legal and practical issues relating to the requested CSSB 267(HES) (Work Order No. 25-LS1471\C)

TO: Senator Bettye Davis
Chair of the HESS Committee
Attn: Thomas Obermeyer

FROM: Alpheus Bullard
Legislative Counsel

You requested a committee substitute for SB 267 based on an amendment prepared by Jan Ruthdale of the Department of Law. I have several comments.

1. The requested committee substitute directed a person making a postnatal examination of a mother and infant to document "*observations, medical history, and other available information of the infant's prenatal exposure to alcohol in the infant's medical file.*" This is unclear. Whose "observations," whose "medical history," and what is "available information"? I redrafted this to read, "the person's observations," the mother's pertinent medical history" and other "information relevant" to the infant's prenatal exposure to alcohol.

2. The language you requested provides that *"[i]nformation described in this section that was obtained from statements of the mother made during the mother's examination that is confidential medical information of the mother may not be released without the consent of the mother, except upon court order, or as required by AS 47.17.024."* The committee substitute you requested makes changes to a provision that directs that certain information be recorded in an infant's medical file. This means that the mother's information is released to the infant's medical record. Any future provider of medical services to the infant will encounter the information provided by the mother in the infant's file. If the information obtained from the mother by a medical provider is not confidential, this is something of which she should be made aware. I'm not sure what the sense of "release" is supposed to be, but it does not seem to make sense in the context of what the bill requires.

Note too, that the concept of doctor-patient confidentiality would not apply just to "*confidential medical information of the mother*" but all noncriminal information shared by the mother in seeking the advice, care, and/or treatment of a physician for herself or her child. It is a generally accepted principle that individuals seeking medical help or

advice should not be inhibited by any fear that their medical concerns or conditions will be disclosed to others. Patients entrust personal knowledge of themselves to their physicians, which creates an uneven relationship in that the vulnerability is one-sided. There is usually an expectation that physicians will hold that special knowledge in confidence and use it exclusively for the benefit of the patient. See Alaska Rule of Evidence 504(b) which provides:

> **General Rule of Privilege.** A patient has a privilege to refuse to disclose and to prevent any other person from disclosing confidential communications made for the purpose of diagnosis or treatment of the patient's physical, mental or emotional conditions, including alcohol or drug addiction, between or among the patient, the patient's physician or psychotherapist, or persons who are participating in the diagnosis or treatment under the direction of the physician or psychotherapist, including members of the patient's family.

The committee substitute would have such information recorded in the infant's medical file, but not *"released without the consent of the mother, except for court order, or as required by AS 47.17.024."* I don't know how a court would interpret this language, but I believe that it is certainly possible that the changes affected by the committee substitute could be interpreted as an unconstitutional violation of a mother's right to privacy.

3. Senate Bill 267 requires a person licensed under AS 08.64 to document "*an infant's prenatal exposure to alcohol*" in the infant's medical file, and that the information "*may not be used except for the purposes of providing medical diagnosis, treatment, or care.*" AS 47.17.024 imposes a duty on practitioners of the healing arts to notify the Department of Health, Education and Social Services of an infant's condition that the practitioner has determined has been adversely affected by, or is withdrawing from exposure to, a controlled substance or alcohol. The duty imposed by AS 47.17.024 is a different duty than that created under the bill. SB 267 deals only with the documentation of information in an infant's medical file relating to a mother's consumption of alcohol, not a practitioner's determination that an infant has been adversely affected by alcohol. These are legally and practically distinct actions and responsibilities.

If you have any questions, please do not hesitate to contact me.

ALB:lmb
08-051.lmb

Enclosure

February 25, 2008

Representative Doll
Senator Davis
Capitol Building
Juneau Alaska 99801

Greetings,

I would like to thank you both for sponsoring bills to increase the access to support services for people experiencing brain damage caused by fetal alcohol spectrum. This bill will remove one of the major barriers to effective diagnosis, by increasing the knowledge of one of the key indicators. I believe this bill still maintains the relationships between medical provider and parents.

I worked closely for a number of years with a young person experiencing FASD. I witnessed the frustration of fellow staff members and community members, and the negative attitudes toward this individual.

Once it was determined that the person's behaviors were a result of FASD, there was a dramatic change in treatment of this individual. People working with her experienced much less frustration, and were much more effective in working with her. This resulted in a higher quality of life, work, and relationships for the individual.

This bill is a win-win for people with FASD, the people that care for them, and the State of Alaska in general. Thank you for sponsoring this legislation.

Joy Lyon
570 Seater
Juneau AK 99801

25-LS1471\C
Bullard
3/3/08

CS FOR SENATE BILL NO. 267(HES)

IN THE LEGISLATURE OF THE STATE OF ALASKA

TWENTY-FIFTH LEGISLATURE - SECOND SESSION

BY THE SENATE HEALTH, EDUCATION AND SOCIAL SERVICES COMMITTEE

Offered:
Referred:

Sponsor(s): SENATOR DAVIS

A BILL

FOR AN ACT ENTITLED

1 **"An Act relating to requiring certain persons licensed by the State Medical Board to**
2 **document an infant's prenatal exposure to alcohol in the infant's medical file."**

3 **BE IT ENACTED BY THE LEGISLATURE OF THE STATE OF ALASKA:**

4 * **Section 1.** AS 08.64 is amended by adding a new section to article 3 to read:
5 **Sec. 08.64.364. Health care professionals to document an infant's prenatal**
6 **exposure to alcohol.** (a) For the purpose of screening for fetal alcohol spectrum
7 disorder, a person licensed under this chapter attending or making a postnatal
8 examination of a mother and infant shall document the person's observations, the
9 mother's pertinent medical history, and other information relevant to the infant's
10 prenatal exposure to alcohol in the infant's medical file. Information described in this
11 section that was obtained from statements of the mother made during the postnatal
12 examination that is confidential medical information of the mother may not be
13 released without the consent of the mother, except by court order, or as required by
14 AS 47.17.024. The documentation must be in the form or format required by the

1 department.

2 (b) Except as provided in AS 47.17.024, information received under this
3 section may not be used except for the purposes of providing medical diagnosis,
4 treatment, or care of the infant.

5 (c) In this section, "infant" means a child who is less than 12 months of age.

Resources

- SAMHSA FASD Center for Excellence: fasdcenter.samhsa.gov
- Centers for Disease Control and Prevention FAS Prevention Team: www.cdc.gov/ncbddd/fas
- National Institute on Alcohol Abuse and Alcoholism (NIAAA): www.niaaa.nih.gov/
- National Organization on Fetal Alcohol Syndrome (NOFAS): www.nofas.org
- National Clearinghouse for Alcohol and Drug Information: ncadi.samhsa.gov
- These sites link to many other Web sites.

Paradigm Shift

"We must move from viewing the individual as failing if s/he does not do well in a program to viewing the program as not providing what the individual needs in order to succeed."

—Dubovsky, 2000

Strengths of Persons With an FASD

- Build on strengths of persons with an FASD, such as giving them opportunities to help in the classroom.

Photo courtesy of Microsoft

- Use teaching strategies that focus on strengths.
- Find jobs that use the person's strengths.

Strengths of Persons With an FASD

- Highly verbal

- Highly moral—deep sense of fairness
- Kind with younger children and animals

Photo courtesy of Microsoft.

- Able to participate in problem solving with appropriate support

Strengths of Persons With an FASD

- Cuddly and cheerful

- Happy in an accepting and supportive environment
- Loving, caring, kind, sensitive, loyal, and compassionate
- Energetic and hard working
- Fair and cooperative
- Spontaneous, curious, and involved

Permission to use photos on file.

Strengths of Persons With an FASD

- Friendly
- Likable
- Desire to be liked
- Helpful
- Determined
- Have points of insight
- Not malicious

Dubovsky, Drexel University College of Medicine (1999)

Strategies To Improve Outcomes for Individuals With an FASD

Self-Esteem and Personal Issues

- Use person-first language (e.g., "child with FAS," not "FAS kid").
- Do not isolate the person.
- Address issues of loss and grief.
- Do not blame people for what they cannot do.
- Set the person up to succeed.

Strategies To Improve Outcomes for Individuals With an FASD

Strategies for Executive Function Deficits

- Use short-term consequences specifically related to the behavior.
- Establish achievable goals.
- Provide skills training and use a lot of role playing.

Photo property of SAMHSA.

Strategies To Improve Outcomes for Individuals With an FASD

Strategies for Information Processing Problems

- Check for understanding.

Tell me what you just heard me say.

- Use literal language.
- Teach the use of calculators and computers.

- Look for misinterpretations of words or actions and discuss them when they occur.

Strategies To Improve Outcomes for Individuals With an FASD

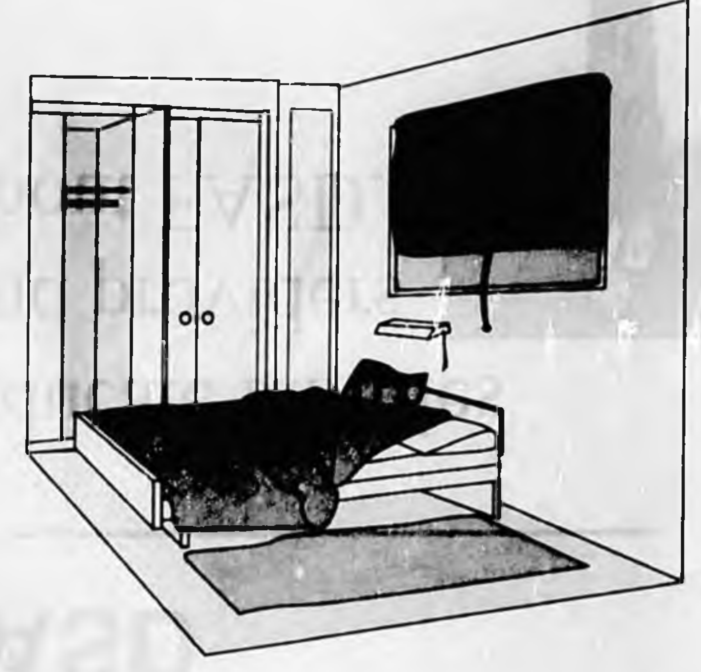
Strategies for Memory Problems

- Provide one direction or rule at a time and review rules regularly.
- Use a lot of repetition.

Strategies To Improve Outcomes for Individuals With an FASD

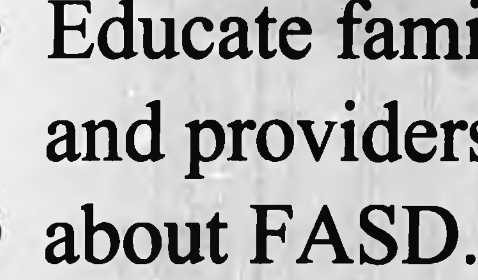
Strategies for Sensory Integration Issues

- Simplify the individual's environment.
- Provide a lot of one-to-one physical presence.
- Take steps to avoid sensory triggers.



Strategies To Improve Outcomes for Individuals With an FASD

- Ask about possible prenatal alcohol exposure at intake.



- Educate families and providers about FASD.

- Ask about substance use during medical appointments.

- Have a thorough diagnostic workup.

Dubovsky, Drexel University College of Medicine (1999)

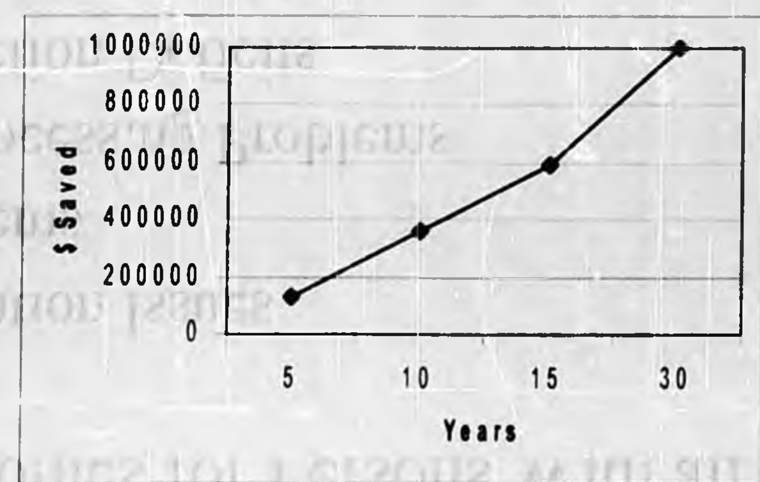
Outcomes

This section includes:

- Strategies To Improve Outcomes for Persons With an FASD
  - Strategies for Sensory Integration Issues
  - Strategies for Memory Problems
  - Strategies for Information Processing Problems
  - Strategies for Executive Function Deficits
  - Strategies for Self-Esteem and Personal Issues
- Strengths of Persons With an FASD
- Paradigm Shift

Economic Costs of FAS

- One prevented case of FAS saves:
  - $130,000 in the first 5 years
  - $360,000 in 10 years
  - $587,000 in 15 years
  - More than $1 million in 30 years



Increased savings through prevention

Lupton, Burd, and Harwood (2004)

- FAS alone cost the United States more than $4 billion in 1998.

- The average lifetime cost for each child with FAS is $2 million.

  - $1.6 million for medical care services

  - $0.4 million for loss of productivity

Increased costs

Lupton, Burd, and Harwood (2004)

Systems of Care

Many Doors, No Master Key: Resources Needed for Brandan, Age 1-2 Years

Health

- Pediatrician
- Neurologists (2)
- Pediatric Ophthalmologist
- Audiologist
- Otolaryngologist
- Pharmacy
- Medical Supply Providers
- Gastroenterologist
- Feeding Specialist
- Nutritionist
- High-Risk Infant Clinic
- FAS Diagnostic Clinic
- Lab and X-Ray Services
- Surgeons
- Pulmonologist
- Respiratory Therapist

Education

- Physical Therapist
- Speech/Language Pathologist
- Infant Educator
- Cultural Recreational Therapy (e.g., drumming)
- Birth-3 Program: Occupational Therapist, Speech/Language Pathologist, Teacher, Aide, Play Therapist

Social and Community Services

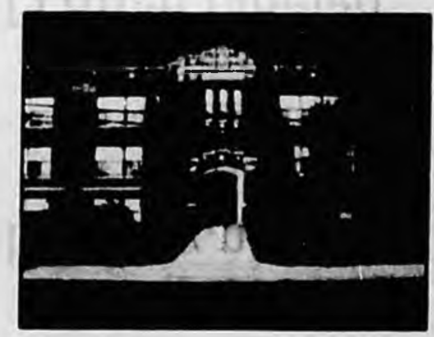
- Local Indian Child Welfare Advisory Committee
- Tribal Social Worker
- Child Welfare/ Case Worker
- Tribal Council
- Respite Providers
- Foster Care System
- Daycare
- Div. of Dev. Disabilities/Case Worker and Family Resource Coordinator
- Substance Abuse Treatment (birth mother)
- Mental Health Counseling (birth mother)
- Parenting Education (birth mother)

Legal and Financial Services

- SSI
- Medicaid
- Guardian Ad Litem
- Judge-Foster Care Issues
- Attorneys for Birth Parents

~ About 40 service providers

Systems of Care for Persons With an FASD



- Health
- Education
- Social and community services
- Legal and financial services

Intervention Issues

- Failure in traditional mental health treatment programs
  - People with an FASD may know what they need to do but cannot follow through
  - Caregivers with unrecognized FASD often labeled neglectful, uncooperative, or sabotaging treatment because they do not follow instructions
- Limited FASD-specific treatment services

General Issues With FASD

- Often undiagnosed among persons without FAS facial features

- More difficulties seen in those without FAS facial features and with higher IQs

- Adaptive functioning more impaired than intelligence

Treatment

This section includes:

- General Issues With FASD
- Intervention Issues
- Systems of Care for Persons With an FASD
- Economic Costs of FAS

Benefits of Identification and Treatment

- Helps decrease anger and frustration for individuals, families, providers, and communities by helping them understand that negative behavior results from the disability and is not willful

- Helps people with an FASD succeed by focusing on why they have trouble in certain programs

- Helps improve outcomes

- Helps prevent future births of children with an FASD

Risks to an Adult of Not Accurately Identifying and Treating FASD

- Unemployment
- Loss of family
- Homelessness
- Jail
- Premature death
- Increased substance abuse

Risks to a Child of Not Accurately Identifying and Treating FASD

- Loss of family
- Increased substance use
- Prema*ure death

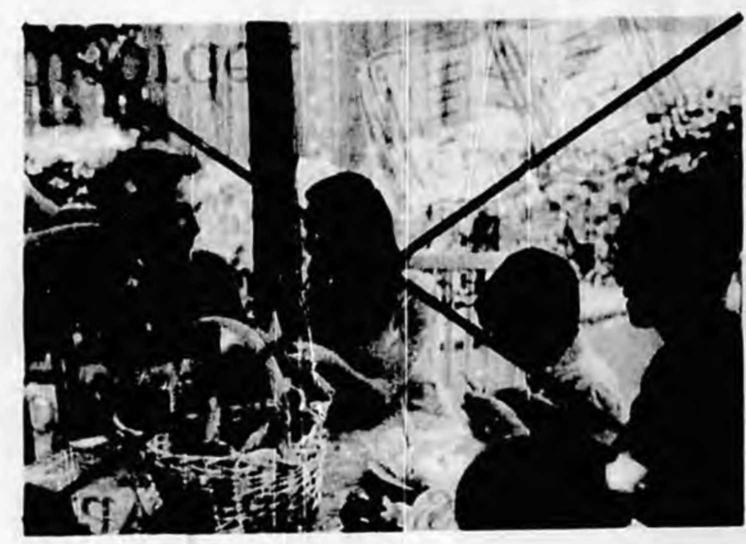


Photo courtesy of Microsoft.

FASD and Mental Health Disorders

- Prenatal alcohol exposure may lead to severe behavioral, cognitive, and psychiatric problems.

DSM-IV

- FASD is not a psychiatric disorder.

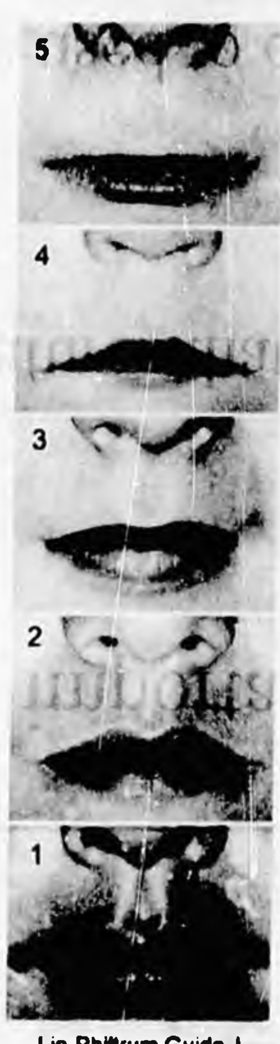
- FASD can co-occur with a mental health or substance abuse disorder.

Differential Diagnosis of Features of FAS

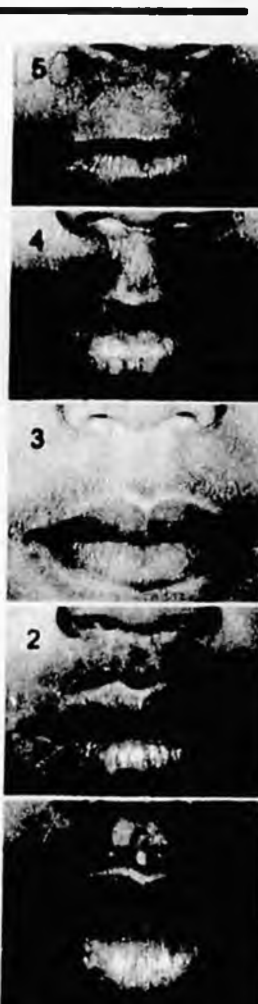
- Differential diagnosis is very important because:
  - Many syndromes can cause features that look like FAS.
  - Facial features alone cannot be used to diagnose FAS.

Diagnosing Fetal Alcohol Syndrome

- Prenatal maternal alcohol use
- Growth deficiency
- Central nervous system abnormalities
- Dysmorphic features
  - Short palpebral fissures
  - Indistinct philtrum
  - Thin upper lip



Lip-Philtrum Guide 1
Caucasian



Lip-Philtrum Guide 2
African American

Source: Astley, S.J. 2004. *Diagnostic Guide for Fetal Alcohol Spectrum Disorders: The 4-Digit Diagnostic Code, Third Edition.* Seattle: University of Washington Publication Services, p. 114.

Diagnosis

This section includes:

- Diagnosing Fetal Alcohol Syndrome
- Differential Diagnosis of Features of FAS
- FASD and Mental Health Disorders
- Risks to a Child of Not Accurately Identifying and Treating FASD
- Risks to an Adult of Not Accurately Identifying and Treating FASD
- Benefits of Identification and Treatment