# SCR

# 12

# ALASKA STATE LEGISLATURE

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**Session:**
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SENATOR KEVIN MEYER
SENATE DISTRICT O

## SPONSOR STATEMENT FOR SCR 12

*"Proclaiming September 9, 2010, as Fetal Alcohol Spectrum Disorders Awareness Day."*

SCR 12 would proclaim September 9, 2010 as Fetal Alcohol Spectrum Disorders Awareness Day (FASD).

Alaska has the highest known incidence of FASD in the United States. This is a condition caused by prenatal exposure to alcohol, which can result in permanent brain damage, birth defects, learning disabilities, behavioral problems and most tragically, the loss of individual potential.

While FASD affects all racial and socioeconomic groups, it is a 100% preventable condition. FASD Awareness Day is observed internationally on September 9th. This serves as a reminder on the ninth day of the ninth month of the year that during the nine months of pregnancy a woman should abstain from alcohol.

SCR 12 would observe FASD Awareness Day by promoting the awareness of the effects of prenatal exposure to alcohol.

## Celeste Hodge

**From:** Laughlin, Wilda J (HSS) [wilda.laughlin@alaska.gov]
**Sent:** Wednesday, February 03, 2010 10:13 AM
**To:** Celeste Hodge
**Subject:** RE: SCR12 - Proclaiming September 9, 2010 as Fetal Alcohol Spectrum Disorders Awareness Day

FISCAL NOTE NOT NEEDED

No note needed. Thanks for checking.
w.

**Wilda J. Laughlin**
**Legislative Liaison, Dept. of Health and Social Services**
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**From:** Celeste Hodge [mailto:Celeste_Hodge@legis.state.ak.us]
**Sent:** Wednesday, February 03, 2010 8:42 AM
**To:** Laughlin, Wilda J (HSS)
**Subject:** RE: SCR12 - Proclaiming September 9, 2010 as Fetal Alcohol Spectrum Disorders Awareness Day

If theirs is none, will I still need a completed fiscal form showing zero dollars? Thanks.

Celeste Graham-Hodge, Legislative Administrator
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**From:** Laughlin, Wilda J (HSS) [mailto:wilda.laughlin@alaska.gov]
**Sent:** Wednesday, February 03, 2010 8:41 AM
**To:** Celeste Hodge
**Subject:** RE: SCR12 - Proclaiming September 9, 2010 as Fetal Alcohol Spectrum Disorders Awareness Day

Hi Celeste—thanks for checking. I don't think there's a fiscal impact, but I'll double check as well.
w.

**Wilda J. Laughlin**
**Legislative Liaison, Dept. of Health and Social Services**
**Phone (907) 465-1613**
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This e-mail, including attachments, is intended for the use of the person or entity to which it is addressed and may contain CONFIDENTIAL or privileged information that is protected by

# TEN THINGS YOU SHOULD KNOW ABOUT FAS

1. Drinking during pregnancy can cause permanent damage to a developing fetus.

2. FAS is one of the most common causes of mental retardation, and is the only cause that is entirely preventable.

3. According to recent State of Alaska DHSS surveillance data, more than 126 children are born at risk for FASD each year in Alaska.

4. Prenatal exposure to alcohol can cause brain damage and other permanent birth defects.

5. Obtaining an FAS diagnosis can improve an individual's ability to function in the world, and may reduce secondary disabilities like depression and school failure.

6. FASD is found in all races and all socio-economic groups – wherever women drink alcohol FASD exists.

7. There is no safe level of alcohol consumption during pregnancy.

8. Women should stop drinking prior to trying to conceive – alcohol can cause damage to a developing fetus even before a woman knows she is pregnant.

9. FASD is 100 percent preventable.

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

From State of Alaska, Office of Fetal Alcohol Syndrome FAQ
http://www.hss.state.ak.us/fas/info/faqs.htm

# Economic Costs of Alcohol and Other Drug Abuse in Alaska, 2005 Update

**Prepared for:**

The Advisory Board on Alcoholism and Drug Abuse
Department of Health & Social Services

**Prepared by:**

McDowell Group

Juneau • Anchorage

December 2005

5480

Alaska, as well as the daily rate information for each facility. There were an estimated 219,400 total nursing home and long-term treatment care bed days in Alaska for all during 2003, while cost per day of care averaged $328 per day, with a range of $213 to $625 per day. The cost of Alaska nursing home care for all illnesses and injuries during 2003 was approximately $71.9 million. Based on estimates published in the NIDA/NIAAA (1998) study, approximately 1 percent of the nation's nursing home care costs can be attributed to alcohol abuse-specific illnesses. The research team applied 1 percent to total nursing home and long term care costs in Alaska during 2003.

### Results

Estimated pharmaceutical costs related to alcohol abuse in Alaska during 2003 were approximately $23.0 million. Alcohol abuse-related nursing home care days totaled 2,194 in Alaska during 2003. Costs from these visits amounted to approximately $719,000.

## Fetal Alcohol Spectrum Disorders

Prenatal exposure to alcohol can cause specific birth defects which may include physical, mental, behavioral, and learning disabilities. Many children with fetal alcohol disorders are not identified until they reach school age or later. Individuals with alcohol-related effects may have difficulties with attention, memory, and problem solving. Heart, liver, and kidney defects are also common, as well as vision and hearing problems.[13] Alcohol-related effects that fall within the broad category of fetal alcohol spectrum disorders (FASD) include:

- fetal alcohol syndrome (FAS),
- partial FAS (PFAS),
- fetal alcohol effects (FAE),
- alcohol-related neurodevelopmental disorder (ARND),
- and other alcohol-related birth defects (ARBD).[14]

During the past ten years, a number of FAS prevalence rates have been established. Studies by the Centers for Disease Control and Prevention indicate a national rate from 0.2 to 1.5 cases per 1,000 births across various populations.[15] Other studies, including those focusing on specific high-risk populations such as Native Americans, other minorities and families living in poverty have indicated rates from 0.5 to 5.0 per 1,000 live births. Clearly, the data is varied and limited.

In establishing a clear number of infants born each year in the United States with Fetal Alcohol Syndrome, the CDC estimates between 1,000 and 6,000 children will be born with FAS each year – a preventable birth defect and disability.

Beginning in 1997, Alaska was one of five states comprising the CDC's Fetal Alcohol Syndrome Surveillance Network (FASSNet), a program established to provide consistent and comparable FAS prevalence rates. Participating states included Arizona, Colorado, New York, Wisconsin and Alaska (however, FAS rates for Wisconsin are not available). At 1.5 per 1,000 live births, Alaska has a significantly higher rate of children born with FAS than other states in the FASSNet program. In

[13] National Organization on Fetal Alcohol Syndrome, *What is FAS/FASD?*, www.nofas.org/faqs.aspx?id=9
[14] US Department of Health and Human Services, SAMHSA Fetal Alcohol Spectrum Disorders Center for Excellence. *The Language of Fetal Alcohol Spectrum Disorders.*
[15] *FAS: Guidelines for Referral and Diagnosis*, CDC, 2004.

addition, Alaska data showed an estimated FAS prevalence rate of 4.8 per 1,000 live births among Alaska Natives. CDC data indicates FAS prevalence rates ranging from 0.3 per 1,000 in Arizona and Colorado to 0.4 in New York.

CDC estimates that other prenatal alcohol-related conditions, such as ARND and ARBD, occur approximately three times as often as FAS.[16] Within the wider category of FASD (which would include individuals with FAS), the US is estimated to have about 10 cases per 1,000 live births.[17]

Alaska's estimated rate of all births impacted by prenatal alcohol exposure is 16.3 cases per 1,000 births, based on the 1995 to 1999 birth years. While these alcohol-related effects are closely associated with FASD, these rates are not directly comparable to national FASD rates of 10 per 1,000 live births due to differences in diagnoses and reporting at the state and national levels. Based on 16.3 cases per 1,000 and the number of live births from 1995 to 1999, approximately 160 infants are born each year in Alaska with FAS and other effects from maternal alcohol use during pregnancy. Of those, approximately 15 are born with Fetal Alcohol Syndrome (FAS).

## FAS vs. FASD

It is important to remember that the information being used to determine the economic costs of care and service delivery to individuals with Fetal Alcohol Syndrome is only a small portion of the overall impact of prenatal exposure to alcohol and the resulting birth defects and disabilities. Beginning in 2000, the State of Alaska began extensive efforts to improve and expand the ability to appropriately diagnose individuals prenatally exposed to alcohol. In 2005, Alaska has a broad and regionally diverse network of diagnostic teams across the state.[18] Data collected from these teams indicate that from July 2000 through March 2005 teams have conducted 755 FASD diagnostic assessments. Of this number, 76 (10.0 percent) were diagnosed with FAS or atypical FAS; 378 (49.9 percent) were diagnosed with Static Encephalopathy; 251 (32.2 percent) were diagnosed with Neurobehavioral Disorder; and 50 (6.6 percent) were found to have no evidence of organic brain damage.

What this data indicates is that the costs associated with all alcohol-related births are much higher than those estimated just for individuals with FAS. And, as noted in the break-through research of Dr. Ann Streissguth in 1996 (Understanding the Occurrence of Secondary Disabilities in Clients with Fetal Alcohol Syndrome [FAS] and Fetal Alcohol Effects [FAE]), individuals with FAE (what is now referred to as FASD) are more likely to develop secondary disabilities and need more services than those with Fetal Alcohol Syndrome and the associated facial dysmorphology. For Alaska and the economic costs associated with all fetal alcohol spectrum disorders, the costs could be as much as 80 percent higher than indicated for FAS alone.

## Economic Cost of Fetal Alcohol Syndrome

The cost of caring for and providing appropriate services to a person with FAS can be significant. These costs may include neonatal care for low birth weight to special speech therapy, behavioral management, or residential care for adults with FAS. Lifetime costs for care for children born in 2003 with FAS are estimated below. However, these costs are excluded from the total health care costs for 2003, as the component of that expenditure in 2003 alone cannot be determined.

[16] CDC, *Tracking Fetal Alcohol Syndrome*, www.cdc.gov/ncbddd/fas/fassurv.htm
[17] National Organization on Fetal Alcohol Syndrome, *What are the Statistics and Facts about FAS and FASD?*, www.nofas.org/faqs.aspx?id=12
[18] For information on available services go to http://health.hss.state.ak.us/fas/teams/default.htm).

## Methodology

To estimate the economic costs from FAS, the research team first determined the number of live births with FAS in Alaska. The Alaska Department of Health and Social Services has closely monitored incidence of FAS in the state since 1998, as part of a U.S. Centers for Disease Control (CDC) monitoring program called the Fetal Alcohol Syndrome Surveillance Network (FASSNet), the ongoing Alaska FAS Surveillance Project and the Alaska Birth Defects Registry. The development of 13 community-based FASD diagnostic teams across Alaska has also assisted in the collection of data related to both FAS and other alcohol-related disabilities included in the FASD umbrella definition.

The Alaska FAS Surveillance Project data collection system is based on reports to the Alaska Birth Defects Registry, and uses medical chart data points to identify children with FAS or other prenatal alcohol-related conditions. DHSS staff consider the surveillance program to be highly rigorous. Alaska clinicians and case workers use a diagnostic process developed by researchers at the University of Washington Fetal Alcohol Syndrome Diagnostic and Prevention Network. Reporting of birth defects to the state registry is mandated by Alaska law. While Alaska's FAS surveillance system is believed to capture the majority of prenatal alcohol-related cases, it is possible that underreporting could make the incidence rate even higher.

For birth years 1995 to 1999, the incidence rate of FAS in Alaska is 1.5 per 1,000 live births.[19] This was the highest rate of the five states that were involved in developing the CDC FASSNet system. (The lowest rate was 0.3 FAS cases per 1,000 births.) However, the incidence of all prenatal alcohol-related conditions, including such conditions as alcohol-related birth defects (ARBD) and alcohol-related neurodevelopmental disorder (ARND), as well as FAS, is 16.3 per 1,000 live births. This incidence rate is assumed to be consistent in birth year 2003.

To estimate FAS costs in Alaska, the research team relied on data published in Health Professions Education Partnership Act of 1998 (Senate Bill 1754). The cost of treating an individual with FAS over his or her lifetime was estimated to be at least $1.4 million in 1995. These costs could include neonatal intensive care, medical and surgical services (not related to neonatal care), special speech therapy, behavioral management, and residential care. Medical and surgical service might include rectifying or monitoring hearing loss or cleft palate surgery. Residential services include special education, home care, speech therapy or institutional care. The 1995 data was adjusted for inflation using the Bureau of Labor Statistics Consumer Price Index for medical care. Additionally, costs of providing care were adjusted by the Alaska differential for cost of living (65 percent in 2003). The resulting total lifetime costs (in 2003 dollars) for providing services to an individual with FAS are estimated at $3.1 million.

The total cost for providing services to an individual with FAS born in Alaska during 2003 was estimated by multiplying the lifetime costs by the number of FAS births during that period.

## Results

Table 18 presents estimated costs for FAS births in Alaska during 2003. During that period, Alaska had about 15 FAS births. Total economic costs resulting from services to all individuals with FAS in Alaska totaled approximately $47.0 million.

[19] *Susan Merrick, FAS Surveillance Project Manager, Alaska Department of Health and Social Services, personal communication, July 2005.*

**Table 18**
**Lifetime Costs of Medical and Residential Services for Children Born with FAS in 2003**

| | Incidence and Costs |
|---|---|
| Alaska births in 2003 | 10,084 |
| FAS incidence per 1,000 live births | 1.5 |
| FAS births | 15 |
| **Lifetime FAS cost** | **$47,037,000** |

Source: Birth data from the Alaska Bureau of Vital Statistics. McDowell Group, based on FAS data from Alaska Department of Health and Social Services; and Health Professions Education Partnership Act of 1998, S. 1754, 108d Congress (1998).

## AIDS and HIV Costs

Intravenous drug abuse among individuals who share unhygienic needles is a significant cause of AIDS and HIV. Although AIDS and HIV no longer require extensive inpatient medical care, both result in high medical expenses worth measuring separately from the hospital and outpatient costs presented above (NIDA/NIAAA, 1998).

### Methodology

The State of Alaska Department of Health and Social Services Epidemiology Section compiles data on HIV and AIDS diagnoses in the state. While the section does not track individuals with HIV and/or AIDS diagnoses, it does compile cumulative counts of the number of diagnoses in the state since the first known HIV diagnosis. Of the known cases of HIV and/or AIDS, 13 percent are associated with intravenous drug use. In addition, the Epidemiology Section tracks known deaths. The section does not track the whereabouts of diagnosed individuals, and as a result no data exists regarding the number of HIV/AIDS patients who may have moved away from Alaska. For the purposes of these estimates the research team assumes that 100 percent of diagnosed individuals remain in the state, though it is recognized that this may not be the case. Additionally, we assume that 100 percent of the known deaths occurred among individuals who had been diagnosed with AIDS, although data is not available on specific cause of death.

Two steps were used to calculate other drug-related AIDS and HIV medical costs. First, AIDS and HIV costs were estimated by applying annual medical expenses from the NIDA/NIAAA (1998) study to the number of known Alaska AIDS and HIV patients in 2003. Cost data was adjusted for inflation and the cost of health care in Alaska using the same sources and methods previously reported. Annual medical expenses for each Alaska HIV patient were estimated at $30,600, while medical expenses for each AIDS patient were $68,200.

The second step was to determine the percent of AIDS and HIV medical expenses that can be attributed to other drug abuse. The Epidemiology Section reported that approximately 13 percent of AIDS and HIV cases were attributed to intravenous drug abuse. This attribution rate was then applied to medical costs for AIDS and HIV patients.

Based on the data from the Alaska Division of Public Health, a total of 597 individuals with HIV or HIV/AIDS lived in Alaska in 2003. Of those, an estimated

Senator Kevin Meyer
Alaska State Capitol
Juneau, AK 99801-1182

February 8, 2010

RE: SCR 12 Fetal Alcohol Spectrum Disorders Awareness Day Proclamation

Dear Senator Meyer,

I am writing this letter in support of Senate Concurrent Resolution No. 12 proclaiming September 9, 2010, as Fetal Alcohol Spectrum Disorders Awareness Day. I was planning to provide testimony by phone, but unfortunately, I am unable to break away from work.

Over the past 22 years as a behavioral health clinician I have witnessed firsthand the devastating consequences of prenatal alcohol and FASD for Alaska's families and communities.

Alaska unfortunately has the highest known rates of FAS/FASD in the United States. As you know, Alaska also ranks high in many other statistics such as domestic violence, sexual assault, and suicide. One of the secondary consequences of prenatal alcohol is that those with an FASD without adequate support often experience significant mental health problems, are at greater risk for suicide, and are frequently exploited and victimized.

Your efforts towards keeping FASD awareness active, and on the forefront of people's minds, will make a difference for Alaska's families and communities. This will happen by communicating the importance of awareness and taking action to prevent future FASD, as well as provide interventions for those who are already impacted.

Thank you for your efforts. If I can answer any questions, or be of help, please let me know.

Respectfully,

Michael Baldwin

5340 Tudor Top Circle
Anchorage, AK 99507
907-250-7736

Advisory Board on Alcoholism and Drug Abuse

abada amhb

Alaska Mental Health Board

**ALASKA MENTAL HEALTH BOARD**
**ADVISORY BOARD ON ALCOHOLISM AND DRUG ABUSE**
431 NORTH FRANKLIN STREET, SUITE 200
JUNEAU, ALASKA 99801
(907) 465-8920

February 8, 2010

Senator Kevin Meyer
Alaska State Capitol
Juneau, Alaska 99801

Re: SCR 12 — FASD Day

Dear Senator Meyer,

The Advisory Board on Alcoholism and Drug Abuse and the Alaska Mental Health Board express their appreciation and support for your resolution declaring September 9, 2010 Fetal Alcohol Spectrum Disorders Day. As you know, fetal alcohol spectrum disorders are 100% preventable. Raising awareness and recognition of this fact will help prevent more Alaskan children from being born affected by prenatal alcohol exposure.

Even more importantly, it will raise awareness of the special, and often very individual, needs of individuals diagnosed with fetal spectrum disorders. Too often the services and supports they need to thrive – at home, at school, and in their communities – are not available. By designating a day to focus on the unique issues of fetal alcohol spectrum disorders and their impact on Alaska, we can not only support Alaskans with FASD but also prevent future Alaskans from experiencing FASD.

Thank you for your continued work on this important issue.

Sincerely,

Debi Keith, Chair
AMHB

James Duncan, Chair
ABADA

# SENATE COMMITTEE REPORT
## First Committee of Referral

DATE: 1/19/10

FURTHER: Rules

**Date of 5-Day Notice:** 2/4/10
(in accordance with Uniform Rule 23)

DATE TURNED IN TO OFFICE: 2/9/10

**Health and Social Services Committee** considered SENATE CONCURRENT RESOLUTION NO. 12

SCR 12 FETAL ALCOHOL SPECTRUM DISORDERS DAY

Proclaiming September 9, 2010, as Fetal Alcohol Spectrum Disorders Awareness Day.

and recommends:

[ ] be **replaced** with [ ] **SCS** or [ ] **CS** _____ (_____)

[ ] adopt **previous** [ ] **SCS** or [ ] **CS** _____ (_____)

[ ] attached amendment(s)

[ ] adopt _____Letter of Intent

[ ] further referral to _____Committee

**SENATE BILL:**
[ ] Same Title
[ ] New Title

**HOUSE BILL:**
[ ] Same Title
[ ] Technical Title Change
[ ] New Title w/ SCR #_____

**NEW FISCAL NOTE(S):**

| Department | Date | Fiscal | Indet | Zero | FN# |
|---|---|---|---|---|---|
| S. HSS | 2/8 | | | ✓ | 1 |
| | | | | | |
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**PREVIOUS FISCAL NOTE(S):**

| Department | Date | Fiscal | Indet | Zero | FN# |
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[ ] **APPROPRIATION - no fiscal note**

| SIGNATURES AND RECOMMENDATIONS: | PRINTED LAST NAME | DO PASS | DO NOT PASS | NO REC | AMEND |
|---|---|---|---|---|---|
| | Thomas | ✓ | | | |
| | ELLIS | ✓ | | | |
| | PASKVAN | X | | | |
| | Dyson | X | | | |
| | | | | | |
| | | | | | |
| CHAIR: | DAVIS | X | | | |

5487

# FISCAL NOTE

**STATE OF ALASKA**
**2010 LEGISLATIVE SESSION**

Fiscal Note Number: 1
Bill Version: SCR 12
(S) Publish Date: 2/10/10

Identifier (file name):
Title: SCR 12 FETAL ALCOHOL SPECTRUM DISORDERS DAY
Sponsor: Senator Meyer
Requester: (S) Health and Social Services Committee

Dept. Affected:
RDU
Component
Component Number

**Expenditures/Revenues** (Thousands of Dollars)

Note: Amounts do not include inflation unless otherwise noted below.

| | Appropriation Required | Information | | | | | |
|---|---|---|---|---|---|---|---|
| **OPERATING EXPENDITURES** | **FY 2011** | **FY 2011** | **FY 2012** | **FY 2013** | **FY 2014** | **FY 2015** | **FY 2016** |
| Personal Services | | | | | | | |
| Travel | | | | | | | |
| Contractual | | | | | | | |
| Supplies | | | | | | | |
| Equipment | | | | | | | |
| Land & Structures | | | | | | | |
| Grants & Claims | | | | | | | |
| Miscellaneous | | | | | | | |
| **TOTAL OPERATING** | **0.0** | **0.0** | **0.0** | **0.0** | **0.0** | **0.0** | **0.0** |
| **CAPITAL EXPENDITURES** | | | | | | | |
| **CHANGE IN REVENUES ( )** | | | | | | | |

**FUND SOURCE** (Thousands of Dollars)

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| 1002 Federal Receipts | | | | | | | |
| 1003 GF Match | | | | | | | |
| 1004 GF | | | | | | | |
| 1005 GF/Program Receipts | | | | | | | |
| 1037 GF/Mental Health | | | | | | | |
| Other Interagency Receipts | | | | | | | |
| **TOTAL** | **0.0** | **0.0** | **0.0** | **0.0** | **0.0** | **0.0** | **0.0** |

**Estimate of any current year (FY2010) cost:**

**POSITIONS**

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| Full-time | | | | | | | |
| Part-time | | | | | | | |
| Temporary | | | | | | | |

**ANALYSIS:** *(Attach a separate page if necessary)*

Prepared by: Celeste Hodge, Committee Aide — Phone 465-4906
Division: Senate Health & Social Services Committee — Date/Time
Approved by: Senator Bettye Davis — Date 2/8/2010
Senate Health & Social Services Committee, Chair

(Revised 11/6/2009 OMB)



5488

# VOICES for FASD

## 2010 LEGISLATIVE PRIORITIES

Governor Parnell has included in his FY11 Mental Health Budget funding for services for children diagnosed with Fetal Alcohol Spectrum Disorder (FASD), treatment for pregnant women and peer navigation. Also, Senator Kevin Meyer has introduced a resolution (SCR 12) proclaiming September 9, 2010 as FASD Awareness Day.

### Support Services for Children with FASD, Treatment for Pregnant Women, Peer Navigation, and FASD Awareness Day

**Increased Access to FASD Treatment Services in Rural Alaska**
$228,600 (in the FY11 Mental Health Budget, HB 302)
This funding will build services in communities with active FASD diagnostic teams so that children diagnosed with FASD can receive appropriate therapies and services as close to home as possible – with priority given to rural communities. Services could include occupational therapy, speech therapy, physical therapy, education supports and specialized mental health services. This funding will: 1) allow for immediate access to services upon diagnosis, avoiding more costly out-of-state Residential Psychiatric Treatment Center (RPTC) care that can be needed when appropriate services are not available; 2) increase the availability of services in the home community; and 3) pay for services that are not reimbursed by Medicaid. This model is similar to the model used to provide individualized services to youth with severe emotional disturbance (SED) in the Bring the Kids Home initiative.

**Substance Abuse Treatment for Pregnant Women**
$500,000 (in the FY11 Mental Health Budget, HB 302)
This funding will increase the number of treatment beds available for residential and/or intensive outpatient substance abuse treatment for pregnant women — followed by aftercare. This increment addresses the limited capacity to serve pregnant women in Alaska. The average wait between assessment and admission is 23.3 days (almost an entire month of the pregnancy). Only 54% of the women who are estimated to have needed substance abuse treatment to prevent harm to their children *in utero* received care in FY08. The intent is to prioritize this funding as follows: 1) expand residential treatment capacity for pregnant women statewide (to alleviate the need to travel to Anchorage/Fairbanks); 2) encourage the expansion of existing family-style treatment models where children can reside at the facility with the mother in treatment; 3) expand intensive outpatient treatment capacity for pregnant women statewide so that when space in a residential or a family-style program is not available, a pregnant woman who needs and seeks treatment can receive it; and 4) expand aftercare resources.

**Peer Navigator Program**
$175,000 (in the FY11 Mental Health Budget, HB 302))
The Parent and Youth Navigator project allows parents and youth to be hired to assist their peers in navigating the service delivery system for youth experiencing serious emotional disturbance (SED). A significant number of these youth experience co-occurring disorders,

such as an FASD, and the mental health service delivery system does not always appropriately respond to the needs of these youth. Navigation services can be key to helping youth and families identify and access appropriate services. Grant funding would also be available for volunteer coordination to develop a volunteer youth advisory group, with grant funding for travel and per diem for volunteer youth and volunteer chaperones. This group would meet to educate various groups about issues from their perspective. Parent/peer navigation and parent and youth input in policymaking is important to ensure that increased in-state capacity is developed to be as responsive to the needs of youth and parents as possible. Grantees will be required to report outcomes such as number of parents involved, results of the interaction, and effectiveness of services.

**SCR 12 Proclaiming September 9, 2010, as Fetal Alcohol Spectrum Disorders Awareness Day**

Senator Kevin Meyer's resolution proclaims September 9, 2010, Fetal Alcohol Spectrum Disorders Awareness Day. Alaska has the highest known incidence of FASDs in the United States. FASDs affect all racial and socioeconomic groups. The disabilities associated with FASDs cause untold emotional stress to individuals and families and cost taxpayers millions of dollars over an affected individual's lifetime. Observing Fetal Alcohol Spectrum Disorders Awareness Day will promote awareness of the effects of prenatal exposure to alcohol and of the fact that there is no known safe level of alcohol consumption during pregnancy. It, will help to prevent FASDs, increase identification of children with FASDs, and improve the lives of those affected by fetal alcohol spectrum disorders.

# VOICES for FASD

## FASD in Alaska Corrections

A 2006 evaluation by the University of Alaska Anchorage (UAA) Behavioral Health & Research Services, reported the following results 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://bhrs.uaa.alaska.edu/pdf/reports/FAS/FAS_KABB_FINAL_Report.pdf

*Sponsored by the Alaska Mental Health Trust Authority, Alaska Mental Health Board and Advisory Board on Alcoholism and Drug Abuse*

# VOICES for FASD

## Alaska FASD Talking Points

- FASDs are a range of disabilities caused when a developing fetus is exposed to alcohol.
- 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), Fetal Alcohol Syndrome (FAS), Partial Fetal Alcohol Syndrome (PFAS), Alcohol-Related Neurodevelopmental Disorder (ARND), Static encephalopathy (alcohol exposed) and Neurobehavioral Disorder (alcohol exposed).
- This lifelong disability can include learning disabilities, problems with memory, heart and kidney problems, impulsiveness, poor judgment, mental retardation and severe emotional disturbance (SED).
- FASD is the most common known cause of cognitive disabilities.
- Alaska has the highest per capita rate of FASD in the United States.
- A person with an FASD without support has at high risk of becoming an alcoholic, suffering from depression, serving time in jail, or becoming homeless.
- FASDs are a leading cause of preventable and permanent birth defects in the United States.
- With early diagnosis, knowledge, and support – our homes, schools and communities can become better equipped to support a person with FASD and minimize or prevent secondary disabilities.

*Sponsored by the Alaska Mental Health Trust Authority, Alaska Mental Health Board and Advisory Board on Alcoholism and Drug Abuse*

# *Anchorage Council on FASD (ACFASD)*

## Fetal Alcohol Spectrum Disorders

- 90% of kids and Adults with Fetal Alcohol Spectrum Disorders (FASD) do not have intellectual disabilities (I.Q. below 70 points), but may still have central nervous system damage that severely affects their ability to live successful, independent lives unless they receive appropriate supports.
- Over 90% of individuals with FASD will also be diagnosed with a mental health disorder during their lifetime.
- Fetal Alcohol Syndrome (FAS) is the diagnosis given only when short height, low weight, small head circumference, certain specific facial features and central nervous system damage all occur.
- It's important to note that the features most people notice about this disorder (the facial characteristics) develop early during the first trimester of pregnancy, possibly even before a woman knows she is pregnant. Severity of the facial differences does not tell us how badly the brain has been affected; only that alcohol exposure happened very early in the prenatal history.
- Prenatal alcohol exposure alters the way the brain of a person with FASD develops, potentially causing a wide range of difficulties in learning and memory, impulse and emotional control. They often have trouble making connections that seem obvious to us.
- People with FASD may appear to understand everything you say, but may not be able to follow through with directions they are given.
- Quite often behavior is what tells us something is different about the way the brain of a person with FASD thinks and understands the world.
- They may not process information very well, especially verbal information.
- Memories and learning skills are intermittent – sometimes available and sometimes not.
- Understanding cause and effect of their actions may be difficult if not be possible.
- They can have difficulty learning from their mistakes - throughout their lifespan.
- Impulse control may not be among their skills.
- They forget, but that also means everyday is a new day and starts with a clean slate.

**PEOPLE DO NOT OUTGROW FASD. THEY WILL LIVE WITH THE CONSEQUENCES OF THEIR PRENATAL EXPOSURE TO ALCOHOL FOR LIFE.**

## THE ROLE OF THE COMMUNITY IN SUPPORTING INDIVIDUALS WITH FASD

- Kids ***and*** adults with FASD need lots of structure in school, day program or job settings.
- Adapt the physical environment to address sensitivities to noise, sound, smells, textures, lighting. These types of changes work for everybody, not just for people with neurological differences.
- Give simple ONE-step directions. Be willing to repeat MULTIPLE times.
- Use the same words when you repeat directions. (i.e. don't replace "coat" with "jacket")
- Think STAGE not AGE – they may be developmentally behind their peers and be more comfortable playing with younger children. (Do NOT mistake this for potentially good babysitters – you wouldn't leave a 7yr old in charge of another 7yr old.)
- As adults they may continue to behave in an immature way. Adapt materials and programs to meet them where they are developmentally.
- Avoid unstructured or free-time.
- They may have poor executive functioning (sequencing) skills – SHOW THEM – and be willing to show anew every day.
- They may have difficulty leading groups or activities. Provide an assistant or let them co-lead.
- They can be eager and enthusiastic – channel that enthusiasm to work for you when others seem bored or indifferent.
- Rewards and corrections should be done immediately after the action occurs – remember the memory issues.
- Each individual has something they are good at – be the detective who discovers each one's unique talent or strength!

For more information or to schedule FASD trainings please contact Cheri Scott at cheris@stonesoupgroup.org or 907-561-3701

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**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), 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.

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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 Clarren, 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

# 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

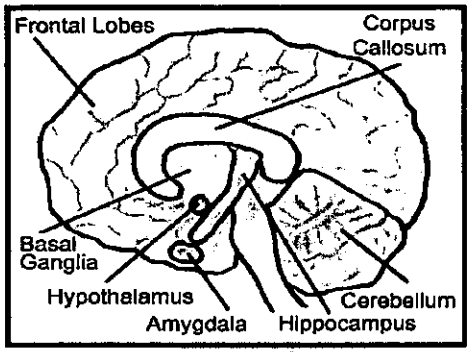
**Amygdala** – central part of emotional circuitry, senses danger, fear and anxiety; plays major role in recognizing faces and facial expressions, social behavior, aggression, and emotional memory; critical for stimulus-reinforcement association learning.

**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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## About the Arctic FASD RTC

In 2008, the Centers for Disease Control and Prevention awarded the *Center for Behavioral Health Research and Services* a three-year grant to develop a Fetal Alcohol Spectrum Disorders Regional Training Center to acquaint a broad range of health and allied healthcare professionals and students with prevention, referral, identification, and treatment of Fetal Alcohol Spectrum Disorders. Four similar centers are operating elsewhere in the country.

## Contact Information

*Arctic FASD RTC* staff can be reached at (907) 561-2880 or via email at
⇒ arcticfasdrtc@uaa.alaska.edu

Please visit our website for more information about FASD, our work in the community, and upcoming trainings and workshops at:

**www.uaa.alaska.edu/arcticfasdrtc**

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*UAA is an AA/EO employer and educational institution.*

**Arctic FASD Regional Training Center**
**Center for Behavioral Health Research & Services**
**University of Alaska Anchorage**
**P.O. Box 241626**
**Anchorage, AK 99524-1626**

UAA UNIVERSITY of ALASKA ANCHORAGE

# Arctic FASD Regional Training Center

**Our mission is to educate health and allied healthcare providers and students about FASD prevention, identification and screening, referral, and treatment**

Funded through the Centers for Disease Control and Prevention. Grant # CDC 1U84DD000439

## What is FASD?

Fetal Alcohol Spectrum Disorders (FASDs) are permanent birth defects caused by the consumption of alcohol during pregnancy.

FASDs affect all areas of an individual's life including:

- problems with memory, motivation, speech language, and attention
- cognitive deficits that affect understanding consequences of behavior, concepts of time, and planning
- damage to the central nervous system and learning disabilities

Some facial characteristics of FASDs include widely spaced eyes, small eye openings, and thin upper lip.

FASDs are not limited to any specific population; they cross all social and cultural boundaries.

FASDs are 100% preventable!

## Objectives

The **Arctic FASD Regional Training Center (RTC)** will:

- train physicians, nurses, psychologists, speech and language therapists, social workers, and other professionals as well as students in these health and allied health-care professions on topics related to FASD prevention and interventions
- help assure that health and allied healthcare providers have basic knowledge about FASD prevention, referral, identification, and treatment as they encounter at-risk groups
- raise awareness of FASDs, develop resources related to FASD education, and disseminate resources to professionals, educators, and members of the public

## Education and Training

The Arctic FASD RTC is in the process of developing an educational curriculum targeting the specific needs of health and allied healthcare professionals who work with pregnant woman or individuals with FASD.

The Arctic FASD RTC educational curriculum is aligned with the Centers for Disease Control and Prevention's (CDC) seven FASD Core Competencies and will be tailored to the specific needs of our region's communities.

## FASD Competencies

The CDC notes seven competency areas necessary for all health and allied health-care professionals. These competencies include:

- historical, biomedical, and clinical background of fetal alcohol syndrome (FAS) and other disorders related to prenatal exposure to alcohol, known collectively as FASDs
- services aimed at preventing alcohol-exposed pregnancies in women of childbearing age through screening and brief interventions for alcohol use
- concepts and models of addiction for women of childbearing age, including those who are pregnant, to provide appropriate prevention services, referral, and case management
- effects of alcohol on the developing embryo and fetus
- screening, diagnosing, and assessing infants, children, adolescents, and adults for FASDs
- long-term case management and coordination for persons with FASDs
- ethical, legal, and policy issues related to FASDs

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## What is FASD?

[illegible] has the highest per capita rate of Fetal [illegible] Spectrum Disorder (FASD) in the [illegible]. This lifelong disability is caused when [illegible] developing fetus is exposed to alcohol.

[illegible] range of lifelong disabilities that [illegible] include learning disabilities, depression, [illegible] with memory, heart and kidney [illegible], impulsiveness, and poor judgment. [illegible] is also the most common known cause [illegible] mental retardation. A person with an FASD [illegible] support has a high risk of becoming [illegible] alcoholic, suffering from depression, [illegible] time in jail, or becoming homeless.

[illegible] early diagnosis, knowledge, support, [illegible] passion and hope - our homes, schools and [illegible] communities can become better equipped to [illegible] support a person with FASD and minimize or [illegible] prevent secondary disabilities.

*Sponsored in part by:*

*[illegible] Council ○ Tlingit Haida Indian Tribes of [illegible] ○ Juneau FASD Diagnostic Clinic ○ Alaska [illegible] of Behavioral Health ○ Northern Light [illegible] Church ○ Advisory Board on Alcoholism [illegible] Drug Abuse ○ Alaska Mental Health Board ○ [illegible] Mental Health Trust Authority ○ Office of [illegible] Children's Services ○ Juneau Youth Services ○ [illegible] Human Services ○ Juneau Catholic [illegible] ○ Catholic Community Service ○ [illegible] Church of the Nativity ○ Resurrection Lutheran [illegible] ○ Glory Hole ○ Arctic FASD Regional Training Center ○ SEARHC*

Alaska Mental Health Board
Advisory Board on Alcoholism and Drug Abuse
431 N. Franklin St. Suite 200
Juneau, Alaska 99801

# Fetal Alcohol Spectrum Disorder (FASD)
# Southeast Alaska Regional Conference

"Embracing the Reality, Celebrating the Passion, and Creating the Hope"

**Dates: February 18-20, 2010**
**Location: Centennial Hall, Juneau, Alaska**

No Registration Fee
Please register by January 29

## FASD Southeast Alaska Regional Conference

## Presenters include:

Dr. Sterling Clarren is the Robert A. Aldrich Professor of Pediatrics and past Head of the Division of Congenital Defects at the University of Washington School of Medicine in Seattle, Washington. He is currently the medical doctor for UAW FAS Diagnostic and Prevention Network clinic and is the Director of Inpatient Services for Children's Hospital and Regional Medical Center.

Carolyn Hartness is a consultant and educator working with FASD issues since 1991. She has served on teams that address FASD issues — including the FASD Diagnostic and Prevention Network at the University of Washington, Northwest Portland Area Indian Health Board's FASD Tribal Project, and FAS Center for Excellence. She has also created successful prevention and intervention models used in correctional facilities.

Kathryn Kelly has been the Project Director for the FASD Legal Issues Resource Center at the University of Washington since 2001. The project provides assistance to judges, attorneys, parents, advocates and others in cases of individuals with FASD in Juvenile and Adult Criminal Court. She is also project director of FASD and King County Drug Court.

Barbara Day Max is the executive director of Agape, an alcohol and drug treatment program in Washington. Agape is currently partnering with the Washington State Division of Alcohol and Substance Abuse and the University of Washington to open the Parent-Child Assistance Program (PCAP) providing extensive case management services in a home visitation model.

Deb Evenson is the executive director of FAS Alaska Consultant and Training Services, and has worked as a master teacher and behavior specialist for over 35 years. She is a pioneer in discovering practical solutions that work with youth and families affected by FASD and co-director of the Alaska Affiliate to the National Organization on Fetal Alcohol Syndrome (NOFAS).

Kee Warner is the founder and Executive Director of Whitecrow Village FASD Society and has been involved with FASD initiatives for over 20 years. She is past chair of Canadian Federation for Invisible Disabilities and has received awards for her work improving the lives of people with FASD. Currently, she is program consultant and clinical supervisor for the British Columbia Ministry of Health Structured for Success program.

Cheri Scott is the Parent Navigator Training Coordinator for the Stone Soup Group in Anchorage. She is the mother of an adopted son with FASD and certified trainer for Parent Navigators and FAS 101.

Judge Mike Jeffrey is the Superior Court judge in Barrow and a strong advocate from the bench for more enlightened and compassionate treatment of people with FASD.

Jennifer Jackson is a parent of an adopted child with FASD, consultant, and author of "Silent No More" a book of poetry that describes living with FASD.

Morgan Fawcett was born with FASD. He is an international speaker, composer and performer on the Native American flute. In his presentations, which include performances on the flute, he speaks authentically about his disabilities.

Arctic FASD Regional Training Center provides education and training on Fetal Alcohol Spectrum Disorders to Alaskan communities and is a major resource in helping Alaskans cope with FASD.

*Additional presenters include: Judge Patricia Collins, Genevieve Casey, Sandy Fiscus, Gil Lucero, Gail Tharpe-Lucero, Vance Sanders, Geri Mata, Charlene "Lena" Takeuchi, Margaret, Vorlyk, Father Thomas Weiss, Teri Tibbett, and the Juneau Diagnostic Clinic Team.*

## Workshops include:

*[illegible] FASD ○ Diagnosis: Cutting Edge ○ Medicine ○ Community Strategies That Work to [illegible] Community Support and Involvement ○ Parent Navigating ○ Early Childhood Development and FASD ○ FASD: Teens and Sexuality ○ Giving a Name to Pain ○ The Successful Advocate: How to Work with the System and How to Have the System Work For You ○ Educate Yourself, Family and Community ○ Traditional Tlingit Healing and Values ○ Healing Circle ○ Strategies in Dealing with a Person with an FASD in a Justice System ○ Supervising Those in the Workplace with an FASD ○ Effective Community Advocacy ○ FASD Prevention ○ 3M Project ○ Design for Success: Creating a More Relaxing and Friendly Space for Living and Working with FASD ○ Why Case Managers: The Key to Better Living Skills and The Hope of Success ○ Homelessness and FASD ○ How an FASD Diagnosis is Made ○ and more*

For more information, please visit:
www.ccthita.org/2010fasdconference.html
For questions about registration, please contact
Donna James at (907) 463-7169.

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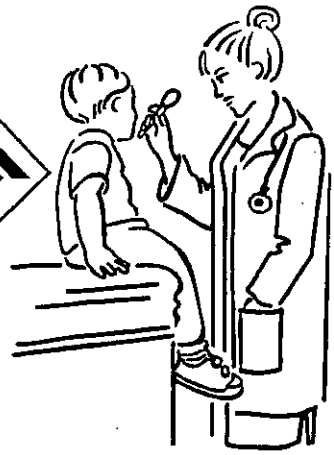
# Understanding Fetal Alcohol Spectrum Disorders
## Getting a Diagnosis



Jean is a recovering alcoholic. Her daughter has been to the hospital 10 times for heart and kidney problems. At 2, she can't walk or talk.

Katie is 5. She has no friends, throws tantrums, and can't read like other kids. Her teacher says she can't sit still or pay attention. Her birth mother drank on the weekends. Her adoptive mother is upset.

Dana is in substance abuse treatment. Her 13-year-old daughter has been suspended from school three times and has no friends. The school psychologist isn't sure what's wrong.

These children have baffling problems. Even a psychologist is stumped. Since the birth mothers drank alcohol, the children might have various types of fetal alcohol spectrum disorders (FASD).

### 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. FASD is not a diagnostic term. It refers to several conditions.

The most well-known diagnosis is fetal alcohol syndrome (FAS). Signs of FAS include distinct facial features (smooth philtrum [groove between nose and upper lip], thin upper lip, small eye openings), growth deficiencies, and central nervous system (CNS) defects. The Institute of Medicine has identified three other diagnoses[1]:

- Partial FAS: facial anomalies and other symptoms without all the signs of FAS
- Alcohol-related neurodevelopmental disorder (ARND): CNS defects and behavior problems or cognitive deficits (e.g., speech delays, hyperactivity)
- Alcohol-related birth defects (ARBD): damage to organs, bones, or muscles

### How Can I Recognize FASD?

Only trained professionals can make a diagnosis. Teachers or relatives may identify a problem, but they cannot diagnose an FASD.

Signs that may indicate the need for assessment include:

- Sleeping, breathing, or feeding problems
- Small head or facial or dental anomalies
- Heart defects or other organ dysfunction
- Deformities of joints, limbs, and fingers
- Slow physical growth before or after birth
- Vision or hearing problems
- Mental retardation or delayed development
- Behavior problems
- Maternal alcohol use

### Why Is Diagnosis Important?

Because most people with FASD have no visible signs of alcohol exposure, their problems may be wrongly blamed on poor parenting or on other disorders. Early diagnosis and intervention contribute to positive long-term outcomes.[2] Accurate diagnosis can:

- Help the person receive appropriate services.
- Aid communication among clinicians, caregivers, educators, and families.
- Provide better self-awareness and understanding by family members.

WHAT YOU NEED TO KNOW

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Substance Abuse and Mental Health Services Administration
Center for Substance Abuse Prevention
www.samhsa.gov

SAMHSA
Fetal Alcohol Spectrum Disorders
Center for Excellence

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## How Is FASD Detected?

An expert trained to assess birth defects and FASD can make a diagnosis. Ideally, a team diagnoses the specific disorder. The team may include:

- Geneticist
- Developmental pediatrician
- Neurologist
- Dysmorphologist (physician specializing in birth defects)
- Education consultants
- Psychologists, psychiatrists, and social workers
- Occupational therapists
- Speech and language specialists

Tests usually include a complete physical (height, weight, vision, hearing, cardiogram, etc.), evaluation of the face, and an IQ test (e.g., WISC, WAIS). Occupational therapy, speech, neurologic, and psychiatric evaluations are used to check for:

- Cognitive deficits, such as memory problems, or developmental delay
- Executive functioning deficits, such as problems following multistep directions
- Motor delays or deficits, such as clumsiness or tremors
- Attention deficits and hyperactivity
- Poor social skills, such as interrupting others and misreading cues
- Behavior problems, such as aggression or not finishing tasks

Examples of specific tests clinicians use include Conners Rating Scales,[3] Vineland Adaptive Behavior Scales,[4] and Children's Memory Scale.[5]

## Where Can I Go for a Diagnosis?

Depending on your community, you might go to a developmental pediatrician, an FASD clinic, a genetics clinic, or another specialist. The National Organization on Fetal Alcohol Syndrome (NOFAS) maintains a Web-based directory of FASD services at www.nofas.org/resource/directory.aspx.

## How Do I Prepare for an Assessment?

It will help to record your child's history and behavior and make copies of any written reports. Bring the documents and photos of your child at various ages. Areas to note include:

- History of prenatal alcohol exposure
- Child's growth pattern
- Physical characteristics, such as atypical facial features
- Medical history, such as illnesses, surgeries, and vision or hearing problems
- Signs of CNS damage or behavior problems, such as memory problems or poor impulse control

## What Do I Do With the Results?

Your child may be eligible for various services. A targeted treatment plan will help improve outcomes. Sharing the assessment results with your child's school can help in identifying appropriate services and teaching strategies. Your child might qualify for an individualized education plan, including services such as speech therapy and counseling.

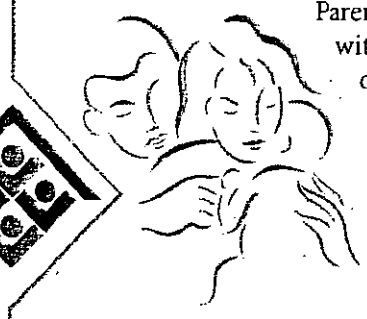
You can also contact the department of social services or developmental disabilities services to ask what support is available. It might also be possible to obtain financial support, such as Supplemental Security Income. Finally, it is important to share the information with your child's pediatrician and other health care providers to help obtain appropriate medical and mental health services.

## References


1. Stratton, K., Howe, C., & Battaglia, F. (Eds.). (1996). *Fetal alcohol syndrome: Diagnosis, epidemiology, prevention, and treatment.* Institute of Medicine, Washington, DC: National Academy Press.
2. Streissguth, A. P., Barr, H. M., Kogan, J., & Bookstein, F. (1996). *Understanding the occurrence of secondary disabilities in clients with fetal alcohol syndrome (FAS) and fetal alcohol effects (FAE).* Final Report. Seattle, WA: Fetal Alcohol and Drug Unit, University of Washington School of Medicine.
3. Conners C.K. *Conners' Rating Scales—Revised.* North Tonawanda, NY: Multi-Health Systems.
4. Sparrows, S.S.; Balla, D.A.; and Cicchetti, D.V. *Vineland Adaptive Behavior Scales.* Circle Pines, MN: AGS Publishing.
5. Cohen, M. *Children's Memory Scale.* San Antonio: Harcourt Assessment.


**If you're pregnant, don't drink. If you drink, don't get pregnant.**
**For more information, visit fascenter.samhsa.gov or call 866-STOPFAS.**

# Adopting and Fostering Children With Fetal Alcohol Spectrum Disorders



Parenting has been called the toughest but most fulfilling job in the world. Parenting children with special needs, such as fetal alcohol spectrum disorders (FASD), brings its own set of challenges.

Many parents of children with an FASD are adoptive or foster parents. Some knew about FASD when they welcomed their children into their family, while others did not. In any case, information is the key to success in raising children with an FASD.

Learning about FASD can help parents understand how their children are affected, which parenting strategies work best, and how to get services and support. For people who want to adopt or foster a child with an FASD, knowing the facts can help them make an informed decision.

## 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 intended for use 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). In the United States, FASD occurs in about 10 per 1,000 live births, or about 40,000 babies per year.[1]

There is little information available about FASD and adoption or foster care. One study of children in foster care in Washington State revealed a rate of FAS 10 to 15 times higher than in the general population, suggesting that children in foster care are more likely to have an FASD.[2] Estimates for international adoptions vary by country. In Russian orphanages, the rate of FAS alone has been estimated at 1 to 10 per 100.[3]

## Meeting the Challenges Associated With FASD

Brain damage and physical defects are the primary disabilities associated with FASD. Lifelong behavioral or cognitive problems may include:

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

These challenges can lead to other problems called secondary disabilities, which may include:

- Disrupted school experience
- Alcohol and substance abuse
- Mental illness
- Dependent living
- Problems with employment
- Inappropriate sexual behavior
- Involvement in the criminal or juvenile justice system
- Confinement (prison or inpatient treatment for mental health or substance abuse problems)[4]

A child with an FASD is likely to need services throughout his or her life and may never be able to live independently. The lifetime cost for one child with FAS can be $2 million.[5]

Despite their challenges, children with an FASD have a number of strengths. For example, they tend to be caring, creative, determined, and eager to please.[6] They also respond well to structure, consistency, concrete communication, and close supervision. With a supportive home, an early diagnosis, and appropriate services, many children with an FASD can avoid secondary disabilities and reach their full potential.[4]

WHAT YOU NEED TO KNOW

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Substance Abuse and Mental Health Services Administration
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www.samhsa.gov

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## Gathering Information

Many children who have an FASD lack an accurate diagnosis and their problems may not be clear. Prospective parents may request a copy of a child's complete medical and family history. However, because records may not tell the whole story, they may also ask specific questions about:

- Possible prenatal exposure to alcohol or drugs
- The physical and mental health of the mother and any siblings
- The developmental history of the child, including possible delays
- Independent evaluations from a physician

Most States require adoption and foster care agencies to share information with prospective parents about the health and social history of the child and birth parents. Some States require more information sharing than others, but few specifically address alcohol.[7] Full investigation and disclosure is best for everyone so that placements are successful, parents are prepared, and children get the help they need.

## Conclusion

Parenting offers many rewards, despite its hurdles. Those who choose to become a parent or caregiver to a child with an FASD experience great joy along with the challenges. The child can benefit from a stable, loving home with parents and caregivers who understand his or her needs. Ultimately, adoptive and foster parents can change the outlook for individuals with an FASD, one day at a time.

**Tips for Adopting or Fostering Children Prenatally Exposed to Alcohol or Other Drugs**

1. Work with informed professionals in quality adoption agencies.
2. Explore your feelings about alcohol and drug abuse, particularly among pregnant women.
3. Discuss the child's background with your social worker so that you have a realistic picture of the birth parents' substance use and related lifestyle.
4. Ask for written summaries of the child's diagnoses, medical complications, treatment services, and necessary followup care.
5. Ask for information on services and resources to meet the child's needs, including eligibility for adoption subsidies and Medicaid.
6. Find out how to reduce the impact of the child's biological risks by providing a nurturing, responsive, and healthy caregiving environment.
7. Recognize that you must be prepared for and able to tolerate the uncertainties that are part of adopting a child prenatally exposed to drugs or alcohol.
8. Resist negative stereotypes of children prenatally exposed to drugs or alcohol, which ignore the individuality of each child and the role of a healthy environment.
9. Recognize the importance of timely identification of problems and early intervention.

Adapted from Edelstein, S. 1995. *Children With Prenatal Alcohol and/or Other Drug Exposure: Weighing the Risks of Adoption.* Washington, DC: CWLA Press.

## References


1. May, P.A., and Gossage, J.P. 2001. Estimating the prevalence of fetal alcohol syndrome: A summary. *Alcohol Research & Health* 25(3):159–167.
2. Astley SJ; Stachowiak J; Clarren SK; Clausen C. Application of the fetal alcohol syndrome facial photographic screening tool in a foster care population. *Journal of Pediatrics* 141(5): 712-717, 2002.
3. Center for Adoption Medicine. University of Washington. 2005. http://www.adoptmed.org/display/ShowJournal?moduleId=171564&categoryId=13631
4. Streissguth, A., and Kanter, J., eds. 1997. The Challenge of Fetal Alcohol Syndrome: Overcoming Secondary Disabilities. Seattle: University of Washington Press.
5. Lupton, C., Burd, L., Harwood R. Cost of fetal alcohol spectrum disorders. *Am J Med Genet* 127C(676): 42-50, 2004.
6. Teaching Students With Fetal Alcohol Syndrome/Effects: A Resource Guide for Teachers. Ministry of Education, Government of British Columbia, 1996. http://www.bced.gov.bc.ca/specialed/fas
7. U.S. Department of Health and Human Services. Administration for Children and Families. National Adoption Information Clearinghouse. 2003 Adoption State Statutes Series Statutes-at-a-Glance: Collection of Family Information About Adopted Persons, Birth Parents, and Adoptive Parents. http://naic.acf.hhs.gov/general/legal/statutes/collection.pdf


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

For more information, visit **fasdcenter.samhsa.gov** or call 866-STOPFAS.

www.stopalcoholabuse.gov


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# Independent Living for People With Fetal Alcohol Spectrum Disorders

In the film "Big," a 13-year-old is stuck in an adult body. He has to get a job, find a home, and pay his own bills. The film is a fantasy, but these tasks can be a scary reality for adults with fetal alcohol spectrum disorders (FASD).

WHAT YOU NEED TO KNOW

## 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.

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). Each year, as many as 40,000 babies are born with an FASD. Hundreds of thousands of adults have these disorders.

Most adults with an FASD look like you or me, but they have cognitive problems that make it hard to live independently. In particular, their social development is stunted and they have poor judgment. Their behavior is unpredictable from one day to the next and can get them into serious trouble.

Many people with an FASD do not understand how impaired they are, which puts them at even greater risk. They have a strong desire to be "normal." Most appear normal to others, raising unreasonable expectations and setting the stage for failure.

FASD may be associated with substance abuse, unemployment, and jail time. With appropriate support, such negative outcomes can be avoided.[1]

## What Is Independent Living?

Independent living refers to the ability to function in a community without support. However, many people hire others to help repair their cars, cut their grass, and fix broken windows. In collaboration with a spouse, friends, and paid service providers, people can run their households more efficiently. Thus, "interdependent living" is a more accurate term than independent living.

## Can People With an FASD Live Independently?

A supportive community is important for everyone, but it is essential for people with an FASD. They need a strong circle of support made up of family members, mentors, social workers, job coaches, and others who understand the realities and limitations of FASD.

Parents or guardians of children with an FASD should start planning early for the transition to adulthood, when eligibility for many services will end.

Most adults with an FASD will need more help than others to meet the more routine demands of work and home. Areas where assistance may be important include employment, money management, housing, and social skills. Many require close supervision to help them make day-to-day decisions and stay safe.

In a 1996 study of adults with an FASD conducted by the University of Washington:

- 50 percent had trouble finding a job.
- 60 percent had trouble keeping a job.
- 18 percent achieved independent living, but most had employment problems.
- About 80 percent had trouble managing money and making decisions.[1]

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The box shows the percentages who require help with other daily tasks.

- Getting social services, 70%
- Getting medical care, 66%
- Having relationships, 56%
- Shopping, 52%
- Cooking meals, 49%
- Staying out of trouble, 47%
- Structuring leisure time, 47%
- Keeping clean, 36%
- Using public transportation, 24%[1]

## How Can People With an FASD Support Themselves?

Appropriate training and assistance can help many people with an FASD find and hold jobs. Job training for persons with an FASD should begin during high school, with the student's education team taking the lead in planning the transition from school to work.

The Federal Rehabilitation Services Administration may be able to help with job placement and support services such as job coaches. States and private organizations, such as the Arc, may also offer assistance.

The key to successful employment for individuals with an FASD is an employer who understands FASD, has reasonable expectations, and can provide a supportive environment. Helpful strategies include:

1. Using concrete language
2. Establishing consistency and routine
3. Providing ongoing training
4. Reviewing job expectations frequently
5. Helping to interpret the wishes and actions of other employees and customers

People with an FASD often find it difficult to access financial benefits. Many States base eligibility for developmental disabilities benefits on IQ. Many people with an FASD have normal IQs and do not qualify. They may be eligible for Social Security Disability Insurance or Supplemental Security Income from the Federal Government if they can meet the strict definition of disability needed to qualify.

Individuals with an FASD typically lack skills managing money. They may receive a paycheck or benefits check and immediately spend it, rather than budgeting for rent and other expenses. Consulting a lawyer about designating a "representative payee" can help. The payee can be a family member, case manager, or other person who receives an individual's checks, pays their expenses, and provides spending money on a daily or weekly basis.

## What About Housing?

Housing for adults with an FASD may be hard to find. Those who meet certain criteria may be eligible for Federal housing programs such as public housing, housing vouchers, Section 811 for persons with disabilities, and rural housing programs. States, localities, and nonprofit organizations also may offer housing, but their eligibility criteria and accessibility vary widely.

Supportive housing that offers help with tasks such as cleaning, grocery shopping, and bill paying would be ideal, but few programs are designed for people with an FASD. Group homes for individuals with mental retardation or mental illness may be an option. However, they can be a poor fit for people with an FASD, who may function at a higher level than their housemates or have different needs. Independent living with services may work for persons who do not need constant supervision.

## Resources

- Rehabilitation Services Administration, www.ed.gov/about/offices/list/osers/rsa/index.html?src=mr
- Job Accommodation Network, U.S. Department of Labor, www.jan.wvu.edu/sbses/vocrehab.htm
- National Council on Independent Living, 703-525-3406, ncil@ncil.org, www.ncil.org
- U.S. Department of Housing and Urban Development, www.hud.gov
- "F.A.S.: When the Children Grow Up," www.knowledgenetwork.ca/know_tool/fas/resources/documentary/index.html

## Reference

1. Streissguth, A., and Kanter, J., eds. 1997. *The Challenge of Fetal Alcohol Syndrome: Overcoming Secondary Disabilities.* Seattle: University of Washington Press.

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

**For more information, visit fascenter.samhsa.gov or call 866-STOPFAS.**