

# Alaska FASD Partnership

*Advocacy* ▪  
*Diagnosis* ▪ *Case*  
*Management* ▪  
*Prevention*  
 ▪ *Substance Abuse*  
*Treatment for*  
*Pregnant Women* ▪  
*Parent Navigation* ▪  
*Training for Parents*  
 ▪ *Public Awareness* ▪  
*Education* ▪ *Housing*  
 ▪ *Employment* ▪  
*Alternatives to*  
*Incarceration* ▪  
*Court Interpreters* ▪  
*Training for Judges* ▪  
*Supported Housing* ▪  
*Case Workers* ▪  
*Training for*  
*Educators* ▪ *Life*  
*Skills* ▪ *Traditional*  
*Healing* ▪  
*Intervention* ▪  
*Training for Medical*  
*Professionals* ▪  
*Family Support*



## Fetal Alcohol Spectrum Disorders in the Schools Panel Presentation for the Senate Education Committee March 16, 2011

### **Presenters:**

**Cindy Anderson** - Director Special Education, Anchorage School District (Anchorage)

**Deb Evensen** - FASD Education Consultant, statewide (Homer)

**Monica Leinberger** - FASD Specialist, Lower Kuskokwim School District (Bethel)

**Mary Andrews** - Mother of child with FASD (Bethel)

**Terrell Andrews** – Teenager, with FASD (Bethel)

**Jeanne Gerhardt-Cyrus** - Mother of children with FASD (Kiana)

**Ivory Gerhardt-Cyrus** – Teenager, with FASD (Kiana)

**Mindy Cason** – UAA student, young adult with FASD (Nikiski, Anchorage)

This presentation is sponsored by the Alaska FASD Partnership in collaboration with the Advisory Board on Alcoholism and Drug Abuse and the Alaska Mental Health Board. The panel will speak on the topic of Fetal Alcohol Spectrum Disorders (FASD) in the education system.

All panelists have direct experience with FASD and will explain their observations and personal experiences. They will also be available for questions at the end of their presentation.

Cindy Anderson will present on the efforts of the Anchorage School District; Deb Evensen will discuss a statewide perspective; Monica Leinberger will discuss FASD programs at the Lower Kuskokwim School District; others on the panel will offer personal experiences and observations.

Included in this packet you'll find background information on FASD, an overview of the efforts of the Alaska FASD Partnership, and a report from the FASD Southeast Alaska Regional Conference Report 2010.

Thank you for the opportunity to present.

The brain is the organ most sensitive to prenatal alcohol damage. [Dr. Edward P. Riley lecture, September 25, 2002]

**Damage to the brain from alcohol exposure can have an adverse affect on behavior.** Alcohol exposure appears to damage some parts of the brain, while leaving other parts unaffected. Some children exposed to alcohol will have neurological problems in just a few brain areas. Other exposed children may have problems in several brain areas. The brain dysfunction is expressed in the form of inappropriate behaviors. Their behavior problems should be viewed with respect to neurological dysfunction. Although psychological factors such as abuse and neglect can exacerbate behavior problems in FASD, we are looking primarily at behavior that is organic in origin. To better understand FASD behavior issues, shift perspective from thinking the child "won't" to "can't." (Diane Malbin, MSW, Trying Differently Rather Than Harder, )

**Sometimes the person's behavior is misinterpreted as willful misconduct** (Debra Evensen, [www.fasalaska.com](http://www.fasalaska.com)), but for the most part, maintaining good behavior is outside of the child's control, especially in stressful or stimulating situations. Behavior problems in children with FASD are often blamed on poor parenting skills. While good parenting skills are required, even alcohol exposed children raised in stable, healthy homes can exhibit unruly behavior. The most difficult behaviors are seen in children who were prenatally exposed to alcohol and who also suffer from Reactive Attachment Disorder.

**Most children with FASD have some attachment issues,** may display inappropriate sexual behaviors, show poor judgment, have difficulty controlling their impulses, are emotionally immature, and need frequent reminders of rules. As a result, many will require the protection of close supervision for the rest of their lives.

## Fetal Alcohol Spectrum Disorders (FASD)

Alcohol causes more damage to the developing fetus than any other substance, including marijuana, heroin, and cocaine. (Institute of Medicine, 1996)

### "Soft Signs"

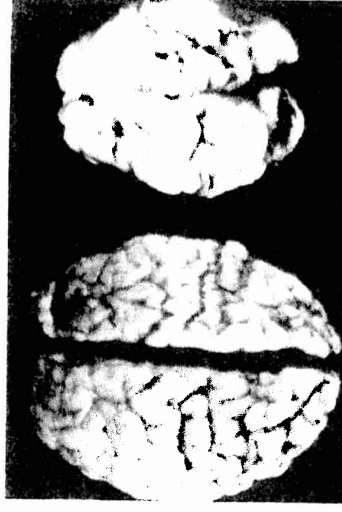
(Psychological signs of FASD brain damage)

- Immature social development: overly friendly to strangers
- Emotional lability:
- Poorly developed conscience:
- Lack of consistent impulse control:
- Inability to learn from consequences
- Good expressive language skills
- Talented in art, music or mechanics.
- Attention deficits: not always hyperactive, but easily distracted by external stimuli
- Short-term memory deficits
- Inappropriate social interactions
- Difficulty managing money:
- Poor concept of time
- Grandiose ideas and unrealistic life goals, distorted perceptions
- Poor judgment
- Vulnerability and naiveté

"The greatest obstacle our children with fetal alcohol disorders must overcome is chronic frustration from not being able to meet the unrealistic expectations of others." – Dr. Calvin Sumner, nationally recognized expert.

Fasstar Information Series Brochure 0408B1

# FASD and the Brain



(Photo courtesy of Sterling Claren, MD)  
Brain of a baby with no alcohol exposure      Brain of baby with heavy alcohol exposure

## How Prenatal Alcohol Exposure Affects Development of the Brain

By Teresa Kellerman

Fasstar Enterprises  
Fetal Alcohol Syndrome: Support, Training, And Resources

[www.fasstar.com](http://www.fasstar.com)

# FASD and the Brain

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**Alcohol** is a "teratogen" (substance that is toxic to the baby's developing brain). Damage can occur in various regions of the brain. The areas that might be affected depend on which areas are developing at the time the alcohol is consumed. Since the brain and the central nervous system are developing throughout the entire pregnancy, the baby's brain is always vulnerable to damage from alcohol exposure.

The regions of the brain that might be affected by prenatal alcohol exposure include:

**Frontal Lobes** – this area controls impulses and judgment. The most noteworthy damage to the brain probably occurs in the prefrontal cortex, which controls what are called the **Executive Functions**.

**Corpus Callosum** - passes information from the left brain (rules, logic) to the right brain (impulses, feelings) and vice versa; related to attention deficits, psychosocial function, and verbal learning.

**Basal Ganglia** – involved in cognitive function; affects spatial memory and behaviors like perseveration and the inability to switch modes, work toward goals, and predict behavioral outcomes, and the perception of time.

**Hypothalamus** - controls appetite, emotions, temperature, and pain sensation

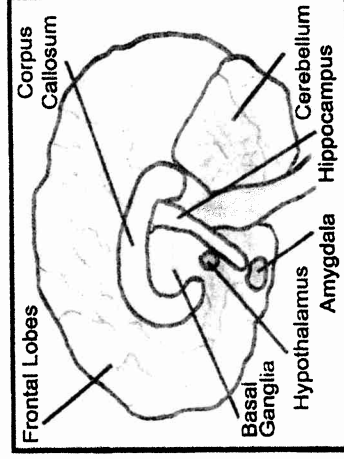
**Amygdala** – central part of emotional circuitry, senses danger, fear and anxiety; plays major role in recognizing faces and facial expressions, social behavior, aggression, and emotional memory; critical for stimulus-reinforcement association learning.

**Hippocampus** - plays a fundamental role in spatial and verbal memory retrieval; damage can cause chronic stress, anxiety, and depression; dysfunction is related to symptoms of schizophrenia.

**Cerebellum** – controls balance, coordination and movement; impacts learning and cognitive skills.

The hypothalamus, amygdala, and hippocampus are part of the **limbic system**, regulating emotions, social and sexual behavior, fight or flight" response, and empathy.

## Fetal Alcohol Spectrum Disorders (FASD)



## Executive Functions of the Prefrontal Cortex

Effects of alcohol exposure on behaviors related to executive functions of the prefrontal cortex:

- inhibitions: socially inappropriate behavior
- problem solving: inability to figure out solutions spontaneously
- sexual urges: inability to control sexual impulses, especially in social situations
- planning: inability to apply consequences from past actions
- time perception: difficulty with abstract concepts of time and money
- internal ordering: like files out of order, difficulty processing information
- working memory: storing and/or retrieving information
- self-monitoring: needs frequent cues, requires "policing" by others
- verbal self-regulation: needs to talk to self out loud, needs feedback
- motor control: fine motor skills more affected than gross motor
- regulation of emotion: moody "roller coaster" emotions, may withdraw or lash out
- motivation: apparent lack of remorse, need external motivators
- judgment – inability to make wise decisions

## Alcohol Exposure by Trimester:

1. During the first trimester, as shown by the research of Drs. Clarren and Streissguth, alcohol interferes with the migration and organization of brain cells. [Journal of Pediatrics, 92(1):64-67]
2. Heavy drinking during the second trimester, particularly from the 10th to 20th week after conception, seems to cause more clinical features of FASD than at other times during pregnancy, according to a study in England. [Early-Human-Development; 1983 Jul Vol. 8(2) 99-111]
3. During the third trimester, according to Dr. Claire D. Coles, the hippocampus is greatly affected, which leads to problems with encoding visual and auditory information (reading and math). [Neurotoxicology And Teratology, 13:357-367, 1991]

**Not all damage from alcohol exposure is seen on brain scans**, as lesions might be too small to be detected, yet large enough to cause significant disabilities.

**Children do not need to have full Fetal Alcohol Syndrome (FAS) to have significant difficulties due to prenatal exposure to alcohol.** According to research done by Drs. Joanne L. Gusella and P.A. Fried, even light drinking (average one-quarter ounce of absolute alcohol daily) can have adverse affects on the child's verbal language and comprehension skills. [Neurobehavioral Toxicology and Teratology, Vol. 6:13-17, 1984] Drs. Mattson and Riley in San Diego have conducted research on the neurology of prenatal exposure to alcohol. Their studies show that children of mothers who drank but who do not have a diagnosis of FAS have many of the same neurological abnormalities as children who have been diagnosed with full FAS. [Neurotoxicology and Teratology, Vol. 16(3):283-289, 1994]

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**Subject:** EED efforts to support students with FASD

**From:** Brocious, Todd D (EED)  
**Sent:** Friday, February 25, 2011 3:02 PM  
**To:** Tibbett, Teri (HSS)  
**Subject:** EED efforts to support students with FASD

Hi Teri,

Here is the overview on EED's efforts to support students with Fetal Alcohol Spectrum Disorders. If you have any clarifying questions on what I've provided below or needs that arise as you prepare for the Alaska FASD Partnership **FASD and the Education System** Panel presentation before the Senate Education Committee on March 16<sup>th</sup>, please don't hesitate to contact me. Have a great weekend. Todd

#### **EED Resources**

- EED's most frequently used FASD educational resources are its two 3.5 hour long eLearning courses dedicated to FASD-- created in collaboration with a cadre of state and national FASD experts. These web-based resources are free for a broad spectrum of professionals and care providers who support individuals/students with FASD.
- One FASD eLearning course is tailored to educators. It instructs learners on what FASDs are, their primary and secondary characteristics, their most common impacts on behavior and learning, and also provides information to learners on the types of teaching strategies and environmental accommodations that empower affected students to be more successful in school. Thousands of public school employees from the majority of Alaska's school districts have utilized this resource to comply with **AS 14.20.360 Required alcohol and drug related disabilities training** since its creation in 2003 and approximately 600 district personnel from more than 30 districts are enrolled in the course this school year.
- EED also collaborated with the Department of Health and Social Services to create a second multi-disciplinary FASD eLearning course for non-educators who support individuals with FASD. This course is useful for a broad spectrum of professional service providers as well as for parents. DHSS uses this course to complement its FAS 101 and 201 curricula trainings efforts.
- EED has a collection of other eLearning courses relevant to FASD free for district use, including Mandated Reporting of Child Abuse and Neglect, Positive Behavior Supports and Interventions (under revision), Domestic Violence and Sexual Assault, and more than a dozen courses on an array of Special Education topics.
- EED both provides on-site FASD training and assists districts in identifying qualified FASD trainers upon request.
- EED manages multiple websites with FASD prevention/intervention resources for district use like eLearning, School Health, School Safety, Special Education, Alternative Schools Healthy Students Initiative, Title IV Part A Safe and Drug-Free Schools.
- EED is in the final stages of refining the draft Health and Safety portion of its Education Plan. The plan, which directly and indirectly addresses substance abuse and other risk behaviors by school-aged youth. It is tentatively scheduled to go to the Alaska State School Board for review in June.
- The Healthy Alaska electronic newsletter published by EED approximately 9 times a year is regularly used to notify district personnel to professional development opportunities, grant opportunities, and resources available to them related to FASD prevention/intervention.

#### **EED Programs**

- EED continues to manage the federal No Child Left Behind Title IV Part A Safe and Drug-Free Schools Program. This program provides districts with funding to reduce violence and substance use/abuse. EED provides

technical assistance to districts, directs them to evidence-based effective intervention and prevention programs, assists districts in constructing comprehensive prevention programs, assists districts in data collection and analysis, and monitors Title IV Safe and Drug-Free programs for compliance with federal requirements. All funding for this program has been eliminated and the last of the Title IV supported programming will end in September 2011.

- Positive Behavioral Interventions and Supports—EED is currently contracting with the Special Education Services Agency to provide on-site PBIS training to a collection of Alaska schools and to create 3 eLearning courses on PBIS for district use. This evidence-based program improves school climate, student behavior, and learning for all students.
- EED's Alternative Schools Healthy Relationships Initiative provides a broad spectrum of health-related support services to the state's alternative schools serving students who report engaging in elevated rates of risk behaviors relevant to FASD. The initiative has increased student access to health services, increased the number of health education classes provided to them, increased mental health services, increased access to life coaches, increased support for homeless students, and increased services for pregnant and parenting students.

### **EED Evaluation/data**

- EED co-manages the Youth Risk Behavior Survey which is the nationally recognized gold standard survey instrument to measure student reported risk behaviors. The survey captures data on the risk factors that both directly and indirectly cause FASDs. EED and DHSS create a broad array of flyer, brochures, powerpoints, and website resources to maximize the utility of this data. The data is commonly used to evaluate the effectiveness of intervention and prevention programs in schools and other settings. EED has been utilizing this survey since 1995.
- EED collects and annually reports disciplinary data on alcohol and illicit drug use in schools for all public schools statewide. EED developed and maintains a Suspensions, Expulsions, and Truancies data collection system to accomplish this.

### **EED Positions with responsibilities related to FASD**

- EED's Health and Safety Coordinator position with its emphasis on preventing Domestic Violence and Sexual Assault is co-sponsoring and co-managing a collection of teacher trainings on the Fourth R curriculum, an evidence-based curriculum proven to reduce intimate partner violence and increase knowledge of substance abuse.
- EED's Special Education Unit provides support to those students with FASDs qualifying for special education services by providing leadership, technical assistance, and supervision to school districts. The staff support school districts in providing special education and related services to children with disabilities and gifted children from ages 3-21. Special Education also provides funding to support EED's courtesy eLearning courses for districts and provides funding to support both regional and statewide training opportunities for educators on FASD.
- EED's Counseling/Mental Health/PBIS Education Specialist coordinates the PBIS program, works with multiple agencies on interdepartmental initiatives like Bring the Kids Home
- EED's eLearning Program and Title IV Safe and Drug-Free Schools Education Specialists provide resources, technical assistance, and program monitoring of prevention and intervention efforts.

### **Memberships on relevant Committees**

- EED currently participates on the Alaska FASD Partnership Steering Committee, the Alaska Interagency Coordinating Committee on the Prevention of Underage Drinking, the Preventative Health and Health Services Block Grant Advisory Committee, the Alaska Mental Health Board, the School Health Collaborative, and the

Bring the Kids Home Committee, The Governor's Initiative on Domestic Violence and Sexual Assault Prevention Workgroup, and The Council on Domestic Violence and Sexual Assault's Advisory Council.

Todd Brocious

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Education Specialist

Safe and Drug-Free Schools, Quality Schools, HIV, Elearning

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*Alternatives to Incarceration* ▪  
*Court Interpreters* ▪  
*Training for Judges* ▪  
*Supported Housing* ▪  
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*Intervention* ▪  
*Training for Medical Professionals* ▪  
*Family Support*



## Alaska FASD Partnership

The Alaska Fetal Alcohol Spectrum Disorders (FASD) Partnership is a coalition of over 75 organizations and individuals committed to addressing issues related to FASD in Alaska.

The mission of the Alaska FASD Partnership is to promote prevention of FASD and effective, life-long interventions for those affected by prenatal exposure to alcohol, and their families.

The Partnership was formed in early 2010 after a groundswell of stakeholder effort and public comment to the Advisory Board on Alcoholism and Drug Abuse and its partners about the need for a more organized effort to address FASD in Alaska.

Seven workgroups of the Partnership are actively addressing a variety of issues to determine gaps and barriers to serving people impacted by FASD, developing policy and funding recommendations, promoting public awareness and workforce development, promoting collaborations, research, training, and more. They are:

- Diagnosis and Parent Navigation
- Family and Peer Support
- Prevention and Treatment for Pregnant Women
- FASD and the Education System
- FASD and the Legal System
- Services for Adults with FASD
- Professional Development

The Partnership is guided by a steering committee represented by individuals, organizations, and state agencies, including the Departments of Health & Social Services, Corrections, Education and Early Development, Labor and Workforce Development, and the Alaska Court System.

A list of statewide coalition members and membership form follows ...

Visit our webpage or contact us via the information below.

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 ▪ Employment ▪  
 Alternatives to  
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 Court Interpreters ▪  
 Training for Judges ▪  
 Supported Housing ▪  
 Case Workers ▪  
 Training for  
 Educators ▪ Life  
 Skills ▪ Traditional  
 Healing ▪  
 Intervention ▪  
 Training for Medical  
 Professionals ▪  
 Family Support



## Partnership Members

Abused Women's Aid in Crisis (AWAIC) (Anchorage)  
 Advisory Board on Alcoholism and Drug Abuse (statewide)  
 Alaska Behavioral Health Association (statewide)  
 Alaska Center for Children & Adults (Fairbanks)  
 Alaska Children's Services (Anchorage)  
 Alaska Mental Health Board (statewide)  
 Alaska Mental Health Trust Authority (statewide)  
 All-Alaska Pediatric Partnership (Anchorage)  
 Anchorage Coordinated Resources Project (Mental Health Court) (Anchorage)  
 Anchorage School District (Anchorage)  
 Arctic FASD Regional Training Center (Anchorage/statewide)  
 Assets Inc. (Anchorage)  
 Association for the Education of Young Children-SEAK (Southeast Alaska)  
 Big Brothers Big Sisters of Alaska (statewide)  
 Boys & Girls Home of Alaska (Fairbanks)  
 Camp Fire USA Alaska Council (statewide)  
 Christian Health Associates (Anchorage)  
 Copper Basin Neurodevelopmental Center (Anchorage)  
 Deltana Community Services Partnership (Delta Junction)  
 Dena A Coy/Southcentral Foundation (Anchorage)  
 Diocese of Juneau (Juneau)  
 Fairbanks Community Behavioral Health Center (Fairbanks)  
 Family Centered Services of Alaska (Fairbanks)  
 Gastineau Human Services (Juneau)  
 Governor's Council on Disabilities and Special Education (statewide)  
 Hoonah Indian Association (Hoonah)  
 Hope Community Resources (Kodiak)  
 Independent Living Center (Homer)  
 Kenai Peninsula FASD Program (Kenai Peninsula)  
 Ketchikan Indian Community (Ketchikan)  
 Kinetictions (Juneau)  
 Kobuk Valley Consulting (Kiana)  
 Kodiak Area Native Association (Kodiak)  
 Juneau Family Health and Birth Center (Juneau)  
 Juneau FASD Diagnostic Clinic (Juneau)  
 Juneau Partnership for Families and Children (Juneau)  
 Lower Kuskokwim School District (Bethel)  
 Lynn Canal Counseling Services (Haines)  
 Nenana City School District (Nenana)  
 Nome Youth Facility (Nome)  
 Nondalton Tribe (Nondalton)  
 Regional Wellness Forum (Seward Peninsula)  
 Set Free Alaska, Inc. (Wasilla)  
 Southcentral Foundation FAS Diagnostic Team (Anchorage)  
 Southeast Regional Resource Center (SERRC) (statewide)  
 Southern Kenai Peninsula (SKP) Communities Project (Kenai Peninsula)  
 Stone Soup Group (Anchorage, statewide)  
 Tongass Substance Screening (Ketchikan)  
 UAA Department of Health Sciences (Anchorage/statewide)  
 UAA Center for Human Development (Anchorage/statewide)

...and many individuals



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## Become a member of the FASD Partnership

You are invited to join the Alaska Fetal Alcohol Spectrum Disorders (FASD) Partnership, a coalition of organizations and individuals committed to addressing issues related to fetal alcohol spectrum disorders in Alaska. There are no dues or cost for membership.

I/We \_\_\_\_\_ agree on this date \_\_\_\_\_ to include my/our name as a member of the Alaska FASD Partnership. I/We understand that I/our organization will be informed of and invited to participate in efforts related to FASD, such as advocacy, budget and policy, diagnosis, case management, prevention, public awareness, alternatives to incarceration, substance abuse treatment for pregnant women, training for professionals and paraprofessionals, supported housing, family support, and other issues related to FASD. I/we may participate in or decline to participate in whatever efforts we choose.

Please fill out and **MAIL** or **FAX** this form to **907-465-4410 fax**:

☐ Organization      ☐ Individual

Contact Person \_\_\_\_\_

Organization Name \_\_\_\_\_

Address \_\_\_\_\_  
 \_\_\_\_\_

Email \_\_\_\_\_

Phone contact(s) \_\_\_\_\_

For organizations and individuals: What is your affiliation/interest in FASD?

\_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

For organizations: What services do you provide related to FASD?

\_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

## **Recommendations from December 2010 Summit Alaska FASD Partnership Steering Committee**

### **Diagnosis**

- Use of telemedicine in expanding diagnosis statewide
- Expand use of screening tools/EPSTD (Early Periodic Screening, Diagnosis and Treatment)
- Train primary care/behavioral health providers

### **Family/Peer Support**

- Provide Family FASD Camps to rural areas
- Work with Alaska Peer Support Consortium (AKPSC) to develop Peer Specialist network
- Train primary care/behavioral health providers in FASD

### **Prevention and Treatment for Pregnant Women**

- Train substance abuse treatment providers and alcohol beverage servers
- Vary “Do Not Drink When You Are Pregnant” signage in public places
- Support FASD messages on pregnancy tests
- Expand substance abuse screening for females of child-bearing age

### **Education**

- Educate district superintendents and staff about successful models
- Present to State Board of Education
- Expand use of FASD 101 and FASD 201 at in-services, conferences, etc.
- Present to State Board of Education
- Expand LKSD/ASD models statewide

### **Legal System**

- Change mitigating factors related to FASD
- Expand screening at Department of Corrections (DOC) and Division of Juvenile Justice (DJJ)
- Expand training for DOC/DJJ staff
- Improve transition services for individuals with FASD (assistance with housing, treatment, medication, employment, training, education, case management, etc.)

### **Professional Development**

- Expand training opportunities for professionals (primary care and behavioral health providers, educators, probation and correctional officers, attorneys and judges, etc.)
- Distribute resources (books, pamphlets, digital information) statewide
- Expand training (FASD 101 & 201 and “FASD Into Action,” etc.) across professions and cultures.

### **Adult Services**

- Promote transition services (housing, treatment, medication, employment, training, education, case management, etc.) from foster care, education and correctional systems.
- Train employers, educators, peer specialists, and substance abuse treatment providers
- Expand diagnosis for adults
- Develop FASD services system for adults

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Training for Judges ▪  
Supported Housing ▪  
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Training for  
Educators ▪ Life  
Skills ▪ Traditional  
Healing ▪  
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Family Support



## What is Fetal Alcohol Spectrum Disorder?

Fetal Alcohol Spectrum Disorders (FASDs) are a range of birth defects caused by maternal consumption of alcohol during pregnancy. FASDs can include:

- Fetal Alcohol Syndrome (FAS)
- Partial Fetal Alcohol Syndrome (PFAS)
- Alcohol-Related Neurodevelopmental Disorder (ARND)
- Static encephalopathy (alcohol exposed)
- Neurobehavioral Disorder (alcohol exposed)

The term FASD is not in itself a clinical diagnosis, but describes the full range of disabilities that may result from prenatal alcohol exposure. Currently, the only expression of prenatal alcohol exposure that is defined by the International Statistical Classification of Diseases and Related Health Problems is FAS, assigned ICD-9 and ICD-10 diagnoses.

FASD-related disabilities result when alcohol crosses the placental barrier and causes the developing brain cells and structures in the fetus to be under-developed or malformed, causing permanent brain damage. Primary disabilities can include poor memory, attention deficits, impulsive behavior, and poor cause-and-effect reasoning. Secondary disabilities, or by-products of the primary disabilities, can include behavioral problems, poor self-esteem, addiction disorders, homelessness, unemployability, etc.

National prevalence rates for Fetal Alcohol Syndrome (FAS) range from 0.2 to 1.5 per 1,000 live births; prevalence rates for FASD were reported to occur approximately three times as often (Centers for Disease Control, 2004).

According to a 2007 report in the *Journal of Psychological Practice*, "FASD is of serious concern to behavioral health practitioners due to high prevalence rates, soaring economic costs, and lifelong implications of the disorder ... It is critical that practitioners working with children and families are aware of FASD and are prepared to screen for the disorder."

### The Range of FASDs

**Fetal Alcohol Syndrome (FAS)** is a congenital medical condition which can include growth deficiency and body deformation, abnormal facial features, central nervous system damage, especially to the brain, and prenatal exposure to alcohol.

→

**Partial Fetal Alcohol Syndrome (PFAS)** is a diagnostic classification for patients who present with most, but not all, of the growth deficiency and/or facial features of FAS, central nervous system damage (structural, neurological and/or functional impairment), and prenatal exposure to alcohol.

**Alcohol Related Neurodevelopmental Disorders (ARND)** is a diagnostic classification, coined by the Institute of Medicine in 1996, for patients who present with central nervous system damage (structural, neurological, and/or functional impairment).

### **FASD 4-Digit Diagnostic Code**

In 1997, the Washington State FAS Diagnostic and Prevention Network developed the FASD 4-Digit Diagnostic Code, which is widely used in the diagnosis of FASD. Besides continuing to diagnose FAS and PFAS, they have added the following terms in lieu of ARND or FAE:

**Static encephalopathy (alcohol exposed).** The term *encephalopathy* refers to any significant abnormal condition of the structure or function of brain tissues. The term *static* means that the abnormality in the brain is unchanging – neither progressing nor regressing. This diagnostic classification is for patients who present with central nervous damage and prenatal alcohol exposure.

**Neurobehavioral Disorder (alcohol exposed).** This is a diagnostic outcome classification for patients who present with central nervous system dysfunction (mild functional impairment with no evidence of structural or neurological abnormalities) and prenatal alcohol exposure.

**Note:** Outcomes such as ARND, Static Encephalopathy (alcohol exposed), and Neurobehavioral Disorder (alcohol exposed) are far more prevalent than FAS or partial FAS.

**Source:** What Are FASD, FAS, Partial FAS and ARND? Fetal Alcohol Syndrome Diagnostic & Prevention Network, University of Washington, Seattle. <http://depts.washington.edu/fasdnpn/htmls/fasd-fas.htm>

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## Alaska FASD Talking Points

- FASDs are a range of disabilities caused when a developing fetus is exposed to alcohol.
- One of every four Alaskans dependent on or abusing alcohol is a woman, and one of every 25 women whose babies are born alive said she drank while pregnant, according to the Center for Behavioral Health Research and Services (UAA).
- The term FASD is not in itself a clinical diagnosis, but describes the full range of disabilities that may result from prenatal alcohol exposure, including Fetal Alcohol Syndrome (FAS), Partial Fetal Alcohol Syndrome (PFAS), Alcohol-Related Neurodevelopmental Disorder (ARND), Static encephalopathy (alcohol exposed) and Neurobehavioral Disorder (alcohol exposed).
- FASD is a lifelong disability that may include learning disabilities, memory problems, impulsiveness, poor judgment, attention deficits, heart and kidney problems, mental retardation, and severe emotional disturbance (SED).
- FASD is the most common known cause of mental retardation.
- Alaska has the highest per capita rate of FASD in the United States.
- A person with an FASD, without support, is at high risk for from depression, substance abuse, serving time in jail, or becoming homeless.
- Early diagnosis and support allows families, schools and communities to work together to address prevention, interventions and on-going support.
- Primary disabilities refer to the brain damage that result in impaired cognitive function of people with FASD.
- Secondary disabilities are those not present at birth, but occur as a result of the primary disabilities. These may include mental health problems, disrupted school experience, trouble with the law, inappropriate sexual behavior, alcohol/drug problems, dependent living, problems with employment, problems with parenting, etc.

# Alaska FASD Partnership

*Advocacy* ▪  
*Diagnosis* ▪ *Case Management* ▪  
*Prevention*  
 ▪ *Substance Abuse Treatment for Pregnant Women* ▪  
*Parent Navigation* ▪  
*Training for Parents*  
 ▪ *Public Awareness* ▪  
*Education* ▪ *Housing*  
 ▪ *Employment* ▪  
*Alternatives to Incarceration* ▪  
*Court Interpreters* ▪  
*Training for Judges* ▪  
*Supported Housing* ▪  
*Case Workers* ▪  
*Training for Educators* ▪ *Life Skills* ▪ *Traditional Healing* ▪  
*Intervention* ▪  
*Training for Medical Professionals* ▪  
*Family Support*



## FASD in Alaska's Correctional Institutions

A 2006 evaluation by the University of Alaska Anchorage (UAA) Behavioral Health & Research Services, reported the following based on surveys distributed to personnel at each of Alaska's correctional institutions:

- Estimated percentage of the inmates on current caseload who may have FAS = 27%
- Percentage of Corrections staff who have referred an inmate for FAS screening or diagnosis = 25%
- Percentage of Corrections staff who say they have the appropriate skills and knowledge to deal with alcohol abuse among the inmates or offenders on their caseload = 56%
- Percentage of Corrections staff who say they have the appropriate skills and knowledge to deal with offenders or inmates who have FASD = 55%
- Percentage of Corrections staff who say they have the support of their administration to deal with inmates or offenders on their caseload who have FAS = 56%
- Percentage of Corrections staff who say the current social service programs within the correctional system are appropriate for inmates or offenders on their caseload who have FAS = 30%
- Percentage of Corrections staff who say the current educational service programs within the correctional system were appropriate for the inmates or offenders on their caseload who have FAS = 35%
- Corrections respondents had an average of 9-10 year experience working in corrections in Alaska.

**Source:** *FAS Knowledge, Attitudes, Beliefs and Behavior (KABB): 2006 Survey of Alaskan Professionals*. Behavioral Health Research and Services, FAS Evaluation, University of Alaska Anchorage. [http://bhrrs.uaa.alaska.edu/pdf/reports/FAS/FAS\\_KABB\\_FINAL\\_Report.pdf](http://bhrrs.uaa.alaska.edu/pdf/reports/FAS/FAS_KABB_FINAL_Report.pdf)

# Alaska FASD Partnership

Advocacy ▪  
 Diagnosis ▪ Case  
 Management ▪  
 Prevention  
 ▪ Substance Abuse  
 Treatment for  
 Pregnant Women ▪  
 Parent Navigation ▪  
 Training for Parents  
 ▪ Public Awareness ▪  
 Education ▪ Housing  
 ▪ Employment ▪  
 Alternatives to  
 Incarceration ▪  
 Court Interpreters ▪  
 Training for Judges ▪  
 Supported Housing ▪  
 Case Workers ▪  
 Training for  
 Educators ▪ Life  
 Skills ▪ Traditional  
 Healing ▪  
 Intervention ▪  
 Training for Medical  
 Professionals ▪  
 Family Support



## What is Fetal Alcohol Spectrum Disorder?

Fetal Alcohol Spectrum Disorders (FASDs) are a range of birth defects caused by maternal consumption of alcohol during pregnancy. FASDs can include:

- Fetal Alcohol Syndrome (FAS)
- Partial Fetal Alcohol Syndrome (PFAS)
- Alcohol-Related Neurodevelopmental Disorder (ARND)
- Static encephalopathy (alcohol exposed)
- Neurobehavioral Disorder (alcohol exposed)

The term FASD is not in itself a clinical diagnosis, but describes the full range of disabilities that may result from prenatal alcohol exposure. Currently, the only expression of prenatal alcohol exposure that is defined by the International Statistical Classification of Diseases and Related Health Problems is FAS, assigned ICD-9 and ICD-10 diagnoses.

FASD-related disabilities result when alcohol crosses the placental barrier and causes the developing brain cells and structures in the fetus to be under-developed or malformed, causing permanent brain damage. Primary disabilities can include poor memory, attention deficits, impulsive behavior, and poor cause-and-effect reasoning. Secondary disabilities, or by-products of the primary disabilities, can include behavioral problems, poor self-esteem, addiction disorders, homelessness, unemployability, etc.

National prevalence rates for Fetal Alcohol Syndrome (FAS) range from 0.2 to 1.5 per 1,000 live births; prevalence rates for FASD were reported to occur approximately three times as often (Centers for Disease Control, 2004).

According to a 2007 report in the *Journal of Psychological Practice*, "FASD is of serious concern to behavioral health practitioners due to high prevalence rates, soaring economic costs, and lifelong implications of the disorder ... It is critical that practitioners working with children and families are aware of FASD and are prepared to screen for the disorder."

### The Range of FASDs

**Fetal Alcohol Syndrome (FAS)** is a congenital medical condition which can include growth deficiency and body deformation, abnormal facial features, central nervous system damage, especially to the brain, and prenatal exposure to alcohol.

→

**Partial Fetal Alcohol Syndrome (PFAS)** is a diagnostic classification for patients who present with most, but not all, of the growth deficiency and/or facial features of FAS, central nervous system damage (structural, neurological and/or functional impairment), and prenatal exposure to alcohol.

**Alcohol Related Neurodevelopmental Disorders (ARND)** is a diagnostic classification, coined by the Institute of Medicine in 1996, for patients who present with central nervous system damage (structural, neurological, and/or functional impairment).

### **FASD 4-Digit Diagnostic Code**

In 1997, the Washington State FAS Diagnostic and Prevention Network developed the FASD 4-Digit Diagnostic Code, which is widely used in the diagnosis of FASD. Besides continuing to diagnose FAS and PFAS, they have added the following terms in lieu of ARND or FAE:

**Static encephalopathy (alcohol exposed).** The term *encephalopathy* refers to any significant abnormal condition of the structure or function of brain tissues. The term *static* means that the abnormality in the brain is unchanging – neither progressing nor regressing. This diagnostic classification is for patients who present with central nervous damage and prenatal alcohol exposure.

**Neurobehavioral Disorder (alcohol exposed).** This is a diagnostic outcome classification for patients who present with central nervous system dysfunction (mild functional impairment with no evidence of structural or neurological abnormalities) and prenatal alcohol exposure.

**Note:** Outcomes such as ARND, Static Encephalopathy (alcohol exposed), and Neurobehavioral Disorder (alcohol exposed) are far more prevalent than FAS or partial FAS.

**Source:** What Are FASD, FAS, Partial FAS and ARND? Fetal Alcohol Syndrome Diagnostic & Prevention Network, University of Washington, Seattle. <http://depts.washington.edu/fasdnpn/htmls/fasd-fas.htm>



# Fetal Alcohol Spectrum Disorders



## FASD *and the* Education System

### Hosted Luncheon

Wed. March 16 • 12-1pm  
Butrovich (2<sup>nd</sup> Floor)

*Rep. Sharon Cissna*  
*Sen. Donny Olson*  
*and Alaska FASD Partnership*

### Panel

- Cindy Anderson, Director, Special Education, Anchorage School District
- Monica Leinberger, FASD Specialist, Lower Kuskokwim School District
- Mary & Terrell Andrews (Bethel)
- Jeanne & Ivory Gerhardt-Cyrus (Kiana)
  - Mindy Cason (Anchorage)

**Legislative  
Health & Caucus**



# FETAL ALCOHOL SPECTRUM DISORDERS: TIPS FOR ELEMENTARY SCHOOL TEACHERS



- John, a 5th grader, constantly returns late from recess.
- Susan, a fourth grader, acts out in the lunch line, screaming and kicking.
- Peter, a second grader, cannot do addition problems on worksheets.

Lazy? Uncooperative? Victims of poor parenting? No. These students may have fetal alcohol spectrum disorders (FASD). Some of the most challenging students in schools today have FASD. Many have no formal diagnosis but their grades and behavior indicate a problem.

## WHAT ARE FETAL ALCOHOL SPECTRUM DISORDERS?

FASD is an umbrella term describing the range of effects that can occur in an individual whose mother drank alcohol during pregnancy. These effects may include physical, behavioral, mental, and/or learning disabilities with possible lifelong implications. Children do not grow out of the disorders.

FASD is not a diagnostic term. It includes conditions such as:

- Fetal alcohol syndrome (FAS)—a pattern of neurologic, behavioral, and cognitive deficits, as well as specific facial features (smooth philtrum, small palpebral fissures, thin upper lip)
- Alcohol-related neurodevelopmental disorder (ARND)—neurologic abnormalities such as problems with memory and motor skills
- Alcohol-related birth defects (ARBD)—defects in the skeletal and major organ systems

Imaging studies have shown structural changes in various regions of the brain. These include thinner or absent corpus callosum, reduced basal ganglia, and smaller cerebellum.<sup>1</sup> These changes contribute to a lack of understanding that manifests behaviorally. For example, persons with FASD may have difficulty with executive function and have trouble with problem solving and planning.

## HOW ARE STUDENTS AFFECTED BY FASD?

Students with FASD may have many learning challenges, such as:

- Visual and auditory processing problems
- Difficulty with reading comprehension
- Memory problems
- Sensitivity to sensory input
- Attention deficits
- Problems with social behaviors
- Problems following multiple directions or rules
- Difficulty with math and abstract reasoning
- Inability to understand cause and effect
- Difficulty organizing tasks and materials

Due to auditory processing problems, these students may not respond to traditional teaching methods, such as lectures. They may act out in frustration because they do not understand what is going on. They may “melt down” due to sensory overload and may fidget a lot. They may struggle in math class.

Most do not learn from punishment because they cannot generalize rules. In addition, many have impulse control problems. Children with FASD typically lack social skills, such as listening, asking for help, waiting their turn, and sharing.



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## HOW CAN WE RECOGNIZE FASD?

FASD may be difficult to spot. In fact, many students with FASD are undiagnosed or misdiagnosed. Most people with FASD do not have facial anomalies. Some have low IQs but many have normal or above-average IQs.

If a student exhibits behavior or learning problems, you might want to suggest psychoeducational testing. These tests can help identify central nervous system dysfunction. The information also can provide a foundation for a diagnosis by a physician trained in FASD. It is important to provide a supportive, nonjudgmental environment. Encourage parents to talk about possible FASD, seek a diagnosis, and share the results with the school.

## HOW CAN WE HELP STUDENTS WITH FASD?

Every child is different, and much of what works with students with FASD may be learned through trial and error. Here are some general tips for working with students with FASD:

1. Use literal terms. Avoid words with double meanings, slang, and idioms (e.g., “school of hard knocks”). Do not use metaphors and similes.
2. Be consistent. Use the same words for key phrases and oral directions.
3. Repeat, repeat, repeat. You may need to reteach information multiple times.
4. Follow a routine. Routines help students with FASD know what to expect and decrease their anxiety.
5. Keep it simple. Students with FASD learn better in a simple environment with few distractions. One-on-one or small groups work best when possible.
6. Be specific. Say exactly what you mean. Give directions step by step. Break large tasks into smaller tasks. Use pictures, charts, or other visual aids. Show the student what to do.

7. Provide structure. Structure helps students with FASD make sense of their world.

8. Supervise. Students with FASD can be naive and gullible and lack social skills. They need constant supervision to develop patterns of appropriate behavior.

In addition, recognizing the underlying reason for challenging behaviors can help in developing strategies. For example:

- John does not process the passage of time. Use daily reminders, such as music, a peer mentor, or a teacher prompt.
- Susan is often overstimulated. Have her stand at the front or back of the lunch line so that she is not stuck between other students. Eating in a quiet room with a small group and an adult would help.
- Peter cannot add numbers in his head. Use manipulatives, such as blocks.

## WHERE CAN I LEARN MORE?

For more information, see:

- “8 Magic Keys: Developing Successful Interventions for Students with FAS,” by Deb Evensen and Jan Lutke, [fascenter.samhsa.gov/gg/fact\\_sheets.cfm](http://fascenter.samhsa.gov/gg/fact_sheets.cfm)
- Resources for Educators, [depts.washington.edu/fadu](http://depts.washington.edu/fadu)
- British Columbia Ministry of Education, [www.bced.gov.bc.ca/specialed/fas](http://www.bced.gov.bc.ca/specialed/fas)

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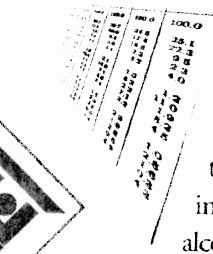
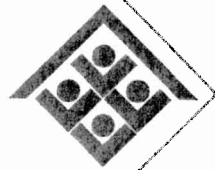
### REMINDER FOR TEACHERS AND PARENTS

**If you're pregnant, don't drink. If you drink, don't get pregnant.**

For more information, visit [fascenter.samhsa.gov](http://fascenter.samhsa.gov) or call 866-STOPFAS.

# FETAL ALCOHOL SPECTRUM DISORDERS BY THE NUMBERS

WHAT YOU NEED TO KNOW



## WHAT IS FASD?

Fetal alcohol spectrum disorders (FASD) is an umbrella term describing the range of effects that can occur in an individual who was prenatally exposed to alcohol. These effects may include physical, mental, behavioral, and/or learning disabilities

with lifelong implications. FASD is not a diagnostic term used by clinicians. It refers to specific conditions such as fetal alcohol syndrome (FAS), alcohol-related neurodevelopmental disorder (ARND), and alcohol-related birth defects (ARBD).

Data on FASD are limited due to lack of diagnostic criteria. Only FAS has diagnostic guidelines. A diagnosis of FAS has three major components: distinctive facial features, growth deficiencies, and brain damage. Associated behavioral or cognitive problems may include mental retardation, learning disabilities, attention deficits, hyperactivity, poor impulse control, and social, language, and memory deficits.

ARND and ARBD describe cases in which individuals were prenatally exposed to alcohol and have some, but not all, the signs of FAS. ARND refers to various neurologic abnormalities, while ARBD describes defects in the skeletal and major organ systems. Individuals with ARND and ARBD do not have the distinctive FAS facial features.

## IS FASD A SIGNIFICANT PROBLEM?

FASD is the leading known cause of mental retardation.

In the United States:

- Prevalence of FAS in the United States is estimated to be between 0.5 and 2 per 1,000 births.<sup>1</sup>
- Prevalence of FAS, ARND, and ARBD combined is at least 10 per 1,000, or 1 percent of all births.<sup>1</sup>
- Based on estimated rates of FASD per live births, FASD affects nearly 40,000 newborns each year.<sup>1</sup>
- The cost to the nation of FAS alone may be up to \$6 billion each year.<sup>2</sup>
- For one individual with FAS, the lifetime cost is at least \$2 million.<sup>2</sup>

## WHO IS AT RISK?

Any woman of childbearing age is at risk of having a child with an FASD if she drinks alcohol. Alcohol can harm a fetus at any time, even before a woman knows she is pregnant. Many women drink early in pregnancy but stop drinking when they learn they are pregnant. Others cannot stop drinking without help. Women who have given birth to children with an FASD and continue to drink are at very high risk of having additional children with an FASD.

### *Drinking Among Women Age 15 to 44*

In the United States:

- 1 in 2 reports any alcohol use in the past month.<sup>3</sup>
- Approximately 1 in 4 reports binge drinking (defined as 5 or more drinks on one occasion).<sup>3</sup>
- About 1 in 20 reports heavy alcohol use (defined as binge drinking on at least 5 days in the last month).<sup>3</sup>

### *Drinking Among Pregnant Women*

In the United States:

- 1 in 30 pregnant women reports high-risk drinking (defined as 7 or more drinks per week, or 5 or more drinks on any one occasion).<sup>4</sup>
- 1 in 9 pregnant women binge drinks in the first trimester.<sup>3</sup>
- 1 in 30 pregnant women drinks at levels shown to increase the risk of FASD.<sup>5</sup>
- More than 1 in 5 pregnant women report alcohol use in the first trimester, 1 in 14 in the second trimester, and 1 in 20 in the third trimester.<sup>3</sup>
- Those who are unmarried and over 30 tend to have the highest rates of alcohol use in pregnancy.<sup>6</sup> However, in 2004, the rate of past month binge drinking among pregnant women age 15 to 17 (8.8%) was more than twice that of pregnant women age 26 to 44 (3.8%).<sup>3</sup>
- Alcohol use varies by race. The chart shows alcohol use among white, African-American, and Hispanic pregnant women.<sup>3</sup> Estimates were not available for other ethnic groups.



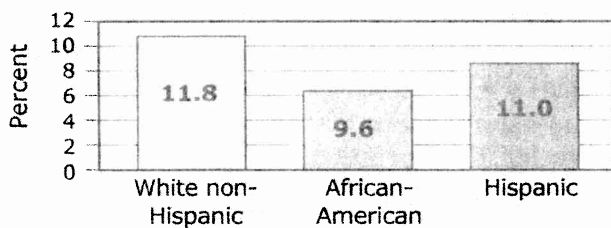
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- The rates of binge drinking and heavy drinking during pregnancy varied little among white and Hispanic women. African-American women had slightly higher rates.<sup>3</sup>
- Among women of childbearing age entering substance abuse treatment, 4% were pregnant. 18% of pregnant women entering treatment disclose that alcohol is their primary substance of abuse.<sup>7</sup>

Past Month Alcohol Use, Pregnant Women



### Research on Risk Factors

A profile of 80 women in Washington State who have given birth to a child with FAS reveals several risk factors:

- 96% had at least one mental health disorder.
- 95% had a history of sexual or physical abuse.
- 61% had less than a high school education and 25 percent had some college education.
- 77% had an unplanned pregnancy, 81% had no birth control, and 92% wanted some form of birth control.
- 59% had an annual gross household income less than \$10,000.<sup>8</sup>

The study also identified factors that had helped pregnant women avoid alcohol. These included mental health treatment and large social support networks.

### WHAT PROBLEMS DO PEOPLE WITH AN FASD FACE?

People with an FASD are vulnerable to a range of difficulties, such as failure in school, substance abuse, mental illness, and involvement in the criminal justice system. A study conducted by the University of Washington shows the percentage of persons age 6 to 51 with an FASD who had difficulties in the following areas:

- 94% had mental health problems.
- 83% of adults experienced dependent living.
- 79% of adults had employment problems.
- 60% of those age 12 and older had trouble with the law.
- 50% experienced inpatient treatment for mental health or substance abuse problems or spent time in prison.
- 45% engaged in inappropriate sexual behavior.
- 43% had disrupted school experiences (e.g., dropped out).
- 24% of adolescents, 46% of adults, and 35% overall had alcohol and drug problems.<sup>9</sup>

### CAN FASD BE PREVENTED?

The most important statistic to remember about FASD is that it is 100% preventable. The only cause of FASD is prenatal exposure to alcohol. If a woman does not drink alcohol during pregnancy, her baby will not have an FASD. Individuals who already have an FASD should receive an accurate diagnosis and appropriate treatment, prevention, and other support services. FASD prevention and treatment strategies present an opportunity to address FASD, raising hope for families everywhere.

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**Stop and think. If you're pregnant, don't drink.**

**For more information, visit [fasdcenter.samhsa.gov](http://fasdcenter.samhsa.gov) or call 866-STOPFAS.**

# THE PHYSICAL EFFECTS OF FETAL ALCOHOL SPECTRUM DISORDERS



*"Alcohol consumed during pregnancy increases the risk of alcohol related birth defects."*

—Surgeon General's Advisory on Alcohol Use in Pregnancy, February 21, 2005

Alcohol is a teratogen, a substance that can harm a fetus. When a pregnant woman drinks alcohol, it passes through her blood and enters the fetus through the placenta. Its harmful effects may be seen in virtually every part of the fetus, including the brain, face, heart, liver, kidneys, eyes, ears, and bones. These effects can affect a person's health for a lifetime.

## WHAT IS FASD?

"Fetal alcohol spectrum disorders" (FASD) is an umbrella term describing the range of effects that can occur in an individual whose mother drank alcohol during pregnancy. These effects may include physical, mental, behavioral, and/or learning disabilities with possible lifelong implications.

The term FASD is not a clinical diagnosis. It refers to conditions such as fetal alcohol syndrome (FAS), alcohol-related neurodevelopmental disorder (ARND), and alcohol-related birth defects (ARBD). In the United States, FASD occurs in about 10 per 1,000 live births, or 40,000 babies per year.<sup>1</sup>

## HOW DOES FASD AFFECT A PERSON'S HEALTH?

The effects of FASD vary widely from person to person. Difficulties in an individual's ability to succeed at home, school, work, and in social situations may arise at different ages.

For many people with an FASD, brain damage is the most serious effect. It may result in cognitive and behavior problems. One obvious sign of brain damage in some babies born with FAS is a small head. We call this condition microcephaly.

Individuals with FAS may have facial anomalies such as small eye openings, a smooth philtrum (groove under the nose), and a thin upper lip. When a person has all three features, together they are a sign of FAS.

Other features, sometimes seen in persons with FAS, include a short nose, a flat mid-face, or a small upper jaw. However, people who do not have FAS can also have these features, so they are not by themselves a sign of FAS.

Due to damage by exposure to alcohol in the womb, babies with an FASD may be born small and underweight. Some have difficulty nursing or eating and their growth continues to lag, resulting in failure to thrive. Some infants with an FASD may also have tremors, seizures, excessive irritability, and sleep problems.

Physical effects of FASD may include heart defects, such as a hole in the wall of the heart that separates its chambers. Other effects are skeletal defects, such as fused bones in the arms, fingers, hands, and toes.

People with an FASD may also have vision and hearing problems, kidney and liver defects, and dental abnormalities. Alcohol can damage the developing fetus from the earliest weeks through the end of the pregnancy.

Other factors associated with women who drink during pregnancy are poor nutrition and lack of prenatal care. These factors may also affect organ and skeletal development. Researchers still have many questions about the impact of prenatal alcohol exposure.

## POSSIBLE PHYSICAL EFFECTS OF FASD

- Brain damage
- Facial anomalies
- Growth deficiencies
- Defects of the heart, kidneys, and liver
- Vision and hearing problems
- Skeletal defects
- Dental abnormalities



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## HOW CAN THE HEALTH EFFECTS OF FASD BE ADDRESSED?

An early diagnosis, appropriate services, and a stable home can greatly improve the health outcomes of individuals with an FASD. It is best to involve a multiple service provider team to develop a treatment plan. The treatment plan must reflect the individual's specific symptoms and problems. Because persons with an FASD tend to have problems following multiple directions, providers should explain their treatment plan in steps or in a format that is easy to follow. The plan should also include frequent followup visits.

It is important that providers share information with a family member or a caregiver who can assist in the person's treatment. When a team of providers is involved, it is important that each of them receive all current and appropriate information about the person.

Medical providers who treat people with an FASD for other medical conditions, such as a heart defect, often treat them the same way as their patients without an FASD. Providers should be sensitive to the cognitive or behavioral differences in people with an FASD. They may need to use clear language, write down the information, and go over it several times so their patients with an FASD can understand their condition.

Persons with an FASD may need many health services. A family of a child with FAS reported using the following health resources in early childhood and elementary school. In all, they used more than 40 providers.<sup>2</sup>

- Pediatricians
- Neurologist
- Pediatric ophthalmologist
- Audiologist
- Otolaryngologist
- Medical supply providers

- Gastroenterologist
- Pharmacy
- Psychiatrist
- Allergist
- Nutritionist
- Feeding specialist
- High-risk infant and followup clinic
- FAS clinic
- Lab and x-ray services
- Surgeons
- Pulmonologist
- Respiratory therapist
- Occupational therapist
- Speech/language therapist
- Sensory integration therapist
- Mental health therapist/family support

In addition, the family used education, social, community, legal, and financial service providers.

## CONCLUSION

The damage caused by prenatal alcohol exposure is permanent. The health effects cannot be reversed, but many of them can be treated with the appropriate combination of interventions and support.

Maintaining an alcohol-free pregnancy is the only way to prevent FASD. By abstaining from alcohol during pregnancy and nursing, a woman can ensure that her baby will be free from alcohol-related defects and have a chance for a healthy life.

## ADDITIONAL RESOURCES

- [www.stopalcoholabuse.gov](http://www.stopalcoholabuse.gov)

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**Stop and think. If you're pregnant, don't drink.**

For more information, visit [fasdcenter.samhsa.gov](http://fasdcenter.samhsa.gov) or call 866-STOPFAS.

[www.stopalcoholabuse.gov](http://www.stopalcoholabuse.gov)



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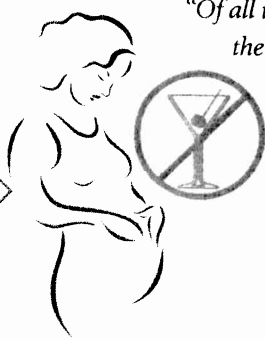


# EFFECTS OF ALCOHOL ON A FETUS

*"Of all the substances of abuse (including cocaine, heroin, and marijuana), alcohol produces by far the most serious neurobehavioral effects in the fetus."*

—Institute of Medicine Report to Congress, 1996<sup>1</sup>

Prenatal exposure to alcohol can damage a fetus at any time, causing problems that persist throughout the individual's life. There is no known safe level of alcohol use in pregnancy.



## WHAT IS THE SCOPE OF THE PROBLEM?

Alcohol is one of the most dangerous teratogens, which are substances that can damage a developing fetus.<sup>1</sup> Every time a pregnant woman has a drink, her unborn child has one, too. Alcohol, like carbon monoxide from cigarettes, passes easily through the placenta from the mother's bloodstream into her baby's blood (See Figure 1)—and puts her fetus at risk of having a fetal alcohol spectrum disorder (FASD). The blood alcohol level (BAC) of the fetus becomes equal to or greater than the blood alcohol level of the mother. Because the fetus cannot break down alcohol the way an adult can, its BAC remains high for a longer period of time.<sup>2</sup>

## WHAT ARE FETAL ALCOHOL SPECTRUM DISORDERS?

"FASD" is an umbrella term describing the range of effects that can occur in an individual whose mother drank alcohol during pregnancy. These effects may include physical, mental, behavioral, and/or learning disabilities with possible lifelong implications. The term FASD is not used as a clinical diagnosis. It refers to conditions such as fetal alcohol syndrome, alcohol-related neurodevelopmental disorder, and alcohol-related birth defects. In the United States, about 130,000 pregnant women each year drink at levels shown to increase the risk of having a child with an FASD.<sup>3</sup> Each year, as many as 40,000 babies are born with an FASD, costing the Nation up to \$6 billion annually in institutional and medical costs.<sup>4</sup>

## HOW DOES ALCOHOL DAMAGE A FETUS?

Defects caused by prenatal exposure to alcohol have been

identified in virtually every part of the body, including the brain, face, eyes, ears, heart, kidneys, and bones. No single mechanism can account for all the problems that alcohol causes. Rather, alcohol sets in motion many processes at different sites in the developing fetus:

- Alcohol can trigger cell death in a number of ways, causing different parts of the fetus to develop abnormally.
- Alcohol can disrupt the way nerve cells develop, travel to form different parts of the brain, and function.
- By constricting the blood vessels, alcohol interferes with blood flow in the placenta, which hinders the delivery of nutrients and oxygen to the fetus.<sup>5</sup>
- Toxic byproducts of alcohol metabolism may become concentrated in the brain and contribute to the development of an FASD.<sup>6</sup>

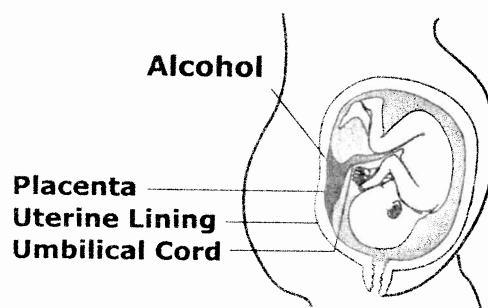


Figure 1: Transmission of alcohol to the fetus

Drinking at any time during pregnancy can harm the fetus. Figure 2 depicts developing parts and systems in the body of a fetus. These body parts and systems represent some of the sites that may be affected by alcohol.



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Drinking alcohol while pregnant can result in cognitive, social, and motor deficiencies and other lifelong problems.

Prenatal exposure to alcohol can cause permanent brain damage. The fetal brain can be harmed at any time, because the brain develops throughout pregnancy. Magnetic resonance imaging (MRI) reveals that some individuals who were prenatally exposed to alcohol have smaller brains. Some parts of the brain may also be damaged or missing, such as the basal ganglia, cerebellum, corpus callosum, and others. Resulting impairments may include, but are not limited to, the following:

- Mental retardation
- Learning disabilities
- Attention deficits
- Hyperactivity
- Problems with impulse control, language, memory, and social skills

Research is under way to learn more about the complex effects of alcohol on a fetus. Increased understanding may lead to improvements in prevention, diagnosis, and treatment of FASD.

Although many questions remain unanswered, this much is clear: **When a pregnant woman uses alcohol, her baby does, too.** That's why abstaining from drinking throughout pregnancy and during breastfeeding is the best gift a mother can give her child—it's a gift that lasts a lifetime.

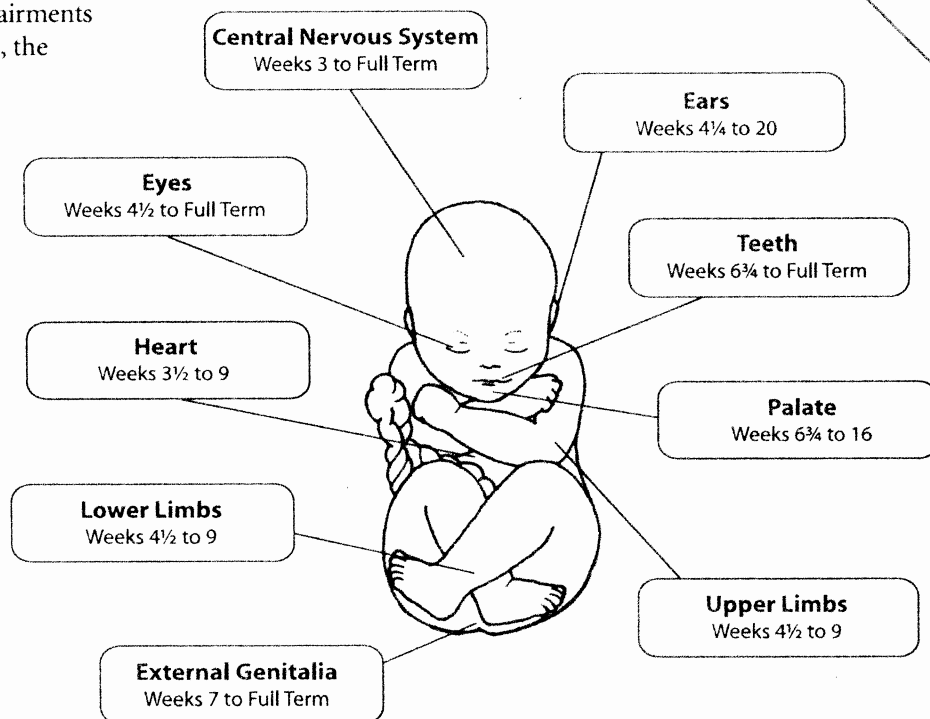


Figure 2: Periods of fetal development<sup>7</sup>

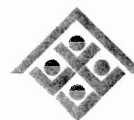
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**Stop and think. If you're pregnant, don't drink.**

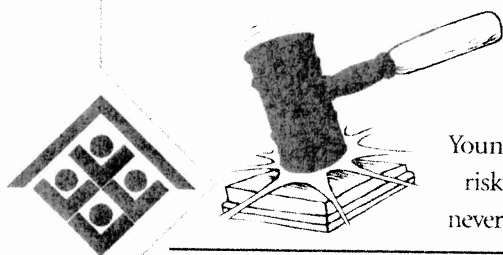
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# FETAL ALCOHOL SPECTRUM DISORDERS AND JUVENILE JUSTICE: HOW PROFESSIONALS CAN MAKE A DIFFERENCE



*[T]here is hope. We can change how lawyers, clients, police, judges, probation officers, prison guards, and family members work with FAS clients.<sup>1</sup>*

—David Boulding, attorney for clients with fetal alcohol spectrum disorders

Young people who are affected by fetal alcohol spectrum disorders (FASD) are at increased risk for involvement with the juvenile justice system.<sup>2,3</sup> Most youth who have an FASD have never received a diagnosis or services, and they reach the system after a long fall through the cracks.

## HOW IS FASD LINKED TO PROBLEMS WITH THE JUVENILE JUSTICE SYSTEM?

Youth with an FASD were born with brain damage that can make it difficult for them to stay out of trouble with the law. They do not know how to deal with police, attorneys, judges, social workers, psychiatrists, corrections and probation officers, and others they may encounter.

Professionals who work with the court system can reach out to young people who may have an FASD to ensure that they receive needed help. Education and training can help professionals identify young people who may have an FASD. This can help them get fair treatment and appropriate services.

## WHAT IS FASD?

“FASD” is an umbrella term describing the range of effects that can occur in an individual whose mother drank alcohol during pregnancy. These effects may include physical, mental, behavioral, and/or learning disabilities with possible lifelong implications.

The term FASD is not used as a clinical diagnosis. It refers to conditions such as fetal alcohol syndrome (FAS), alcohol-related neurodevelopmental disorder (ARND), and alcohol-related birth defects (ARBD). FASD occurs in about 10 per 1,000 live births, or about 40,000 babies per year in the United States.<sup>4</sup>

## WHAT ARE THE CHALLENGES FOR YOUTH WITH AN FASD?

FASD’s effects on the brain can result in cognitive or behavioral deficits. These deficits may include mental retardation, learning disabilities, hyperactivity, attention deficits, and poor social skills. These and other problems associated with FASD may increase the chance that a person will break the law.

Individuals with an FASD typically are impulsive and have trouble foreseeing the consequences of their actions. They

may have a poor sense of personal boundaries. Many are very susceptible to peer pressure and can be easily led. Their judgment is often poor.<sup>2</sup>

FASD also presents challenges throughout the judicial process, from questioning through arrest, hearings, sentencing, and detention. Many youth who have an FASD have poor communication skills, while others may “talk” much better than they can function. They may become confused under pressure. They often cannot understand their rights and may confess or otherwise implicate themselves and others, even if they are not guilty. Youth who have an FASD may believe that if they confess, they will be allowed to go home. They also want people to like them and may provide a false confession in an effort to please the police.

Youth who have an FASD typically have memory problems, which can contribute to forgotten court dates or meetings with probation officers, judges, and attorneys. Their risk for victimization in detention is high, as they may fall prey to other inmates.

It can be difficult for persons with an FASD to learn from their mistakes. Because the judicial process can be lengthy, they may not draw a connection between their actions and the later consequences. Once released from detention, youth who have an FASD may commit similar offenses and cycle through the system again and again.

## HOW CAN THE SYSTEM HELP YOUTH WITH AN FASD?

Youth should be screened for FASD at all entry points into the juvenile justice system. Those who work in the system, especially attorneys and social workers, should look for a history of behavior that suggests an FASD. They also should ask questions about prenatal exposure to alcohol. When they suspect that an FASD is present, they should request a complete



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evaluation by clinicians qualified to diagnose an FASD. The evaluation should include assessments of possible co-occurring psychiatric disorders and adaptive behavior.<sup>5</sup>

Attorneys should be aware of FASD and use their knowledge to advocate effectively for their clients, particularly in proceedings related to:

- Competency—Youth with an FASD may be unable to understand the charges against them and participate in their own defense.
- Diminished capacity—Young people with an FASD may find it difficult to distinguish right from wrong, form intent to commit an offense, and understand consequences.
- Decisions to decline/remand/waive—Youth with an FASD are likely to be safer in a juvenile facility than in an adult prison due to potential victimization.
- Sentencing—In some cases, attorneys may be successful in presenting FASD as a mitigating or exculpatory factor. They also should explore alternative sentencing options.
- Treatment—Court-ordered treatment is sometimes the only way for youth with an FASD to receive appropriate interventions.

Information from evaluations, medical records, family history, and school and employment records should be included in presentencing investigations. The outcome may influence whether or not the youth will be detained, where, for how long, and what support he or she will receive. Appropriate services are essential, including medication or substance abuse treatment (if necessary), vocational training, life skills training, mentoring, and advocacy.

Detention of youth with an FASD may be unproductive. It can increase the risk of recidivism because they may copy the deviant behavior of other juveniles. For probation or aftercare, a highly supervised, structured living arrangement is critical for success. People with an FASD often have difficulty managing their money or tending to household chores. Attorneys should ensure that clients who were receiving developmental disabilities support do not lose their benefits while they are in the system.<sup>6,7</sup>

Throughout the judicial process, communication with young people who have an FASD should be concrete, simple, and repetitive. Youth with an FASD have trouble following multistep instructions and understanding figures of speech. Using frequent reminders, visual cues, and open-ended questions can help them follow rules and understand what is happening.

FASD is not an excuse for breaking the law. However, all youth, including those with an FASD, deserve to be treated fairly by the juvenile justice system. Increased awareness and action at all levels of the system can offer a lifeline to young people with an FASD. In addition, the potential benefits to society, through decreased crime and costs, are tremendous.

## ADDITIONAL RESOURCES

SAMHSA FASD Center for Excellence. 2005. **What You Need To Know: Understanding Fetal Alcohol Spectrum Disorders: Getting a Diagnosis.** Rockville, MD: [fasdcenter.samhsa.gov](http://fasdcenter.samhsa.gov)

Minnesota Organization on Fetal Alcohol Syndrome. **Tools for Success: Working With Youth With Fetal Alcohol Syndrome and Effects in the Juvenile Justice System Resource Guide.** [www.mofas.org](http://www.mofas.org)

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# FETAL ALCOHOL SPECTRUM DISORDERS: WHEN YOUR CHILD FACES THE JUVENILE JUSTICE SYSTEM

*Cherishing children is the mark of a civilized society.*<sup>1</sup>

—Joan Ganz Cooney, Chair, Children's Television Workshop

Youth with fetal alcohol spectrum disorders (FASD) are at high risk of getting into trouble with the law.<sup>2</sup> They face many challenges that make them vulnerable to criminal activity,<sup>3</sup> such as:

- Being easily influenced by peer pressure
- Lacking impulse control
- Not understanding cause and effect
- Not learning from mistakes
- Making poor decisions
- Having memory problems
- Difficulty understanding future consequences



## WHAT ARE FETAL ALCOHOL SPECTRUM DISORDERS?

"FASD" is an umbrella term describing the range of effects that can occur in an individual who was prenatally exposed to alcohol. These effects may include physical, mental, behavioral, and/or learning disabilities with possible lifelong implications. FASD is not a clinical diagnosis. It refers to conditions such as fetal alcohol syndrome (FAS), alcohol-related neurodevelopmental disorder (ARND), and alcohol-related birth defects (ARBD).

## HOW DOES FASD AFFECT MY CHILD'S EXPERIENCE WITH THE JUVENILE SYSTEM?

Youth with an FASD have a high desire to please people in authority. Your child may confess to an offense in order to stay on the good side of police. They may add things they've heard elsewhere. This is why it is important to have an attorney present during questioning, and a family member or professional familiar with FASD.

## WHAT IS COMPETENCY?

Competency refers to a person's ability to understand the charges and to aid in his or her defense. A competency evaluation, by a professional familiar with FASD, may be needed to determine whether the youth with an FASD can face an adjudication hearing. State laws vary, but in most States, children under the age of 12 are usually presumed not to be competent.<sup>4</sup> Competency evaluations should examine maternal drinking and include information such as the youth's:

- Medical and family history
- Home environment

- School records
- History of services received (e.g., therapy)
- Prior involvement in the juvenile system

A diagnosis of an FASD does not mean that your child will not be tried or will not be tried as an adult.<sup>5</sup> However, it may be considered in the judicial decision making process and could result in a lighter sentence, especially if the offense is minor.<sup>6</sup>

A history of problems with the law can provide clues regarding your child's cognitive, social, and adaptive functioning. If your child's offenses are minor and/or involved responses to peer pressure, the court may use a diagnosis of an FASD as a basis for a lighter sentence.

## WHAT HAPPENS WHEN MY CHILD GETS IN TROUBLE WITH THE LAW?

Procedures vary by State. It is best to consult an attorney familiar with the juvenile justice system in your area. Make the attorney aware of your child's FASD and how it affects his or her capacity to participate in the legal process.

In general, procedures in the juvenile justice system include:

- **Police contact.** Kids with an FASD are more likely to be arrested for an offense because they don't know how to respond to the police.
- **Arrest.** A youth can be arrested, brought to a police station, or summoned to appear in court, any of which can be terrifying for someone with an FASD. It helps for a parent to be present to keep the child calm.
- **Police questioning.** If a minor is questioned without parental consent, the information collected might not



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WHAT YOU NEED TO KNOW

be usable as evidence. Teach your child to request an attorney or parent if questioned by the police.

- **Case disposition.** Your child may be ordered to attend hearings. If the court finds your child guilty, he or she will be sentenced. The judge usually gets recommendations from probation officers or defense attorneys before sentencing. In some cases, the accused can agree to plead guilty to a lesser offense. A plea agreement is not binding on the court but may influence the judge. Possible dispositions are community service, restitution, or mediation. These allow the youth to make up for the offense without facing detention.
- **Decisions to decline or retain.** In some cases, the prosecution may try to have your child tried as an adult. This is known as declining the case because the juvenile court declines to handle it. A decision to retain means the case stays in the juvenile system. An FASD diagnosis can be used to argue that your child should remain in juvenile court.<sup>7</sup>
- **Aftercare.** Parents may want to seek an appropriate aftercare program to provide supervision, monitoring, and services when the child returns from a residential or correctional facility.

## WHAT ARE MY CHILD'S RIGHTS?

Your child has the right to:

- Have a lawyer, regardless of ability to pay
- Refuse to talk to police, sign any papers, or share information until he or she has spoken to a lawyer
- Understand the charges
- Plead not guilty and be given a hearing
- Appeal the court's decision on the case
- Offer ideas for consequences if found guilty

Youth with an FASD might not understand their rights or remember what they hear. It is important to talk to the police and to the attorney about what happened during arrest and questioning to make sure the child's rights have not been violated.

## HOW CAN I HELP MY CHILD?

You can advocate for your child by being available at any police questioning and advising your child's attorney about FASD. If your child is sent to a juvenile facility, you can speak with the staff about FASD. You can work with your child's school and the facility to make sure that your child's educational needs are met. You may need to provide a copy of your child's Individual Education Plan.

You might want to have your child carry an information card to give to police. (You can find a sample card at [www.depts.washington.edu/fadu/legalissues/policecard.html](http://www.depts.washington.edu/fadu/legalissues/policecard.html).) The card describes FASD and alerts the police that the child is not waiving any rights and is not capable of waiving any rights.

You can also ensure that your child receives an adaptive functioning evaluation. This can help lawyers and judges figure out the best way to handle your child's case.

The most important thing you can do is to be there for your child and help attorneys, judges, and others in the juvenile justice system understand FASD.

## RESOURCES

SAMHSA FASD Center for Excellence. 2005. **What You Need To Know: Understanding Fetal Alcohol Spectrum Disorders: Getting a Diagnosis.** Rockville, MD: [fasdcenter.samhsa.gov](http://fasdcenter.samhsa.gov)

Minnesota Organization on Fetal Alcohol Syndrome, 2004. **Tools for Success: Working With Youth with Fetal Alcohol Spectrum Disorders in the Juvenile Justice System. A Guide for Parents and Caregivers.**

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# 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).<sup>1</sup> 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

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

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.<sup>2</sup> 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. Streissguth’s report as well as two brief overviews regarding the findings of her study as Attachment A.<sup>3</sup>

A SAMHSA publication, *Fetal Alcohol Spectrum Disorders, The Basics*, includes the following as some of the benefits of identification and treatment of FASD<sup>4</sup>

- 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.<sup>5</sup>

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<sup>2</sup> Dan Dubovsky can be reached at (866) 786-7327.

<sup>3</sup> 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](http://www.cdc.gov/ncbddd/fas/protective.htm). *Secondary Disabilities* from Alaska’s FAS office is located at [www.state.ak.us/fas/info/secondaryDisabilities.htm](http://www.state.ak.us/fas/info/secondaryDisabilities.htm).

<sup>4</sup> We include *Fetal Alcohol Spectrum Disorders, The Basics* as Attachment B.

<sup>5</sup> 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.<sup>6</sup> 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.<sup>7</sup> 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.<sup>8</sup> 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.

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

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<sup>6</sup> *Diagnosing FASD is Tricky*, Minnesota Public Radio, [minnesota.publicradio.org/display/web/2007/09/05/fasd2](http://minnesota.publicradio.org/display/web/2007/09/05/fasd2).

<sup>7</sup> 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.

<sup>8</sup> For information on the CDC's development of strategies program see [www.cdc.gov/ncbddd/fas/intervening](http://www.cdc.gov/ncbddd/fas/intervening).



# LEGISLATIVE RESEARCH REPORT

JUNE 9, 2005



REPORT NUMBER 05.086

## ADDRESSING FETAL ALCOHOL SPECTRUM DISORDERS IN ALASKA

PREPARED FOR REPRESENTATIVE BRUCE WEYHRAUCH

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FACTUAL DATA CONCERNING FASD.....	2
<i>Table 1: The Spectrum of FASD Affects</i> .....	2
Adults with FASD .....	4
THE EDUCATIONAL CAMPAIGN .....	6
Another View .....	7
LEGISLATIVE APPROACHES .....	9
TREATMENT AND EDUCATIONAL OPTIONS.....	11
<i>Table 2: Residential Alcohol Abuse Services for Pregnant Women in Alaska</i> .....	13
Identifying and Treating FASD Children .....	14
CONSIDERATION FOR A PUBLIC EDUCATION CAMPAIGN IN ALASKA.....	16

You asked for information about Fetal Alcohol Spectrum Disorders (FASD) in Alaska. You listed ten questions of specific interest, which we address in the following areas:

- ♦ **Factual data concerning FASD**, including Alaska's ranking and the causes, costs, and impact of FASD on children, their families, and society;
- ♦ **Legislative approaches to eliminating FASD**, including ways to deter women from intentionally consuming alcohol when pregnant and disincentives for vendors to sell alcohol to pregnant women; and

- ♦ **Treatment and educational solutions**, including approaches that have worked in the past based on state and national studies, ideas for treating FASD children, and an educational campaign for the public.

## FACTUAL DATA CONCERNING FASD

Alcohol is an especially powerful teratogen (an agent which causes malformations of the embryo or fetus) that can cause a number of problems known collectively as fetal alcohol spectrum disorders (FASD). This umbrella term is not a clinical diagnosis but refers to a number of conditions such as Fetal Alcohol Syndrome (FAS—the most severe form of FASD), Fetal Alcohol Effect (FAE), alcohol-related neurodevelopmental disorder (ARND), and alcohol-related birth defects (ARBD). Each individual with FASD may have some or all of a wide spectrum of disabilities. In addition, each individual may have these disabilities across a spectrum of severity.<sup>1</sup> Table 1 shows the range of affects as outlined by the California Fetal Alcohol Spectrum Organization.

**Table1: The Spectrum of FASD Affects**

Physical	Mental	Behavioral
Mouth, Teeth, and Facial Defects Cerebral Palsy, Muscular Defects Visual and Eye Defects Hearing and Ear Defects Epilepsy Liver Damage Kidney Damage Heart Defects Weak Immune System Height and Weight Deficiencies Hormonal Disorders Skeletal Defects Genital Defects	Intellectual Disability Mental Retardation Speech & Language Disorders Learning Disorders Attention Disorders Sensory Disorders Mood Disorders Behavioral Disorders Autism Spectrum Disorders Sleep Disorders Memory Disorders	Chronic Unemployment Unplanned Pregnancies Addictions School Expulsions Promiscuity Loneliness Sexual Deviancy Poverty Criminality Homelessness Depression Suicide
<p><b>NOTES:</b> A given individual with FASD can have any combination of problems, across a spectrum of severity.</p> <p><b>SOURCE:</b> "What's FASD Anyway?," California Fetal Alcohol Spectrum Organization, 2003; available at <a href="http://www.calfas.org/whatsfasd.htm">www.calfas.org/whatsfasd.htm</a>.</p>		

Fetal Alcohol Spectrum Disorders are permanent, lifelong conditions that often exact higher costs as the victim ages. The 10<sup>th</sup> Special Report to the U.S. Congress on Alcohol and Health estimated the annual cost of FASD in 1998 to be \$2.8 billion nationwide. Currently, the

<sup>1</sup> "What's FASD Anyway?," California Fetal Alcohol Spectrum Organization, 2003; available at [www.calfas.org/whatsfasd.htm](http://www.calfas.org/whatsfasd.htm).

Substance Abuse and Mental Health Administration in the U.S. Department of Health and Human Services, estimates that each year some 40,000 FASD babies are born in this country, at a reported cost to the nation of about \$4 billion.<sup>2</sup> A recent report estimates the lifetime cost for one individual with FASD in 2002 was \$2 million.<sup>3</sup> Much higher costs occur when the person has severe problems, such as profound mental retardation.<sup>4</sup>

Alaska has the highest rate of FASD of any state in the nation. This is perhaps not surprising given the level of alcohol consumption in the state: in 1999, the 70 percent of Alaskans who drink purchased enough alcohol to provide every man, woman, and child with 516 drinks. Alaska is among the top five states for prevalence of binge drinking (five or more drinks on one occasion or 30 or more drinks per month) among women of reproductive age. Results of a study at an Anchorage hospital indicated that 16.2 percent of urine samples obtained from pregnant women in labor were positive for drugs or alcohol.<sup>5</sup>

Between 1995 and 1999, 1.5 births per thousand in Alaska met the case definition for FAS, and 16.3 births per thousand were reported to be affected by prenatal exposure to alcohol. An analysis of Alaska's diagnostic data indicates that for every one person who has FAS, there are eight-nine additional individuals with significant brain damage from prenatal exposure to alcohol.<sup>6</sup> According to the National Institute on Alcohol Abuse and Alcoholism, data suggest that some minority groups suffer more adverse effect from alcohol consumption, abuse, and alcoholism than do other populations.<sup>7</sup> In Alaska, 89 percent of FASD cases are among the Native population.<sup>8</sup>

Once a woman has given birth to one FASD child, the likelihood that each succeeding pregnancy will be affected increases dramatically. After one child in a sibling group has been diagnosed,

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<sup>2</sup> Substance Abuse and Mental Health Administration, U.S. Department of Health and Human Services, SAMHSA Fetal Alcohol Spectrum Disorders, FASD Center for Excellence, last update April 29, 2005; available at [www.fascenter.samhsa.gov/index.cfm](http://www.fascenter.samhsa.gov/index.cfm).

<sup>3</sup> Jan Lutke and Tina Antrobus, recognized authorities on FASD, point out in "Fighting for the Future: FASD and 'the system': adolescents, adults, and their families," that these figures fail to reflect a multiplicity of emotional and financial costs to families and society through every stage of the life of an individual affected with FASD. We include a copy of this document, the proceedings of a forum in Surry, B.C., June 19-20, 2004, as Attachment A. Jan Lutke is the co-chair of the National Advisory Committee on FASD to Health Canada, Government of Canada, (appointed by the Minister of Health), chair of the sub-committee on Quality of Life Issues, founder and former director of the FAS Support Network of B.C. Tina Antrobus, a recognized expert on FASD in the corrections system, is presently involved in a Youth Justice FASD pilot project of The Asante Centre for Fetal Alcohol Syndrome and the Pacific Legal Education Association (PLEA), funded by the Canadian Department of Justice. Ms. Antrobus sits on a number of provincial and national committees and consults for the FASD Consulting Service of the Canadian Centre on Substance Abuse (CCSA). As a parole officer and coordinator of volunteer services with the Correctional Service of Canada (CSC), Ms. Antrobus was responsible for both the case management of federal offenders on conditional release into the community, and for developing practical reintegration-based programs to assist her clients in transitioning back into the community.

<sup>4</sup> "Fetal Alcohol Syndrome, Frequently Asked Questions," National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control, last updated March 16, 2005; available at [www.cdc.gov/ncbddd/FAS/faqs/htm](http://www.cdc.gov/ncbddd/FAS/faqs/htm).

<sup>5</sup> Alaska Department of Education and Early Development, "Fetal Alcohol Spectrum Disorders," last updated May 1, 2005; available at [www.eed.state.ak.us/tls/fasd/](http://www.eed.state.ak.us/tls/fasd/).

<sup>6</sup> Alaska Department of Education and Early Development.

<sup>7</sup> National Institute on Alcohol Abuse and Alcoholism (NIAAA), "Forecast for the Future: Strategic Plan to Address Health Disparities," (National Institutes of Health, U. S. Department of Health and Human Services, February 8, 2001); available at [www.niaaa.nih.gov/about/health.PDF](http://www.niaaa.nih.gov/about/health.PDF). We include a copy of this document as Attachment B.

<sup>8</sup> "Our Choices, Our Future: Analysis of the Status of Alaska Natives Report 2004," Alaska Native Policy Center, July 2004, p. 57; available at [www.firstalaskans.org/library/ANPCa4.pdf](http://www.firstalaskans.org/library/ANPCa4.pdf).

examination of the remaining siblings disclose that rates of FASD range from 17 percent for older siblings to 77 percent for younger siblings. The implications for families are obvious: many will be raising more than one affected individual. A woman who has given birth to one FASD child will be stretched to her limits to provide a stable home for that child, even if she stops drinking. A woman who gives birth to more than one FASD child will have significantly more trouble providing the stability and extra resources her children need; it is more than likely that the children will enter the foster care system.<sup>9</sup>

Although there is no research on children with FASD in foster care, according to Lutke and Antrobus, of the 800 to 1,000 children available for adoption in British Columbia, at least 80 percent have a history of prenatal alcohol exposure. At least 15 percent of the children adopted from Russia and the Eastern Bloc countries have full FAS. Dr. Ron Federrici, an adoption physician, estimates that fully 38 percent of the children he has seen in some orphanages in Russia are FAS.<sup>10</sup>

Children with FASD may develop behavior patterns that increase their risk of becoming involved with the criminal justice system.<sup>11</sup> Whether housed in juvenile facilities or adult prisons, individuals affected by FASD are undoubtedly more apt to experience rough treatment and other abuses that occur in correctional settings.

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## ADULTS WITH FASD

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With early identification and treatment, children with FASD can get services that can help them and their families throughout their childhood. Once the FASD child has become the FASD adult, however, the system offers few supports, and without lifelong supports, the future for an FASD adult is bleak.

One frequently-cited source states that the impacts of FASD on individuals between the ages of 12 and 51 include the following:

- ◆ 95 percent will have mental health problems,
- ◆ 55 percent will be confined in prisons, drug or alcohol treatment centers, or mental institutions,
- ◆ 60 percent will have "disrupted school experience,"
- ◆ 60 percent will have trouble with the law, and
- ◆ 52 percent will exhibit inappropriate sexual behavior.

Additional impacts of FASD on individuals after the age of 21 are cited as follows:

- ◆ 82 percent will be unable to live independently,

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<sup>9</sup> Lutke and Antrobus, p. 15.

<sup>10</sup> Lutke and Antrobus, p. 15.

<sup>11</sup> NIAAA, "Forecast for the Future: Strategic Plan to Address Health Disparities," p. 9.

- ◆ 70 percent will have employment problems, and
- ◆ More than 50 percent of males and 70 percent of females will have alcohol and drug problems<sup>12</sup>

An FASD victim who does not learn from experience and sees no connection between an action and the punishment that follows repeats the behavior and sometimes, out of confusion and frustration, intensifies it.<sup>13</sup> This presents a problem in the criminal justice system where courts, correctional institutions, and probation authorities use a graduated series of punishments to deter maladaptive behaviors. According to a 2003 news report, Canadian judges are finding a growing number of offenders unfit to stand trial because of FASD. In such cases, judges express concern that the individuals do not understand the charges or enough about the process to instruct their attorneys.<sup>14</sup> Given their compromised understanding of consequences, persons with severe forms of FASD may also experience serious problems in the aggressive and often uncertain environment of prison.

Adults with FASD may become parents with FASD. In the absence of long-term support networks, adequate parenting is extremely difficult. Through their inadequate judgment and inability to learn from the consequences of their actions, parents with severe levels of FASD may endanger their children.<sup>15</sup> Research on adults with FASD as parents appears to be limited. One set of researchers list the following among their findings:

- ◆ Only 30 percent were diagnosed before they became parents; another 11 percent were diagnosed around the time they became parents; the remaining 59 percent were not diagnosed until after becoming parents.
- ◆ The state took 36 percent of the children of FASD mothers into custody.
- ◆ Forty-five percent of FASD fathers abandoned their children.
- ◆ Forty percent of the mothers drank during their pregnancies.

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<sup>12</sup> Kathryn Shea and Stephen Winners, Master of Divinity, "Facts about FASD"; available at [www.taconic.net/seminars/fas-a.html](http://www.taconic.net/seminars/fas-a.html).

<sup>13</sup> The frontal lobes (controlling inhibition and impulse) and the corpus callosum (facilitating the passage of information between the two hemispheres of the brain) are the parts of the brain most affected by prenatal exposure to alcohol. These parts allow normal persons to learn from the consequences of their behavior.

<sup>14</sup> "More FAS offenders being found unfit to stand trial," Canadian Broadcasting Corporation (cbc.ca) Saskatchewan, December 1, 2003; available online at <http://sask.cbc.ca/regional/servlet/View?filename=fas031201>.

<sup>15</sup> Beyond the help that many be available from the family, society provides no supports for FASD parents. Most FASD adults raised by their birth family are depending on individuals who were dysfunctional to begin with. FASD adults who were adopted may still have family to back them up, but because FASD gets more difficult for the family to deal with instead of less, many families experience "burn out." Without strong support, many FASD parents lose custody of their children to child protective services. In order to prevent the permanent loss of grandchildren, families may be able to step in and commit to raising one or more grandchildren. At some point, however, families may no longer have the physical, financial, or emotional wherewithal for the task.

- ♦ Seventeen percent of their children were diagnosed with FASD, and an additional 13 percent were suspected of being FASD.<sup>16</sup>

## THE EDUCATIONAL CAMPAIGN

According to a U. S. Surgeon General advisory on alcohol use in pregnancy issued in February of 2005, fetal alcohol syndrome was first recognized in 1973. That led to public education and awareness initiatives advising women to limit the amount of alcohol consumed during pregnancy. Despite all efforts to inform the public, however, significant numbers of expectant women continue to drink. The Surgeon General, therefore, notes as follows:

Based on the current, best science available we now know the following:

- ♦ Alcohol consumed during pregnancy increases the risk of alcohol related birth defects, including growth deficiencies, facial abnormalities, central nervous system impairment, behavioral disorders, and intellectual development.
- ♦ No amount of alcohol consumption can be considered safe during pregnancy.
- ♦ Alcohol can damage a fetus at any stage of pregnancy. Damage can occur in the earliest weeks of pregnancy, even before a woman knows that she is pregnant.
- ♦ The cognitive deficits and behavioral problems resulting from prenatal alcohol exposure are lifelong.
- ♦ Alcohol-related birth defects are completely preventable.

For these reasons [the Surgeon General advises as follows]:

- 1) A pregnant woman should not drink alcohol during pregnancy.
- 2) A pregnant woman who has already consumed alcohol during her pregnancy should stop in order to minimize further risk.
- 3) A woman who is considering becoming pregnant should abstain from alcohol.
- 4) Recognizing that nearly half of all births in the United States are unplanned, women of child-bearing age should consult their physician and take steps to reduce the possibility of prenatal alcohol exposure.

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<sup>16</sup> Lutke and Antrobus, pp. 22-23. The experience of families, both birth and adopted, are similar and overwhelming. According to Jan Lutke and Tina Antrobus, there is no question that for the birth or adoptive family of an adult severely affected by FASD, resources will eventually be depleted. When the family can no longer meet these needs, one system after another fails (p. 26-27).



- 5) Health professionals should inquire routinely about alcohol consumption by women of childbearing age, inform them of the risks of alcohol consumption during pregnancy, and advise them not to drink alcoholic beverages during pregnancy.<sup>17</sup>

The Surgeon General is joined by many experts in proposing that any woman of child-bearing age who could become pregnant should refrain from drinking alcohol. Since so many pregnancies are unplanned and it is during the third week of gestation (before many women know they are pregnant) that the facial features associated with FAS develop, these experts advise that women who are not practicing birth control do not drink.<sup>18</sup>

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#### ANOTHER VIEW

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While it appears that FASD authorities agree on most aspects of the situation, there is some dissent around the final tenet underpinning the current public education campaign—the assertion that no amount of alcohol consumption can be considered safe during pregnancy. Professor David J. Hanson, Ph.D., Sociology Department, State University of New York, reports the following:

- ◆ A 1996 review of research studies found that Fetal Alcohol Syndrome only occurs among alcoholics.
- ◆ The Royal College of Obstetricians and Gynecologists in 1997 conducted a large study, including 400,000 American women, all of whom consumed alcohol during pregnancy. Not a single case of Fetal Alcohol Syndrome occurred.
- ◆ A 1992 study of eight European countries found that consuming no more than one drink a day did not appear to have any effect on fetal growth.
- ◆ Studies conducted in 1992, 1994, and 1995 found that negative effects appear to be related to higher levels of consumption per occasion and, hence, to higher blood alcohol content levels. As such, researchers warned against consuming more than a single drink in any given day while pregnant.
- ◆ In 1987, the American College of Obstetricians and Surgeons concluded, "there is no evidence that an occasional drink is harmful."<sup>19</sup>

Such findings are not in conflict with National Institute on Alcohol Abuse and Alcoholism findings that some minority groups suffer far more alcohol-related consequences than others.

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<sup>17</sup> U.S. Surgeon General, U.S. Department of Health and Human Services, "U.S. Surgeon General Releases Advisory on Alcohol Use in Pregnancy," News Release, February 21, 2005. We include a copy of this document as Attachment C.

<sup>18</sup> "Working Group on Prevention of Risk Drinking During Pregnancy," National Institute on Alcohol Abuse and Alcoholism/National Institutes of Health (NIAAA/NIH) Conference Workgroup Report, April 23-24, 1998; available at [www.niaaa.nih.gov/FAS/report/introduction.htm](http://www.niaaa.nih.gov/FAS/report/introduction.htm).

<sup>19</sup> David J. Hanson, Ph.D., Professor Emeritus of Sociology, State University of New York, "Fetal Alcohol Syndrome," copyright 1997–2002; available at [www2.potsdam.edu/alcohol-info/FAS/FAS.html](http://www2.potsdam.edu/alcohol-info/FAS/FAS.html).

... on the basis of data from the Centers for Disease Control and Prevention, FAS incidence appears to be six times higher among African Americans than whites, whereas some American Indian communities have a 33 times greater incidence of FAS than the general population. The incidence of alcohol-related neurodevelopmental disorders (ARND) in children exposed to alcohol during prenatal development is several times higher than this.<sup>20</sup>

Based on these and other similar findings, Professor Hanson concludes that public discussions of FASD generally overshoot the target. He speculates that if it were true that FASD could result from the consumption of a single drink, "the majority of the populations of dozens of countries around the world would suffer the effects of FAS."

Professor Hanson emphasizes the following point:

... alcohol consumption might have very subtle or undetectable undesirable effects on children. Therefore, until more is known for certain, pregnant women might well be advised to choose the safest option, that of abstaining during pregnancy.

Nevertheless, he contends that the current policy approach overstates the risk and needlessly frightens those women who are not high-risk and who drink in moderation.<sup>21</sup> The current approach, he argues, leads to subjecting women to increasing controls, compulsory treatment, and even commitment. He stresses the need to present the most accurate information about who is at risk. Most compellingly, he notes that because FASD babies are frequently born to older mothers who abuse alcohol severely and who already have one or two normal children, a campaign claiming that *any amount* of alcohol is a danger contradicts the life experience of the at-risk mother. As such, those women most at risk may be virtually immune to warnings and public advisories such as that produced by the Surgeon General. Furthermore, such claims are just as likely to be dismissed during the subsequent generation by such a woman's normal children. Accurate statements, on the other hand, would agree with women's own life experience. Professor Hanson believes that it is time to "abandon scare tactics for real solutions."

Elizabeth Armstrong, Department of Health Management and Policy, University of Michigan, who has been working and publishing in the FASD field since 1998, and Ernest Abel, departments of Obstetrics and Gynecology and Psychology, Wayne State University, who has been working and publishing in the FASD field since 1984, concur that FASD is not an "equal opportunity birth defect." These researchers assert that poverty and smoking are the "inseparable handmaidens" to FASD. They hold that, while there is a considerable risk for women who abuse alcohol regularly and an even greater risk for the mothers of FASD children who continue to drink, social and moderate drinking does not present a risk factor for FASD.<sup>22</sup>

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<sup>20</sup> NIAAA, "Forecast for the Future: Strategic Plan to Address Health Disparities," p. 8.

<sup>21</sup> Professor Hanson cites instances of pregnant women fearing they would give birth to FASD children because they had inadvertently eaten salad dressing containing wine vinegar (which contains no alcohol), and many health practitioners report women contemplating abortions after consuming small amounts of alcohol before they knew they were pregnant.

<sup>22</sup> Elizabeth M. Armstrong and Ernest L. Abel, "Fetal Alcohol Syndrome: The Origins of a Moral Panic," *Alcohol and Alcoholism*, Volume 35, Number 3, 2000, pp. 276-282; available at <http://alcalc.oupjournals.org/cgi/content/full/35/3/276>. We include this document as Attachment D.

Louise Floyd, Supervisor of Behavioral Science, Centers for Disease Control and Prevention (CDC), concurs that full blown FAS is the result of chronic heavy drinking by individuals who smoke, eat a poor diet, and live in poverty. Ms. Floyd also agrees that one drink occasionally is unlikely to cause problems. She further acknowledges that the current broad-stroke approach may miss the mark with those most and those least at-risk. Nevertheless, since there is no research identifying a safe level of alcohol consumption during pregnancy, since lesser levels of drinking cause lesser levels of FASD effects, and since other factors such as the woman's general health, her diet, and whether she smokes also have an effect on the outcome, the CDC—like other authorities—recommends that pregnant women not drink at all.<sup>23</sup>

## LEGISLATIVE APPROACHES

Although at least 35 states have enacted legislation concerning substance abuse during pregnancy, only occasionally do these policies apply to alcohol as well as to drugs. The Alan Guttmacher Institute reports that while no state has specifically criminalized drug use during pregnancy, prosecutors have tried to use existing criminal laws to deter prenatal drug use. The Institute further reports that 15 states (Arkansas, Colorado, Florida, Illinois, Indiana, Massachusetts, Minnesota, Nevada, Ohio, Rhode Island, South Carolina, South Dakota, Texas, Virginia, and Wisconsin) consider substance abuse during pregnancy to be child abuse under civil child welfare statutes, and three states (Minnesota, South Dakota, and Wisconsin) consider it grounds for civil commitment.<sup>24</sup> South Dakota law defines drinking during pregnancy as child abuse and provides for up to nine months' confinement for pregnant drug or alcohol users.<sup>25</sup>

According to Michael W. MacLeod-Ball of the Alaska Civil Liberties Union, although the ACLU of South Dakota did not have an executive director or a staff attorney in place in 1998 when the child abuse bill was enacted, the current executive director, Jennifer Ring, is unaware of any legal challenges. She notes, however, that to her knowledge, no one has yet been prosecuted under the law.<sup>26</sup>

According to information provided by policy specialists at NCSL, women have been charged in 22 states with child abuse for substance abuse while pregnant. Courts have rejected the charges or reversed imposed penalties in 21 of the 22 states. In each case, courts, including the Supreme Courts of Florida, Kentucky, Nevada, Ohio, and Wyoming, have held that such prosecutions are unconstitutional or without legal basis or both. The most common ruling has been on "statutory construction" grounds, on the principle that criminal statutes must be strictly construed in favor of the defendants. Words such as "person," "child," and "human being" may not be expanded to include

<sup>23</sup> Louise Floyd, Supervisor of Behavioral Science, CDC, telephone conference, May 26, 2005. Ms. Floyd can be reached at (800) 311-3435.

<sup>24</sup> "Substance Abuse during Pregnancy," State Policies in Brief, The Alan Guttmacher Institute, April 1, 2005; available online at [www.guttmacher.org/statecenter/spibs/spib\\_SADP.pdf](http://www.guttmacher.org/statecenter/spibs/spib_SADP.pdf).

<sup>25</sup> Jody Ruskamp, National Conference of State Legislatures Health Program Policy Specialist, response to individual request for information, April 26, 2005. Ms. Ruskamp can be reached at [jody.Ruskamp@ncsl.org](mailto:jody.Ruskamp@ncsl.org) or (303) 364-7700 ext. 1521.

<sup>26</sup> Michael W. MacLeod, Executive Director Alaska Civil Liberties Union, June 1, 2005, personal communication. Mr. MacLeod can be reached by e-mail at [mwm@akclu.org](mailto:mwm@akclu.org) and by phone at (907) 258-0044. We include copies of the two South Dakota bills as passed as Attachment E.

fetuses, courts have held. They have also held that drugs must be transferred between two persons already born in order for drug trafficking laws to apply.

According to civil libertarians, involuntary commitment for pregnant women who purchase alcohol would be a particularly thorny issue. To date, no state has passed such legislation.<sup>27</sup> According to Mr. MacLeod, such an action would be a restriction on the woman's liberty interest, and such a law would have to pass more than the normal rational basis test that applies to most legislative enactments. Additionally, according to Mr. MacLeod, a woman's privacy right would be implicated. Finally, there would appear to be an inappropriate gender-based distinction in barring a woman but not a man from purchasing alcohol. Mr. MacLeod goes on to speculate that a blanket prohibition of the sale of alcohol to pregnant women would not "fly" because it could not be drawn narrowly enough to address the public purpose in question.<sup>28</sup> Jody Ruskamp, health program policy specialist with NCSL, reports that the majority of women prosecuted for prenatal substance abuse have been low-income members of minority groups. Should Alaska repeat this pattern, the constitutional concerns of racial bias could also arise.

According to women's rights proponents, the usual way of looking at preventing prenatal alcohol exposure is to pit the privacy and other constitutional rights of the mother against the fetal right for protection. In such adversarial situations, the role of the state is punitive, seeking ways to punish the woman for her behavior, while ignoring the responsibilities of the father. Advocates of women's rights point out that any system that pits the fetus against the woman raises fears of an erosion of a woman's right to choose.

Another objection cited by opponents to punitive intervention is that since harm occurs to the fetus primarily during the first trimester, the goal of avoiding future harm would not justify the substantial liberty infringement. This view recognizes that much of the harm occurs before the woman may know that she is pregnant.<sup>29</sup>

According to NCSL, at least 15 states address alcohol vendor responsibility for selling and serving alcohol to pregnant women by requiring signs warning of the dangers of drinking alcohol during pregnancy to be posted on the premises. The wording and placement of the signs varies from state to state. Georgia, New Jersey, Tennessee, Washington, and West Virginia require that the sign specify Fetal Alcohol Syndrome be named. Missouri requires the sign to be eleven inches by fourteen inches and displayed in a conspicuous place. Nebraska assures uniformity of content and size by supplying the signs to all retail licensees. New Jersey requires that the sign be posted on the wall and the towel dispenser in the women's restroom, that it mention Fetal Alcohol Syndrome by name, and identify FAS as "one of the leading causes of mental retardation." Washington requires that the sign mention possible outcomes of alcohol consumption shortly before conception or during pregnancy. The NCSL staff found no state laws requiring that vendors be responsible for refusing to serve alcohol to pregnant women.<sup>30</sup>

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<sup>27</sup> Jody Ruskamp, NCSL.

<sup>28</sup> Michael W. MacLeod, April 5, 2005, personal communication.

<sup>29</sup> Peter D. Jacobson, Gail L. Zellman, C. Christine Fair, "Reciprocal Obligations: Managing Policy Responses to Prenatal Substance Exposure," *The Millbank Quarterly*, Volume 81, Number 3, 2003, p. 490.

<sup>30</sup> Shira Gitomer, National Conference of State Legislatures' Health Program, individual correspondence regarding requested research. Ms. Gitomer can be reached at (303) 856-1482.

According to Elizabeth M. Armstrong and Ernest L. Abel, authors of "Fetal Alcohol Syndrome: Origins of a Moral Panic," public education efforts to reduce FASD, such as warning labels on alcoholic beverages and signs posted in places that sell alcohol, have no noticeable effect on reducing drinking during pregnancy. In fact, they claim, more women drink while pregnant currently than did before the appearance of such labels and signs.<sup>31</sup>

In addition to posting signs, in Alaska, vendors may not sell to minors nor to customers who are already dangerously inebriated. AS § 04.21.055 allows for refusal of service, as follows:

A licensee, an agent, or an employee may refuse to sell, give, or serve alcoholic beverages to a person if the licensee, agent, or employee reasonably believes that the consumption of alcohol by that person may result in serious harm.

According to case law, there is a general common law duty in Alaska, independent of statute, requiring vendors to conduct themselves with reasonable care and prudence when dispensing alcohol.<sup>32</sup> Whether the common law duty or AS § 04.21.055 could be expanded to cover selling alcohol to a woman known to be both pregnant and a high-risk drinker, would be a question for the Legislative Legal Services section.

## TREATMENT AND EDUCATIONAL OPTIONS

Treatment and education are approaches to the eradication of FASD that seek to create a successful outcome by convincing a woman to avoid drinking or by providing supports for the woman's efforts to quit drinking. The Center for Substance Abuse Treatment points out that laws that require the reporting of prenatal substance abuse can have an effect opposite to the lawmakers' intentions: such laws often result in women not seeking prenatal or birth-related medical care. As such, the closer the state moves to either committing or incarcerating pregnant women, the more potentially dangerous pregnancy and birth become for women and their children.<sup>33</sup>

According to professionals in substance abuse, women are much more accepting of alcohol abuse treatment, and therefore more successful at it, when the treatment setting is accepting of them. The more the treatment setting has in common with her home, the more accepting it feels. Eighty-nine percent of FASD children in Alaska are Alaska Native, and 58 percent of the Alaska Native population still lives in rural and remote Alaska.<sup>34</sup> Arranging for the care of her children while she is gone may be easier for a mother if she is in her hometown, with an intact extended family to support her, than if she is in a city alone. However, it is difficult for a woman with or without children to leave her village and seek treatment in a larger community. Away from her family, her familiar landscape, and her preferred foods, she is apt to feel adrift and stressed.

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<sup>31</sup> Armstrong and Abel.

<sup>32</sup> *Nazareno v. Urie*, 638 P.2d 671 (Alaska 1981).

<sup>33</sup> NARAL Foundation, "Limitations on the Rights of Pregnant Women," February 21, 2002, p. 6. We include a copy of this document as Attachment F.

<sup>34</sup> "Our Choices, Our Future," p. 5.

Using the facility locator at the website of the Substance Abuse and Mental Health Services Administration (SAMSHA), we identified substance abuse treatment facilities that would be “familiar” to a variety of women from rural Alaska. Because the locator does not specify which facilities treat alcohol abuse and accept pregnant women, we contacted them to ascertain this information. Pregnant women need treatment programs that address childcare, transportation, histories of abuse, and medical needs associated with pregnancy itself.<sup>35</sup> Many facilities do not accept pregnant women, some because their remote location from medical assistance would make doing so dangerous for the women and their children. We were told by a number of facilities during the follow-up contact that, as funding becomes scarcer, facilities which are willing to offer services to pregnant women are also becoming scarcer. Other facilities are outpatient only.

Looking at the conditions listed by the SAMHSA locator, the five which would provide the most supportive environment for change are as follows: both long and short term residential programs, so the length of stay could be modified to individual needs; out patient care, so that follow-up services could be provided; a treatment program created for pregnant women; residential beds for the clients’ children, so she wouldn’t have to make the choice between the children she already has and the one she is carrying; and staff members who speak her native language. We list the treatment facilities with these characteristics in Table 2.

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<sup>35</sup> NARAL Foundation, p. 9.

**Table 2: Residential Alcohol Abuse Services for Pregnant Women in Alaska**

Community	Facilities	Services		
		Residential	Out-Patient	Supplementary
Anchorage	Alaska Women's Resource Center, 610 C Street	Long term	yes	Residential beds for clients' children
	Alaska Women's Resource Center, 611 West 47th Street	Long and short term	yes	
	Booth Memorial Youth and Family Services	Long term		
	Southcentral Foundation Dena A Coy	Long and short term	yes	Residential beds for clients' children
Fairbanks	Ralph Perdue Center	Long and short term	yes	American Sign Language and other services for the hearing-impaired
	Women's and Children's Center for Inner Healing	Long term		Residential beds for clients' children
	Graf Rheeneenhaanjii Substance Abuse Services	Long term		Accepts women 18 years and under
Juneau	Rainforest Recovery Center	Hospital in-patient	yes	ASL and other services for the hearing impaired
Ketchikan	Gateway Center for Human Services Substance Abuse Services Division	Short term	yes	Special women's groups
Kodiak	Safe Harbor (Kodiak Council on Alcoholism Inc.)	Long and short term	yes	American Sign Language, Arabic, Russian
Kotzebue	Maniilaq Recovery Center	Long and short term		Inupiat
<p><b>NOTES:</b> Of 28 substance abuse facilities statewide, 11 treat alcohol abuse and accept pregnant women. Ideally, facilities include long and short term residential treatment, outpatient services for follow-up, beds for the clients' children, and staff who speak the clients' native language.</p> <p><b>SOURCE:</b> All substance abuse facilities as identified by the Substance Abuse &amp; Mental Health Services Administration (SAMHSA), U. S. Department of Health and Human Services website. Follow-up calls eliminated facilities not providing services either for pregnant women or for alcohol abuse.</p>				

Pamela Watts of Rainforest Recovery Center (formerly Juneau Recovery Hospital) reports that since the Child in Need of Aid (CINA) law has mandated a limit on the length of time that children can be in foster care before parental rights are terminated, mothers have been sobering up faster. In this context, she notes that involuntary patients do as well as voluntary. However, the ultimate issue is the severity of the addiction. Pregnancy and motherhood motivate women to change, up to a point. When the addiction gets strong enough, it will often override everything else.<sup>36</sup> A

<sup>36</sup> Pamela Watts, Rainforest Recovery Center, personal communication, April 11, 2005. Ms. Watts can be reached at (907) 586-9508.

compounding factor in convincing women about the dangers of drinking during pregnancy is that FASD babies are more likely to be born to older problem drinkers and have older siblings who are normal. The women's own life experiences tell them that the universal warning against the dangers of drinking any alcohol at all is not true.<sup>37</sup> Furthermore, no treatment has proven to be effective for alcoholics with FASD.<sup>38</sup> As a result, second generation FASD is fast becoming a problem.<sup>39</sup>

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## IDENTIFYING AND TREATING FASD CHILDREN

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The first step in treating children is identifying them. Since the classic FAS facial abnormalities are lacking in most FASD children, and since many have average I.Q.s or even above, identification can be difficult and usually requires a number of experts. Multiple-disciplinary diagnostic teams include a developmental pediatrician, psychologist, speech-language pathologist, occupational therapist, physical therapist, and social worker. Each diagnosis would normally cost around \$4,000. According to Ric Iannolino, the Tlingit & Haida FASD Diagnostic Team coordinator and the only paid staff member in Juneau, because all members of the team are volunteers, the Tlingit & Haida FASD Diagnostic Team provides an "incredible bargain." This team is part of an international effort with Canada and Queensland, Australia.<sup>40</sup> Juneau's Tlingit & Haida FASD Diagnostic Team has been in existence for 18 months, during which they have diagnosed 25 clients. Mr. Iannolino reports that, as is the case for a number of safety net programs these days, their funds are only guaranteed through December 30, 2005, and they have no idea whether they will be funded after that. Current experience, Mr. Iannolino says, is that there is greater need and fewer services available than before.<sup>41</sup>

Once identified, FASD children need teachers, counselors, and other support personnel who are knowledgeable about FASD. In a statewide survey of professionals' knowledge, beliefs, and attitudes regarding FAS conducted by the Alaska Department of Education and Early Development, Office of FAS, only about six percent of the educators polled felt they had the skills and knowledge needed to deal with students with FAS. Forty-six percent felt they did not have the appropriate skills and knowledge, and another 46 percent felt they had only some of the appropriate skills and knowledge needed.<sup>42</sup>

Authorities who work with FASD children agree that early intervention is a critical element, and the earlier the intervention, the better the outcome. Stable, structured, nurturing environments are necessary. Special needs preschool programs that enroll child and parent can provide the

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<sup>37</sup> Working Group on Prevention of Risk Drinking in Pregnancy.

<sup>38</sup> All substance abuse treatment programs require an ability to learn from experience and to generalize knowledge. Since FASD affects the portions of the brain that perform these functions (the corpus callosum and cerebral cortex), the FASD client may seem to understand while in treatment, but is then apt to relapse as soon as alcohol becomes available or as soon as life becomes stressful. Many can stay sober for a given length of time and then relapse "on schedule."

<sup>39</sup> Lutke and Antrobus, pp. 63–64.

<sup>40</sup> All three groups deal with indigenous populations living in isolated environments and having high numbers of FASD children.

<sup>41</sup> Ric Iannolino, Tlingit & Haida FASD Diagnostic Team Coordinator, personal communication. Mr. Iannolino can be reached at (907) 463-7373.

<sup>42</sup> Alaska Department of Education and Early Development, "Fetal Alcohol Spectrum Disorders," last updated May 1, 2005; available at [www.eed.state.ak.us/tls/fasd/](http://www.eed.state.ak.us/tls/fasd/).



most enriched experience. During the early years, it is important to focus on establishing healthy parent/child relationships, motor and language development, and sensory processing. These children have great trouble meeting adult expectations. Parents are often overwhelmed by the sheer size of the problem, and because of the wide spectrum of possible problems and degrees of severity, no one strategy works with all FASD children. Nevertheless, monitoring an FASD child's medical and nutritional needs as well as addressing the caretakers' needs are key to a successful outcome.

Due to significant learning disabilities, many of these children need special education services. Although there are similarities among FASD children, each is unique and must be evaluated individually. Experts recommend having FASD children assessed in the following areas:

- ♦ Speech/language
- ♦ Cognitive functioning
- ♦ Psychiatric functioning
- ♦ Neurological functioning
- ♦ Physical ability

When developing the educational plan based on the child's individual needs, it is important to include the following educational issues:

- ♦ Hyperactivity
- ♦ Impulsivity
- ♦ Distractibility
- ♦ Poor social skills
- ♦ Poor memory
- ♦ Poor ego development
- ♦ Sensory processing dysfunction
- ♦ Sensory defensiveness
- ♦ Scattered cognitive skills
- ♦ High levels of anxiety and arousal
- ♦ Learning disabilities

Experts suggest that the learning environment support the strengths of the individual child and contain no distracting elements. It should consist of a low-key or soft room color, low lighting (non-florescent), comfortable temperature, structure, space for movement activities, visual organization, and a sensory area. Programs need a balance of child/teacher directed activities such as those provided by the High Scope and Montessori curricula, hands-on learning, small class size, flexibility of scheduling, few and normally predictable transitions, realistic expectations,

multi-sensory learning, a focus on sensory and ego development, functional social and life skills and consistent adults with a high tolerance for frustration.

It is important that staff be knowledgeable about FASD. Empathy and a firm and consistent manner are needed. Staff need to be non-controlling with as little ego investment as possible in seeing rapid change. A nurturing personality with a sense of humor is critical in helping these children achieve success.<sup>43</sup>

## CONSIDERATION FOR A PUBLIC EDUCATION CAMPAIGN IN ALASKA

As the Surgeon General has noted, the drinking of alcohol by pregnant women has not diminished over the years of advisory information. Some researchers contend that the current approach is equally doomed as long as such efforts target the wrong women. These authors point to evidence that women who give birth to children with FASD are not a part of the general drinking population, but in fact represent a small percentage of women of child-bearing age, those most disadvantaged by poverty. As such, they conclude that FASD will not be reduced until the focus is appropriately on at-risk women and the things that put them at risk.<sup>44</sup>

According to one FAS organization web site, in order to avoid working with solutions that are “too simple” we need to ask, “Who are the women that drink during pregnancy? [and] What is the context of their lives?” While such women have a wide range of education and come from all ethnic backgrounds, their lives generally share the following:

- ◆ Poverty;
- ◆ A history of drinking from an early age;
- ◆ FASD related conditions of their own;
- ◆ A history of having been seriously abused;
- ◆ Partners who do not want them to quit drinking; and
- ◆ Fewer than four supports in their lives.

The organization’s literature further states that unemployment rates are increasing, and pregnant women drink more when they are unemployed; that changing political and economic factors are reducing services and removing supports; that in view of these factors, policy makers must become creative in finding responsive community based programs and trying new things. The

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<sup>43</sup> Kathryn Shea, C.S.W., and Stephen Winners, Master of Divinity, “Educating Children with FAS/FAE,” available at [www.taconic.net/seminars/fas-c.html](http://www.taconic.net/seminars/fas-c.html).

<sup>44</sup> Elizabeth M. Armstrong and Ernest L. Abel, “Fetal Alcohol Syndrome: The Origins of a Moral Panic,” *Alcohol and Alcoholism*, Volume 35, Number 3, 2000, pp. 276-282; available at <http://alcalc.oupjournals.org/cgi/content/full/35/3/276>.

organization joins a number of other authorities in observing that the current approach to community education for prevention is not working.<sup>45</sup>

These authorities recommend a massive campaign targeting the women most likely to give birth to FASD children, development of an alcohol abuse treatment model that works for FASD adults, and supports for adults with FASD.<sup>46</sup>

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

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<sup>45</sup> "FASD Prevention." Northern Family Health Society Prince George, December 2002; available online at [www.nfhs-pg-org.prevent/](http://www.nfhs-pg-org.prevent/).

<sup>46</sup> In 2001, the National Institute on Alcohol Abuse and Alcoholism (NIAAA), with co-funding from the National Institutes of Health, provided a special research grant to the University of Alaska to develop "pathways to Alaska Native sobriety." The NIAAA, likewise, noted as follows: "There is a serious need to increase the awareness of minority populations and professionals about the effects of alcohol abuse and to integrate this knowledge into the curricula and research agendas of all institutions, particularly those primarily serving minority communities." NIAAA, "Forecast for the Future: Strategic Plan to Address Health Disparities," p. 3 and 15.

