FASD RESOURCES

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Erie County Council for the Prevention of Alcohol and Substance Abuse

Prepared by Glenn Ferguson
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FASD – General Information
Fetal Alcohol Spectrum Disorders
FACT SHEET

What are fetal alcohol spectrum disorders?
Fetal alcohol spectrum disorders (FASDs) is the name given to a group of conditions that a person can have if that person's mother drank alcohol while she was pregnant. These conditions include physical and intellectual disabilities, as well as problems with behavior and learning. Often, a person has a mix of these problems. FASDs are a leading known cause of intellectual disability and birth defects.

What causes FASDs and how can they be prevented?
FASDs are caused by a woman's drinking alcohol while she is pregnant. There is no known amount of alcohol that is safe to drink while pregnant. All drinks that contain alcohol can harm an unborn baby. There is no safe time to drink during pregnancy. Alcohol can harm a baby at any time during pregnancy. So, to prevent FASDs, a woman should not drink alcohol while she is pregnant, or even when she might get pregnant. FASDs are 100% preventable. If a woman doesn’t drink alcohol while she is pregnant, her child will not have an FASD.

What are some signs of FASDs?
Signs of FASDs can be physical or intellectual. That means they can affect the mind or the body, or both. Because FASDs make up a group of disorders, people with FASDs can show a wide range and mix of signs.

Physical signs of FASDs can include abnormal facial features such as narrow eye openings and a smooth philtrum (the ridge between the upper lip and nose), small head size, short stature, and low body weight.

Rarely, problems with the heart, kidneys, bones, or hearing might be present.

Intellectual and behavioral signs of FASDs might include problems with memory, judgment or impulse control, motor skills, academics (especially in math), paying attention, and low IQ. Specific learning disabilities are also possible.

What can I do if I think my child has an FASD?
Talk to your child’s doctor or nurse. If you or the doctor thinks there could be a problem, ask to see a specialist (someone who knows about FASDs) such as a developmental pediatrician, child psychologist, or clinical geneticist. In some cities, there are clinics whose staffs have special training in recognizing and dealing with children with FASDs. Also contact your local early intervention agency (for children younger than 3 years of age) or local public school (for children 3 years of age or older). To find out who to call, contact the National Information Center for Children and Youth with Disabilities at www.nichcy.org/states.htm or by calling 1-800-695-0285.

To learn more about FASDs, go to the Centers for Disease Control and Prevention (CDC) website at www.cdc.gov/ncbddd/fas, or the National Organization on Fetal Alcohol Syndrome at www.nofas.org.

To help your child reach his or her full potential, it is very important to get help for FASDs as early as possible.
THE LANGUAGE OF FETAL ALCOHOL SPECTRUM DISORDERS

HISTORY OF FETAL ALCOHOL SPECTRUM DISORDERS

For centuries, people have known that alcohol can harm a fetus. However, a specific medical link was not identified until 1899. Dr. William Sullivan compared the pregnancy outcomes of 120 alcoholic prisoners with 28 of their relatives. The infant mortality rate among the alcoholic women was higher. In 1957, Jacqueline Rouquette wrote about prenatal alcohol exposure. Then, in 1968, Dr. Paul Lemoine published a study in which he described 127 children with distinctive facial features and other symptoms related to prenatal alcohol exposure. Five years later, researchers in Seattle published findings of a similar study. They named the condition fetal alcohol syndrome (FAS).

DEFINITION OF FETAL ALCOHOL SPECTRUM DISORDERS

Experts now know that the effects of prenatal alcohol exposure extend beyond FAS. "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 diagnostic term used by clinicians. It refers to conditions such as:

- Fetal alcohol syndrome, including partial FAS
- Fetal alcohol effects (FAE)
- Alcohol-related neurodevelopmental disorder
- Alcohol-related birth defects

FETAL ALCOHOL SYNDROME

FAS consists of a pattern of neurologic, behavioral, and cognitive deficits that can interfere with growth, learning, and socialization. FAS has four major components:

- A characteristic pattern of facial abnormalities (small eye openings, indistinct or flat philtrum, thin upper lip)
- Growth deficiencies, such as low birth weight
- Brain damage, such as small skull at birth, structural defects, and neurologic signs, including impaired fine motor skills, poor eye-hand coordination, and tremors
- Maternal alcohol use during pregnancy

Behavioral or cognitive problems may include mental retardation, learning disabilities, attention deficits, hyperactivity, poor impulse control, and social, language, and memory deficits.

Partial FAS describes persons with confirmed alcohol exposure, facial anomalies, and one other group of symptoms (growth retardation, central nervous system defects, or cognitive deficits).

FETAL ALCOHOL EFFECTS

Fetal alcohol effects (FAE) describes children with prenatal alcohol exposure who do not have all the symptoms of FAS. Many have growth deficiencies, behavior problems, cognitive deficits, and other symptoms. However, they do not have the facial features of FAS. Although the term FAE is still used, the Institute of Medicine has coined more specific terms. These include alcohol-related neurodevelopmental disorder and alcohol-related birth defects.
**ALCOHOL-RELATED NEURODEVELOPMENTAL DISORDER**

Alcohol-related neurodevelopmental disorder (ARND) refers to various neurologic abnormalities, such as problems with communication skills, memory, learning ability, visual and spatial skills, intelligence, and motor skills. Children with ARND have central nervous system deficits but not all the physical features of FAS. Their problems may include sleep disturbances, attention deficits, poor visual focus, increased activity, delayed speech, and learning disabilities.

**ALCOHOL-RELATED BIRTH DEFECTS**

Alcohol-related birth defects (ARBD) describe defects in the skeletal and major organ systems. Virtually every defect has been described in some patient with FAS. They may include abnormalities of the heart, eyes, ears, kidneys, and skeleton, such as holes in the heart, underdeveloped kidneys, and fused bones.

**Origin and Impact of FASD**

**CAUSE OF FASD**

The only cause of FASD is alcohol use during pregnancy. When a pregnant woman drinks, the alcohol crosses the placenta into the fetal blood system. Thus, alcohol reaches the fetus, its developing tissues, and organs. This is how brain damage occurs, which can lead to mental retardation, social and emotional problems, learning disabilities, and other challenges.

No alcohol consumption is safe during pregnancy. In addition, the type of alcohol (beer, wine, hard liquor, wine cooler, etc.) does not appear to make a difference.

**PREVALENCE OF FASD**

FASD occurs in about 10 per 1,000 live births, or about 40,000 babies per year. FAS, the most recognized condition in the spectrum, is estimated to occur in 0.5 to 2 per 1,000 live births. It now outranks Down syndrome and autism in prevalence.

**ASSESSMENT OF FASD**

It is extremely difficult to diagnose a fetal alcohol spectrum disorder. A team of professionals is needed, including a physician, psychologist, speech pathologist, and physical or occupational therapist. Diagnostic tests may include physical exams, intelligence tests, and occupational and physical therapy, psychological, speech, and neurologic evaluations.

Diagnosis is easier if the birth mother confirms alcohol use during pregnancy. However, FAS can be diagnosed without confirming maternal alcohol use, if all the symptoms are present.

**IMPACT OF FASD**

Children with FASD often grow up with social and emotional problems. They may have mental illness or substance abuse problems, struggle in school, and become involved with the corrections system. Costs of FAS alone are estimated at between 1 and 5 million dollars per child, not including incarceration. This estimate does not include cost to society, such as lost productivity, burden on families, and poor quality of life.

**REFERENCES**


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.
12 Common Myths about Fetal Alcohol Syndrome

by Lylee Williams

Adapted from Community Action Guide: Working Together for the Prevention of Fetal Alcohol Syndrome as adapted from Ann Streissguth, Ph.D., University of Washington

**MYTH #1: FAS means mental retardation.**

FACT: Some people with FAS are mentally retarded and some are not. People with FAS can have normal and above-average intelligence. While there is injury to the brain, each affected person will have specific areas of strengths and weaknesses.

**MYTH #2: Behavior problems linked to FAS and partial FAS are all the result of poor parenting.**

FACT: Definitely NOT! Brain injury can lead to behavioral problems because people with brain injuries do not process information in the same way that other people do. Children with brain injuries are challenging to raise, and their parents need help and support—not criticism and judgment.

**MYTH #3: Children affected by FAS will grow out of it when they grow up.**

FACT: Unfortunately, they do not ‘grow out of it’. FAS lasts a lifetime, even though the symptoms and types of problems can change with age.

**MYTH #4: Admitting that a child has brain injury is to give up on him/her.**

FACT: We need NEVER give up on any child with any problem. Instead, we need to understand the needs of those affected by FAS and explore ways to help them.

**MYTH #5: Diagnosing children affected by FAS will “brand” them for life.**

FACT: A diagnosis tells you what the problem is, helps you figure out how to treat the problem, and relieves the person of having to meet unrealistic expectations.

**MYTH #6: Those affected by FAS can be effectively helped by a single agency or discipline.**

FACT: The needs of those affected by FAS are such that many interventions and cooperation among numerous community services are required.
MYTH #7: Those affected by FAS lack motivation when they do not act in a way that we consider responsible.
FACT: It is more likely that the explanation lies in memory problems, the inability to solve problems effectively, or simply a state of being overwhelmed.

MYTH #8: The problem of FAS can be solved with existing research knowledge.
FACT: Research is needed on ALL aspects of FAS—epidemiology (study of the incidence of disease), prevention, early intervention, and treatment.

MYTH #9: The problem of FAS in society will go away.
FACT: FAS is preventable, but alcohol is so much a part of our society that practical and realistic activities that address the problem of alcohol abuse must continue.

MYTH #10: Women who are birth parents of FAS-affected babies chose to drink during their pregnancy and did not care if they damaged their children.
FACT: A drinking problem is never easy to overcome. Pregnancy is an excellent time for women with drinking problems to stop or reduce their use of alcohol. They do need respect, understanding, caring and support to accomplish this.

MYTH #11: The incidence of FAS is higher in First Nations communities.
FACT: FAS is related to the use of alcohol during pregnancy, not to race or ethnicity. Levels and cultural values related to drinking alcohol vary across First Nations communities and thus the prevalence of FAS varies as well.

MYTH #12: Forcing pregnant women who misuse alcohol and drugs into prisons or treatment centers will prevent their continued use.
FACT: Alcohol and drugs are available everywhere in our society, even in supposedly ‘protected’ environments. Rather than imposing solutions on a woman, it is important to support her as she works towards a chosen and sustaining change for herself and her children.
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 Bivens, 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 prematurely 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 0310B

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FASD and the Brain

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Alcohol is a 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 (empathy, 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.

**Executive Functions of the Prefrontal Cortex**

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

- **Inhibition:** 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 retrieving information
- **Self-monitoring:** Needs frequent cues, requires “policing” by others
- **Verbal self-regulation:** Needs to talk to self out loud, needs feedback
- **Empathy:** Diminished sense of remorse, inability to understand others
- **Regulation of emotion:** Moody “roller coaster” emotions, may withdraw or lash out
- **Motivation:** Needs external motivators to carry out mental tasks
- **Judgment:** Inability to make wise decisions

**Alcohol Exposure by Trimester:**

1. **During the first trimester**, as shown by the research of Drs. Charren and Steine, alcohol interferes with the migration and organization of brain cells. [Journal of Pediatrics, 92(1):44-67]

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]
Sobering Work
Unraveling alcohol's effects on the developing brain

By D. Christensen

At parties, young women often want to talk to James R. West. Sure, he's a charming guy, but they especially want to talk about his work—and how it may touch them personally. The issue is potentially close at hand: West studies the effects of alcohol on a baby's developing brain.

"People always ask me, How much is too much?" says West, a neurobiologist at the Texas A&M University Health Science Center in College Station. "We don't really know."

A decade ago, scientists thought there would be a straightforward answer. But recent findings indicate that alcohol doesn't have a single threshold as it acts on different biochemical pathways and different parts of the brain. So, it isn't clear when and where in human fetuses the trouble starts.

Fetal alcohol syndrome was first described in France in the late 1960s and in the United States a few years later. The condition was difficult to recognize because not every woman who drinks heavily during pregnancy bears a baby with the characteristic physical and behavioral abnormalities.

Today, out of each 10,000 children born in the United States, between 3 and 30 suffer from fetal alcohol syndrome. These babies are small at birth, with distinctive facial features, including a flattened area between the nose and upper lip, narrow upper lips, small eyes and noses, and narrow foreheads.

Their mother's drinking has affected their central nervous system as well: Fetal alcohol syndrome is the leading cause of nonhereditary mental retardation.

Children with the outward signs of the syndrome may represent only the most severe example of a spectrum of detrimental effects. Alcohol-exposed children who lack the characteristic facial features of fetal alcohol syndrome may still suffer from attention problems, hyperactivity, aggression, and psychiatric illnesses. Some youngsters may have trouble functioning independently, though they have normal intelligence as measured by IQ tests.

Many recent studies indicate that alcohol doesn't uniformly interfere with the function of every cell in a fetal brain. Sensitive imaging techniques have revealed that alcohol damages some parts of the developing human brain more than others.

Moreover, it targets particular biochemical pathways vital to the development, function, migration, and survival of certain nerve cells, says Kenneth Warren of the National Institute on Alcohol Abuse and Alcoholism in Bethesda, Md. No single mechanism is likely to account for all of the structural, functional, and behavioral problems that have been attributed to prenatal alcohol exposure, he says.

The ultimate goal of research in this area is to identify new ways of blocking or mediating some of alcohol's harmful effects, says Warren. Better knowledge of underlying mechanisms may help researchers figure out how to rescue cells or predict which infants are most at risk from alcohol exposure, he says.

When researchers started looking at the brains of youngsters with fetal alcohol syndrome, the damage seemed so pervasive that the investigators assumed alcohol must affect every system in the developing brain. For example, alcohol might disrupt cell function by altering the integrity of the membranes. Alternatively, alcohol might damage or kill cells indiscriminately by increasing the production of free radicals, toxic byproducts of oxygen metabolism.

"One of the major changes in the alcohol field in the last 10 years has been the identification of proteins that alcohol might interact with directly," says Michael E. Charness of Harvard Medical
School in Boston. For example, researchers have identified specific effects on molecules that regulate development and others that participate in cell signaling.

The cell-adhesion molecule called L1 guides cell migration in the developing brain. This protein regulates nerve-cell adhesion and movement, processes critical to getting the cells to their proper position in a developing brain. Charness and his colleagues gave specific nerve cells growing in laboratory cultures alcohol concentrations equivalent to those resulting when a woman has one to two drinks. This alcohol can prevent nerve cells guided by L1 from adhering to each other, Charness says. In a pregnant woman, this effect may interfere with the fetus's developmental steps, he says. Whether these changes would be significant enough to disrupt brain function in people or animals, however, is still unknown.

Ethanol is the alcohol in beer, wine, and other drinks. In experiments reported in the March 28 Proceedings of the National Academy of Sciences, Charness and his colleagues found that some other forms of alcohol, such as octanol, can block ethanol's action. Their results suggest that ethanol targets a specific area on L1, Charness says.

Besides encouraging cell adhesion, L1 can trigger nerve cells to grow toward each other and form connections. Ethanol concentrations mimicking a woman's exposure to a single glass of wine seem to slow the growth of such connections, reports Cynthia F. Bearer of Case Western Reserve University School of Medicine in Cleveland.

Other researchers have found that genetic mutations in L1 result in damage to the corpus callosum, the bundle of fibers that connects the brain's two sides, Charness says. Interestingly, this part of the brain is often abnormal in children with fetal alcohol syndrome.

In the past few years, researchers have also explored alcohol's effects on molecules that play a role in nerve signaling. One recent study has shown that high concentrations of alcohol—the equivalent of about twice the legal limit for driving in most states—block cells' receptors for a chemical known as glutamate, which stimulates nerve-cell signaling. The study at Washington University School of Medicine in St. Louis also found that alcohol activates receptors for gamma-aminobutyric acid, better known as GABA, which inhibits signaling.

Work by other scientists indicates that ethanol may interfere with serotonin, another important chemical in nerve signaling.

When they don't receive enough input from other cells, "neurons get the message they are not developing normally," says John W. Olney of Washington University. "This activates a program that says, 'You will not reach your biological destiny, so kill yourself.'"

In young rats going through a brain growth spurt equivalent to that of a third-trimester human fetus, a single episode of intoxication lasting about 4 hours is enough to kill off groups of nerve cells, Olney and his colleagues reported in the Feb. 11 Science. By changing the time at which the animals are exposed to alcohol and thus when their normal nerve signaling is disrupted, the researchers can trigger nerve-cell loss from many different regions of the brain, says lead researcher Chrysanthy Ikonomidou of Humboldt University in Berlin.

His team found no evidence that exposure to low concentrations of alcohol, even for a longer period of time, cause damage to a fetus. Therefore, Olney says, "one glass of wine with dinner is not likely to be harmful. But beyond that, it is anyone's guess because there is no way we can extrapolate from rats to man with any precision."
Since 1991, the proportion of pregnant women drinking, on average, the equivalent of at least a glass of wine a day has quadrupled, according to the federal Centers for Disease Control and Prevention. Today, 1 in 29 women carrying unborn babies report such drinking, which CDC calls "risky." About half of these women also reported binge drinking, or downing the equivalent of more than five glasses of wine on any one occasion.

Because researchers haven't been able to establish a safe amount of alcohol for given periods of pregnancy, public health messages tell women to avoid drinking any alcoholic beverages during their pregnancies.

Many animal studies find no harmful effects on fetuses from exposures to less alcohol, adjusted for body size, than the amount needed to give a person a buzz. Although it's impossible to say with certainty that fetal development in any two species will have identical sensitivity to alcohol, some scientists contend that probably only high doses of alcohol damage a fetus.

Research on the effects of alcohol on brain cells supports the idea that more alcohol is worse than less alcohol, West says. He adds that drinking any amount of alcohol relatively quickly is probably more dangerous than drinking an equal amount over a longer period of time.

Right now, there's no "morning-after pill" to give to pregnant women who drink or any other method of curing the damage caused by exposure to alcohol during a critical period of fetal development, says Boris Tabakoff of the University of Colorado Health Sciences Center in Denver. "If you wait 'til a woman drinks, and she drinks during [a] critical period, there may be no way to intervene."

The current research on alcohol may eventually translate into treatments for some of those women, Tabakoff says. It's unlikely, however, that all of alcohol's effects on the developing brain could be blocked, he adds.

Charness' work shows that it's possible to use other alcohols to deter ethanol's effects on L1-driven cell adhesion—at least in the test tube. Such findings "may lead eventually to medications that reduce the damaging effects of alcohol in both fetal development and in adults," Charness speculates.

However, Ikonomidou says that her findings—that nerve cells may die within hours after exposure to a single high dose of alcohol—convince her that no treatment will be effective in compensating for alcohol's effects.

One of the dilemmas facing researchers and physicians alike is that it can be difficult to identify both mothers-to-be who're drinking and their affected kids, says Bearer. This problem is especially difficult because some kids with neurologic damage don't have the characteristic facial features of fetal alcohol syndrome.

In the March 1999 Alcoholism: Clinical and Experimental Research, Bearer and her colleagues reported that alcohol metabolites in meconium—the first stool of a newborn—can distinguish between women who drank alcohol late in pregnancy and those who didn't.
Bearer is now trying to see whether such biochemical clues can identify how much alcohol a fetus was exposed to and when. That knowledge may indicate which brain areas were likely to have been damaged, she speculates.

Several researchers are trying to create maps of the areas damaged after fetal animals are exposed to alcohol at certain times, says Kathleen K. Sulik of the University of North Carolina at Chapel Hill. These maps might be useful in pinpointing when during pregnancy, alcohol is most likely to be harmful, says Sulik.

Detailed magnetic resonance images of kids with and without fetal alcohol syndrome have shown that some brain structures are more likely than others to be damaged by alcohol, says Edward P. Riley of San Diego State University. His team finds the frontal cortex and corpus collosum to be especially vulnerable, a result that fits well with Charness' work on L1.

Now, Riley's group is working to correlate the observed brain changes with behavioral and cognitive effects seen in children exposed to alcohol in the womb. Riley says that the preliminary evidence supports such links.

All the researchers agree that there's no easy answer to the question that West often faces, Can a woman drink some limited amount of alcohol without threatening normal fetal development?

"If the agent was, say, something in bathroom cleaner, people would just stay away from it," West says. "However, since it is alcohol, and they don't want to give it up, they are interested in how much they can 'get away with.'"

The scientists vary somewhat in their responses. Charness says, "Biochemical studies suggest there is potential for harm at low doses of alcohol."

West offers, "It's unlikely that a drink once in a while is going to cause any damage, but we don't know for sure."

Sulik adds, "I happen to believe that it takes a high blood-alcohol concentration to cause problems [for the fetus], but the bottom line is that we don't know, and better safe than sorry."

Determining the smallest amount of alcohol that would harm a fetus would require knowing which developmental steps and which underlying mechanisms may be disrupted by alcohol, Riley says. Even if that information became clear in animal studies, translating the findings into practical advice might prove difficult. Species differ in developmental patterns, and many women don't know exactly when they became pregnant.

The consensus of these basic scientists, then, is that the only safe drink for a pregnant woman is one without alcohol. After all, Riley says, "how many cigarettes cause cancer?" Just one cigarette—or one drink—may be unlikely to cause problems, he notes, but so far, the possibility that it does some harm can't be ruled out.

FASD - GENERAL INFORMATION: Suggested Readings

PUBLICATIONS

Alcohol and Pregnancy – a Mother’s Responsible Disturbance by Elizabeth Russell, 2005,
An account of how prenatal alcohol exposure can have dramatic affects on children’s health and wellbeing.

This is the story of how the author’s son grew up mentally retarded, a victim of Fetal Alcohol Syndrome.

A summary of findings and recommendations is presented by the team who conducted a study on people of all ages with Fetal Alcohol Syndrome and Fetal Alcohol Effects. Twenty-one experts from the fields of human services, education, and criminal justice respond by describing their solutions to this problem.


Topics covered in this book include: an overview of FAS and diagnostic process, teratology and brain damage, physical and behavioral manifestations, a model for advocacy, guidelines for employment and education, effective services for high risk mothers, and addressing public policy.

Finding Perspective...Raising Successful Children Affected by Fetal Alcohol Spectrum Disorder by Liz Lawryk, 2005, OBD Triage Institute Inc.
The goal of this book is to provide specialized methods designed for the patient’s unique abilities as opposed to a generalized FASD approach.

This guide answers many of the frequently asked questions about FAS/E including history, diagnosis, and characteristics of children with FAS/E at different stages of their lives.

Provides an overview of the essential FASD information for parents, tips for caregivers, information on the assessment and referral process, as well as diagnostic criteria. It also includes information pertaining to parents’ needs and respite.


WEBSITES

Centers for Disease Control and Prevention
http://www.cdc.gov/ncbddd/fasd

FAS Stars
www.come-over.to/fasstar/faspix/1stGeneration.htm
Stories about and photos of adults with FASD.

FASD Center for Excellence, SAMHSA, Department of Health and Human Services
www.fasdcenter.samhsa.gov/

FASD Connections
www.fasdconnections.ca

FASD Lane
http://www.fasdlane.com/
FASD Lane is a place for adults with Fetal Alcohol Syndrome (FAS), Fetal Alcohol Effects (FAE), or any of the disorders defined as Fetal Alcohol Spectrum Disorders (FASD).

FASD Prevention
www.jenniferposstaylor.com/fasd.html
Committed to putting a STOP to Fetal Alcohol Spectrum Disorders by informing and educating
the public on the most under-diagnosed epidemic in the world today.

Fetal Alcohol and Drug Unit, Department of Psychiatry and Behavioral Sciences, University of Washington School of Medicine
dpts.washington.edu/fadu/

National database of FASD and substance use during pregnancy resources: Canadian Centre on Substance Abuse (CCSA)
www.ccsa.ca/fas

National Organization on Fetal Alcohol Syndrome (NOFAS)
www.nofas.org

Project FACTS: Fetal Alcohol Consultation and Training Services
www.fasalaska.com
GETTING A DIAGNOSIS
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
2. Alcohol-related neurodevelopmental disorder (ARND): CNS defects and behavior problems or cognitive deficits (e.g., speech delays, hyperactivity)
3. 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. 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.

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
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, cardiomgram, 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

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.
Characteristics and Symptoms of Fetal Alcohol Syndrome
© 1999-2003 Teresa Kellerman

A diagnosis of Fetal Alcohol Syndrome (FAS) is based on certain criteria: facial features, small birth weight, central nervous system dysfunction, and a history of prenatal exposure to alcohol. Babies who do not have all the physiological symptoms may be given a diagnosis of Fetal Alcohol Effects (FAE) or partial Fetal Alcohol Syndrome (pFAS). Together, FAS, pFAS, and FAE are referred to collectively as Fetal Alcohol Spectrum Disorders (FASD).

**Facial Features**
Children with FAS may have some or all of the following facial characteristics:
- Small eye openings
- Smooth, wide philtrum
- Thin upper lip

Only babies who were exposed to alcohol during a specific period of pregnancy will have the facial features of FAS. Any of these features can occur in a healthy child as a matter of genetics, features that are inherited from a birth parent. Only when several of these features are present along with central nervous system symptoms together with prenatal alcohol exposure will FAS be considered for diagnosis. Only about 10% of children with FASD receive a diagnosis of FAS.

**Physiological Anomalies**
Babies with FAS may have low birth weight, and may have trouble gaining weight. The head circumference may be smaller than normal. Some infants may have heart defects or other anomalies to the ears, eyes, liver, or joints. Children may show no physical symptoms at all yet still have significant damage to the brain and central nervous system. About 90% of children with FASD have no physical features of the syndrome.

**Developmental Delays**
Many children with FASD have developmental delays. Less than half of children with full FAS have mental retardation. 90% of children with FAE have IQs in the normal range. Most children with FASD appear to be bright and outwardly normal.

**Central Nervous System**
Most infants with FAS are irritable, don't eat well, don't sleep well, and are extra sensitive to sensory stimulation, and have a strong startle reflex. Many are diagnosed with Sensory Integration Disorder (SID) and/or Central Auditory Processing Disorder (CAPD). They may hyperextend their heads or limbs, and may exhibit hypertonia (too much muscle tone) or hypotonia (too little muscle tone) or both. Many children with FASD also have Attention Deficit Hyperactive Disorder (ADHD).

Invisible but Serious
The most serious characteristics of FASD are the invisible symptoms of neurological damage that result from prenatal exposure to alcohol. These symptoms can occur in FAS and FAE:
- Attention deficits
- Memory deficits
- Hyperactivity
- Difficulty with abstract concepts
- Poor problem solving skills
- Difficulty learning from consequences
- Vulnerable and naive
- Stunted social development
- Immature behavior
- Emotional outbursts
- Poor impulse control
- Poor judgment

Note: These symptoms are not "behavior problems" but are a result of permanent, unchanging damage to the brain (static encephalopathy) and are not always within the child's control.

Adults with FASD have difficulty maintaining successful independence. They have trouble staying in school, keeping jobs, or sustaining healthy relationships. Children and adults with FASD are vulnerable to physical, sexual, and emotional abuse.

Without early intervention services, these individuals have a high risk of developing secondary conditions such as mental illness, trouble with the law, trouble with school, substance abuse, and unwanted pregnancies. A majority of adults with FAE are treated for clinical depression, and 23% have attempted suicide.
Fetal Alcohol Syndrome

FAS is a set of mental and physical disorders that can include mental retardation, brain dysfunction, physical abnormalities, learning disabilities, and psychological disorders. FAS occurs as a result of prenatal exposure to alcohol.

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

The effects can be severe or mild, ranging from loss of IQ points, attention deficit disorder and learning disabilities to heart defects, cerebral palsy, brain dysfunction, and death. Many children experience serious behavior and social problems that last a lifetime. Children with so-called “mild” effects are at higher risk than those with full FAS because they are not recognized or diagnosed correctly and do not receive appropriate intervention services.


Over 5,000 babies each year in the U.S. are born with FAS. Between 35,000 and 50,000 are born with related disorders. However, most cases of FASD go undiagnosed or misdiagnosed.

FAS in a Nutshell

♦ FAS is the leading known cause of mental retardation.
♦ Most individuals with FAS have normal intelligence.
♦ FAS causes serious social and behavior problems.
♦ Each year in the U.S. 5,000 babies are born with FAS.
♦ Ten times as many are born with alcohol related disorders.
♦ No amount of alcohol is known to be safe during pregnancy.
♦ Alcohol causes more damage to baby than any other drug.
♦ FAS and related conditions are 100% preventable.

For more information on Fetal Alcohol Syndrome or to download this brochure, visit: www.fasstar.com

Fetstar Enterprises
Fetal Alcohol Syndrome: Support, Training, Advocacy, & Resources

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www.fasstar.com
Primary Disabilities

**Fetal Alcohol Syndrome (FAS)** – FAS is a medical diagnosis for a specific pattern of characteristics resulting from the effects of prenatal alcohol exposure. These characteristics include growth retardation, or being small for age, microcephaly (smaller than normal head), short palpebral fissures (small eye slits), smooth philtrum (vertical groove between the upper lip and nose), a thin upper lip, central nervous system (brain and spinal cord) damage causing behavioral and cognitive (thinking, learning) problems. Evidence of prenatal alcohol exposure is sought but is not necessary for diagnosis to be made.

**Fetal Alcohol Effect (FAE)** – When a person has central nervous system damage like FAS indicated by behavioral and cognitive problems but without the distinctive facial features, the person may have FAE. Though the term appears in earlier studies and continues to be used by laypersons, some researchers in FAS have requested that the term FAE no longer be used due to the belief by some that FAE is less severe than FAS. THIS IS NOT TRUE. In fact, it may just mean that the child merely doesn’t have the facial features or the growth retardation, but the damage to the brain may be just as extensive. Because of the confusion surrounding this term, the following term is now being used more widely.

**Alcohol-Related Neurodevelopmental Disorder (ARND)** is diagnosed when a child meets the criteria for brain damage but does not have all of the facial features or growth retardation of FAS. Again, **ARND IS NOT A LESS SEVERE FORM OF FAS**. In many cases, the brain damage in a patient with ARND is as extensive as that in a patient with FAS.

**Alcohol-Related Birth Defects (ARBD)** are physical abnormalities associated with prenatal alcohol exposure. They include: abnormalities of the eyes and the ability to see and process visual information; the ears and the ability to hear and process auditory information; the structure of the heart and the associated cardiac systems; and abnormalities in the limbs.

**Fetal Alcohol Spectrum Disorder (FASD)** describes a spectrum or range of clinical conditions associated with prenatal alcohol exposure. 1) FAS with full distinctive facial features; 2) Partial Fetal Alcohol Syndrome (PFAS) with some of the distinctive facial features; 3) ARND with little or no distinctive facial features.
Primary Disabilities

Possible facial features associated with FAS/ARND include:

- Short palpebral fissures (small eye slits)
- Short upturned nose
- Low nasal bridge
- Flat philtrum (vertical groove between the upper lip and nose)
- Thin upper lip
- Flat midface
- Small chin
- Simply formed, low set ears

Other possible physical defects include:

- Eye and ear defects
- Respiratory (lung) problems
- Heart murmur
- Limb reduction
- Low birth weight
- Hutchinson’s teeth

The following primary cognitive disabilities associated with FAS/ARND are caused by brain damage. Many of them overlap with diagnoses for other disabilities. Therefore many children will be misdiagnosed or underdiagnosed with such disorders as Attention Deficit Hyperactivity Disorder (ADHD), Oppositional Defiant Disorder (ODD), Obsessive Compulsive Disorder (OCD), Sensory Integration Disorder (SID), and Learning Disabilities (LD), among others:

- Developmental delays – often acts younger than his or her age
- Inconsistent performance – seems to “get it” one day and lost it the next. Leads people to believe that the child is intentionally being difficult.
- Hyperactivity – constantly in motion
- Impulsivity – says and does whatever comes to mind without thinking about consequences
- Attention deficits, distractibility – at times their lack of ability to stay focused on a task for very long is due to attention deficits; may also be easily distracted
- Disorganization – messy, can’t find things, unprepared for school or work
- Poor social skills – has problems making and keeping friends, doesn’t understand social cues or body language
- Literal thinking – doesn’t understand subtle jokes or statements that have double meanings; take things very literally. For example, don’t say, “Hit the road” when you mean “Leave” or “Cut it out” when you mean “Stop.”
- Difficulty with abstractions – struggles with abstract concepts such as math, money management, time, ownership, and consequences.
- Difficulty with transitions – needs help when switching from one activity to another. May become very involved in current activity and will have difficulty changing to a new one especially if it is felt that the current activity is incomplete.
- Memory problems – difficulty storing and retrieving information
- Processing deficits – may think more slowly, may only understand every third word of normally paced conversation.
- Ability to repeat instructions, but inability to put them into action – can “talk the talk but not walk the walk”
- Inability to predict outcomes or understand consequences and cause/effect – poor judgment
- Difficulty generalizing from one situation to another – a lesson learned in one situation does not carry over to a new situation.
GETTING A DIAGNOSIS: Suggested Readings

PUBLICATIONS

**FAS: Guidelines for Referral and Diagnosis** by the National Center on Birth Defects and Developmental Disabilities, CDC and Prevention Department of Health and Human Services and National Task Force on FAS/FAE 2004. Department Of Health And Human Services Centers For Disease Control And Prevention. These guidelines are intended to assist physicians and allied health professionals in the timely identification, referral, and diagnosis of persons with fetal alcohol syndrome. Contact: Centers for Disease Control and Prevention, FAS Prevention, Mail-Stop E-86, 1600 Clifton Rd, Atlanta, GA 30333, Phone (404)498-3947, Email: FASInquiries@cdc.gov or download the resource from website: [www.cdc.gov/ncbddd/fasd/documents/fas_guidelines_accessible.pdf](http://www.cdc.gov/ncbddd/fasd/documents/fas_guidelines_accessible.pdf)

**FASD Information & Diagnosis** by Alberta Clinical Practices Guidelines Program 2004. Edmonton, AB: Alberta Medical Association. This guideline provides an overview of issues related to the diagnosis of FAS and includes the standard diagnostic criteria that have been developed in the US. Contact: Alberta Perinatal Health Program, North Office, Suite 300, Kingsway Professional Centre, 10611 Kingsway Avenue, Edmonton, AB T5G 3C8; Phone (780) 735-1000; Email: LoriKirkey@cha.ab.ca

**Fetal Alcohol Spectrum Disorder: Canadian Guidelines For Diagnosis** by Albert E. Chudley, Julianne Conry, Jocelynn L. Cook, Christine Loock, Ted Rosales, Nicole LeBlanc – CMAJ, MAR. 1, 2005; 172 (5 suppl) Abstract: A subcommittee of the Public Health Agency of Canada's National Advisory Committee on Fetal Alcohol Spectrum Disorder reviewed, analyzed and integrated current approaches to diagnosis to reach agreement on a standard in Canada. The purpose of this paper is to review and clarify the use of current diagnostic systems and make recommendations on their application for diagnosis of FASD related disabilities in people of all ages. The guidelines are based on widespread consultation of expert practitioners and partners in the field. These are the first Canadian guidelines for the diagnosis of FAS and its related disabilities, developed by broad-based consultation among experts in diagnosis.


**Fetal Alcohol Syndrome/Fetal Alcohol Effects: Strategies for Professionals** by Diane Malbin, 1993, Hazelden. This book provides professionals and their clients with information on: how alcohol can affect unborn children during pregnancy; the difference between FAS and FAE; The importance of aftercare resources that are knowledgeable about FAS/FAE.

**Social Cognitive and Emotion Processing Abilities of Children with Fetal Alcohol Spectrum Disorders: A Comparison with Attention Deficit Hyperactivity Disorder.** By Greenbaum, R. L., Stevens, S. A., Nash, K., Koren, G. and Rovet, J. (2009), *Alcoholism: Clinical and Experimental Research*, 33: 1656–1670. Studied were children with FASDs or ADHD. All received tasks of social cognition and emotion processing. Parents and teachers rated children on child’s behavioral problems and social skills using the Child Behavior Checklist, Teacher Report Form, and Social Skills Rating Scale and 4 subtests from the Minnesota Test of Affective Processing to assess emotion processing. Results: Parents and teachers reported more behavior problems and poorer social skills in children in FASD and ADHD. Children with FASDs demonstrated significantly weaker social cognition and facial emotion processing ability than ADHD and control groups.

**CD-ROM**

**Fetal Alcohol Syndrome: Tutor** 2003. March of Dimes
CD-ROM helps health professionals screen and diagnose children with fetal alcohol syndrome. The CD-ROM uses descriptive text, video clips, animations and illustrations to assist users. (item #09-1266-99). Contact; March of Dimes Birth Defects Foundation 1275 Mamaroneck Ave. White Plains, NY 10605 or Phone (770) 280-4115.
SECONDARY EFFECTS OF FASD
Secondary Disabilities

Secondary disabilities are those that result from the primary disabilities. For example, due to damage to certain brain regions, a person with FAS/ARND may have poor judgment. This could lead to the secondary disability of getting into trouble with the law. Ann Streissguth, Ph.D. of the University of Washington, a pioneer and recognized authority in the field of FAS, completed a study in 1996 identifying these secondary disabilities. They include:

- **Trouble with the law** – secondary to poor judgment, inability to understand consequences, and boundary issues
- **Mental health problems** – secondary to damage to brain regions and chemical imbalances
- **Disrupted school experience** – secondary to developmental delays, inconsistent performance, hyperactivity, impulsivity, distractibility, attention deficits, disorganization, poor social skills, difficulty with abstractions, memory problems, processing deficits, difficulty with transitions
- **Confinement** – secondary to poor judgment and boundary issues
- **Alcohol and drug problems** – possibly self medicating to compensate for damage to brain regions and chemical imbalances
- **Problems with employment** – secondary to developmental delays, poor social skills, difficulty with abstractions like time, etc.
- **Dependent living** – secondary to difficulty with abstractions like time, money management, poor social skills, developmental delays
- **Inappropriate sexual behavior** – secondary to boundary issues, poor social skills, inability to understand consequences

With early and ongoing support and services, children with FAS/ARND are less likely to develop these secondary disabilities.

Dr. Streissguth, in the same study, identified factors that decreased incidence or reduced the effect of the secondary disabilities. These factors include:

- Living in a stable and nurturant home for over 72% of life
- Being diagnosed before the age of 6
- Never having experienced violence against oneself
- Staying in each living situation for an average of more than 2.8 years.
- Experiencing a good quality home from ages 8-12 years
- Applied for and eligible for services for the developmentally disabled
- Having a diagnosis of FAS rather than ARND
- Having basic needs met for at least 13% of life
SECONDARY EFFECTS OF FASD: Suggested Readings

NOTE: Secondary effects are also known as secondary disabilities, defined by Streissguth as those disabilities not present at birth but which occur as a result of the primary disabilities (Streissguth, 1996). They include mental health problems, disrupted school experience, trouble with the law, confinement, inappropriate sexual behavior, substance abuse issues, difficulty living independently and employment issues. Secondary effects can be prevented or lessened by better understanding and applying appropriate interventions. Secondary effects may also be referred to as secondary consequences. We prefer the term effects or consequences due to the fact that the term “disabilities” is misleading. Our goal is to reduce the occurrence of secondary effects through our work.

PUBLICATIONS

Adults Living with FAS/E: Experiences and Support Issues in British Columbia by Rutman Deborah, Corey La Berge, and Donna Wheway: FAS/E Support Network of BC 2002. Surrey, BC: FAS/E Support Network of B.C. This report includes excerpts of life stories of individuals with FAS as well as a discussion of a number of issues and experiences that participants have told about day-to-day living with FAS/E. These issues and experiences have been divided into different topic areas (e.g. accomplishments, employment, education, parenting with FAS/E, independence, justice.). The Implications section outlines directions for advocacy, supportive policies and effective practices for adults living with FAS/E as identified through this research.


A summary of recent findings and recommendations is presented by the team who conducted the largest study ever done on people of all ages with FAS/FAE. Topics include articles on diagnosis, effects of heavy prenatal exposure to alcohol, primary and secondary disabilities, medication and FAS, education of young children, practical hints for adults with FASD, preventing and treating sexual deviancy, parent advocacy, and legal issues.

Tough Kids and Substance Abuse: A Drug Awareness Program for Children and Adolescents With ARND, FAS, FAE And Cognitive Disabilities by P Cook, R. Kellie, K. Jones & L. Goossen. 2000. Winnipeg, MB: Addictions Foundation of Manitoba This drug awareness program targeted to “tough kids” provides educators and other youth community professionals with practical strategies related to educating this group about alcohol, inhalant and other drug issues.
HELPING FAMILIES DEAL WITH FASD
### Strategies for Addressing FASD, Birth - Age 3

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<tr>
<th>Sleeping</th>
<th>Eating</th>
<th>Touch/Sensory</th>
<th>Developmental Delays</th>
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<tr>
<td>Trouble falling asleep</td>
<td>Has trouble coordinating</td>
<td>Stiffens, rather than softens</td>
<td>Skills such as walking, talking</td>
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<tr>
<td>Wakes after short periods</td>
<td>sucking and swallowing</td>
<td>when held</td>
<td>are delayed</td>
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<td>Does not develop a regular sleep/wake pattern</td>
<td>Tires easily from feeding</td>
<td>Bathing, brushing teeth or</td>
<td>Physical skills may be clumsy</td>
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<td>(falls asleep)</td>
<td>hair are difficult</td>
<td>Language acquisition is slow</td>
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<td>Pushes nipple or spoon out of</td>
<td>Startles easily</td>
<td>Needs to hear things over and</td>
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<td>mouth with tongue</td>
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### Strategies for Addressing FASD

#### BIRTH – AGE 3
- Slow physical growth
- Sleeping and feeding difficulties
- Slower rate to learn new skills
- Sensitivity to touch, sounds, light

#### AGES 4 – 12
- Good talking skills, but poorer understanding
- Poorer math compared to other skills
- Difficulty making friends with peers/prefer younger children

#### TEENAGERS
- Physical/sexual maturity with emotional/social immaturity
- Easily led by others
- Transparent lying
- Frustration/depression at their inability to fit in

#### ADULTS
- Difficulty keeping jobs
- Ongoing need for structure in life
- Desire for family, independence

### Strategies to Help

#### BIRTH – AGE 3
- Understand a child will be smaller and adjust expectations
- Control the bedtime environment: quiet, dark, heavy
- Provide concrete objects to help
- Focus on strengths
- Ask “show me” to check for understanding

#### AGES 4 – 12
- Rehearse behaviors for risky situations
- Start sex/alcohol education early and repeat often
- Focus on strengths

#### TEENAGERS
- Choose jobs with built in structure
- Seek as much independent living as possible

#### ADULTS
- Choose jobs with built in structure
- Seek as much independent living as possible
Parents who are raising children with Fetal Alcohol Spectrum Disorders (FASD) often ask me what they should do to protect their children as they are growing into adulthood and what they can do to ensure their children are protected in the future. I have advised parents to educate themselves, their community, all the providers and professionals in their children’s lives, and to educate the children themselves about the nature of their FASD so that all involved have a realistic perspective, reasonable expectations to prevent the serious secondary disabilities later, like substance abuse, promiscuity, trouble with the law, depression, and suicide. Some children will qualify for services in the disabilities system, some will qualify in the mental health system, and some will not qualify for any services at all. For those “lucky” enough to become eligible for services, more often than not those services are inadequate or inappropriate, and in some case the service systems place the adult children with FASD at risk because of lack of understanding or case overload. The evidence I have gathered through my interaction with hundreds of parents motivates me to advise adult children to stay at home as long as possible and for parents to provide home care for their children as long as they are able. I seriously advise parents to take care of their health so that they can live a long life and be available to care for and advocate on behalf of their children. This is easier said than done.

What I have observed is that parents of children with FASD over the years develop serious health problems, more than those seen in parents of non-disabled children. Recent research shows that the stress experienced by families raising children with a diagnosis of Fetal Alcohol Effects (FAE) is greater than that of families raising children with a diagnosis of Fetal Alcohol Syndrome (FAS), and that families raising children with suspected FAS or FAE suffer the greatest stress of all.

It is very easy, when raising a child with FASD, to become so wrapped up in the child’s needs and advocating for the child’s safety, health and welfare in the various systems to lose sight of the importance of taking care of one’s health. I therefore urge parents to pay particular attention to living a healthy lifestyle by following these four simple guidelines:

Food: maintain a prudent, balanced diet
Alcohol: drink in moderation, avoid excessive use
Smoking: quit now and/or avoid second hand smoke
De-stress: daily exercise, meditation/prayer, laughter, sharing/support, sleep well

Food: If you follow the Mediterranean diet or a “prudent” diet, you will optimize your health over the long term. The Mediterranean diet consists of lots of whole grains, fruits, nuts and vegetables. The “prudent” diet is balanced with 50%-60% carbohydrates, 15%-30% protein, and less than 30% total fat (Journal of the American Medical Association. September 22/29, 2004). Many parents of children with FASD tend to overeat, probably due to stress. What works for me is to follow the Weight-Watchers plan. I can eat a lot, lose or maintain my weight, and enjoy the camaraderie of a support group. I even get to eat a little bit of chocolate every day, which satisfies by sweet tooth and keeps be from overindulging in less healthy food.

Alcohol: What is “excessive use” of alcohol? We have been advised to “drink responsibly” but not too many people know what that means. The FDA nutritional guidelines advise us to limit our alcohol intake to just two drinks per day for a man and just one drink per day for a woman. And no alcohol at
all for women who are pregnant, who might be pregnant, who could possibly get pregnant, or who are nursing. And no alcohol for people on prescription medications or those with addiction disorder. Alcohol is a risk factor for people who have high blood pressure, heart disease, diabetes, for those with family history of substance abuse and/or cancer. Women beware: even one drink a day can raise your risk of breast cancer (FDA 2000 Dietary Guidelines for Americans). The few health benefits touted by the media are significantly outweighed by all the risk factors of alcohol. Is it worth the risk? Not for me, it isn’t. I have observed that alcohol has done too much harm to people I love, especially my son who has FAS. Out of respect for him and as a precautionary factor to promote health role modeling, I decided years ago that my home would be an alcohol-free home, with no alcohol consumed, served or brought into my home.

Smoking: We have been educated adequately about the dangers of smoking and the risks of inhaling second-hand smoke. We have a smoke-free home and as a family we try to avoid social situations where smoking might occur. Not only is smoke unhealthy for our lungs, but smokers are unhealthy role models for our children. If you smoke, quit. If you live with a smoker, talk to your doctor and encourage the smoker to seek help in quitting.

De-stress: Minimizing the stress in your life is as important as the other health factors. Exercising for 15 minutes a day for 3-5 days a week can do wonders for depression, and will help boost metabolism. Begin each day with prayer or meditation, find something new to be grateful for each day, and look for the blessing behind the problems that inevitably will challenge you. Find the humor in difficult situations and laugh at yourself. It is so easy to take ourselves too seriously. Find a good friend or two who understand, and join a support group where you can share your burdens and joys. Get a good night’s sleep each night, so you can face each day with fresh energy and a clear mind. Do something fun, just for yourself, every day.

These FASD steps are simple, but not necessarily easy to implement. I have thought a lot about maintaining a healthy lifestyle, for myself and for my children, so that I can enjoy life as best I can, so I can be a healthy role model for my children, and so that I can be around for years to come to ensure my children get the love and quality care they deserve. I have made a commitment to a healthy lifestyle many times, and I have slipped many times. And I have started up again, and again. Over the years I am getting better, and although I am now in my late 50’s, I am in good health, and I intend to keep it this way. I have had health problems in the past, and perhaps you have or still struggle with health issues. But don’t give up. It’s never too late to start living well. You owe it to yourself, and to your children.

If you follow these guidelines, you can reduce your risk of death from any cause by 65%. Each of these four by themselves will reduce your risk by 20% to 35% (Journal of the American Medical Association. September 22/29, 2004).

I am committed to following the Staying Alive FASD Survival Plan. How about you?
n with FAS.

**FASD Connections: Serving Adolescents and Adults with FASD**
[www.fasdconnections.ca](http://www.fasdconnections.ca)
The website has a resource listing of FASD key documents on numerous subjects concerning adolescents and adults with FASD. Email: info@fasdconnections.ca

**Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Related Conditions with Carolyn Hartness and Julie Gelo**
These Internet online training videos on FAS are produced by Washington State Department of Social Services and are part of the Foster Parent Webcast Archive. Carolyn Hartness and Julie Gelo are the presenters and they provide an overview of FAS/FAE and intervention strategies that are helpful for the care of children or adults with FASD. The training consists of 2 separate sessions consisting of 3-45 min lectures.

**SAMHSA Fetal Alcohol Spectrum Disorders Center for Excellence**
Download the **What You Need To Know Series** by SAMHA:
- Independent Living for People with Fetal Alcohol Spectrum Disorders
  [www.fasdcert.samhsa.gov/documents/WYNKIndLivin](http://www.fasdcert.samhsa.gov/documents/WYNKIndLivin)
- Understanding Fetal Alcohol Spectrum Disorders: Getting a Diagnosis
  [www.fasdcert.samhsa.gov/documents/WYNKDiagnosis_5_colorJA_new.pdf](http://www.fasdcert.samhsa.gov/documents/WYNKDiagnosis_5_colorJA_new.pdf)
- The Language of Fetal Alcohol Spectrum Disorders
- Tips for Elementary School Teachers

Contact: SAMHSA FASD Center for Excellence, 1700 Research Boulevard, Suite 400, Rockville, MD 20850; Phone 1-866-786-7327 or Email: fascenter@samhsa.gov

**SCREAMS Model**
[www.come-over.to/FAS/ScreamsArticle.htm](http://www.come-over.to/FAS/ScreamsArticle.htm)
How to minimize screaming, yours, not theirs by Teresa Kellerman.

**Social Behavioral Challenges in Children with FAS/E**
[www.fasalaska.com/behavior.html](http://www.fasalaska.com/behavior.html)

**Staying Alive with the FASD Survival Plan**
[www.come-over.to/FAS/StayingAlive.htm](http://www.come-over.to/FAS/StayingAlive.htm)
Sponsored by Teresa Kellerman

**VIDEOS**

This program tells the stories of adults living with FAS and FAE – some who were diagnosed early and others who were not – and the events, programs, and people who made a difference in their lives. 40 min

**Fetal Alcohol and Other Drug Effects: A Four-Part Training Series for Parents and Professionals** 2000. Fetal Alcohol Syndrome Consultation, Education and Training Services, Inc. (FASCETS)
Set of 4 hour-long videos were developed to provide accessible, practical information and training to help parents, families, professionals, and to support program development. Part 1: Diagnostic Criteria: Effects of Prenatal Exposure, Part 2: Common Learning and Behavioral Characteristics, Part 3: Behaviors and Overlapping Diagnoses, and Part 4: Barriers to Identification: Historical, Cultural, Professional and Personal. Contact: FASCETS, PO Box 83175 Portland, OR 97283 Phone (503) 621-1271 or Email: dmalbin@fascets.org.
Barbie is a bright and beautiful young lady. She was adopted and raised by her grandparents since she was one year old. Barbie was diagnosed with Fetal Alcohol Syndrome (FAS) when she was still very young. Her grandparents were open and honest with her about her diagnosis, but it was hard for her to understand what that meant.

Barbie has an IQ in the normal range, but was enrolled in special education. At age 18, she has written language skills of age 16, reading comprehension of age 10, math skills of age 9, and problem solving skills of age 8.

Barbie’s grandparents have educated themselves about Fetal Alcohol Spectrum Disorders (FASD) and they continue to seek support and assistance to help Barbie succeed in a safe, supportive environment.

What do teens and young adults with Fetal Alcohol Spectrum Disorders need?

A “REASONABLE” Plan:

Remove invisible barriers, such as denial, stigma, blame.

Educate everyone at all levels about the nature and neurology of FASD.

Assessments, such as IQ, Vineland, functional assessment, journal.

Service plan based on individual needs, capabilities, and talents.

Objectives with reasonable expectations to ensure success.

New definition of “success” (survive) and new dream for the future.

Acceptance by everyone of the reality that FASDs are brain disorders.

Build a Circle of Support to nurture, guide, and mentor the individual.

Life-long plan for sustaining that support so he/she can thrive.

Everyone is responsible for FASD, its prevention and intervention.

In Barbie’s Words

A story about how a shy young woman came to terms with having a Fetal Alcohol Spectrum Disorder.
In Barbie's Words...

My Mother died when I was six, because she was very sick, and I could not do a thing about it, even though I knew why she got that sick. I would blame myself sometimes, telling myself, "You knew what was in that bottle was not water. Why didn't you stop her?"

I drew myself in more and more as the years went by. Elementary school did not help me get over the pain. The kids treated me different, as if I had the plague. I did not understand why.

Then one day while I was walking to class, a girl from one of my classes wanted to beat me up. When I asked her why, she replied, "Because you're retarded." I was shocked. Why would she say that?

I started to think about it, and could not figure it out, until one day I was asked a simple math question, and I could not figure it out. The problem was times tables. I was not very good at it in 5th grade, like the other kids. It frustrated me when I knew how slow I was in learning. My grandparents always tried to help me with my homework, but in the end I would get mad and quit.

Animals were my escape from all the pain I was feeling. I felt alone because no one wanted to be my friend. The only way to get a friend was to tell my sad past. I did not want people to be my friend because they felt sorry for me, so I made my own world, where I was liked for who I was. This world of mine lasted all through middle school.

Until one day I was visiting the doctor, and my Nana talked about FAS, that I had it. My world was turned upside down, all the unanswered questions made sense. That I could not learn at a normal pace was because of this FAS.

I had to tell my best friend. But how would I explain this to her? My mind started to race. "What if she won't like me no more," I asked myself. The best thing to do was swallow my pride and tell her. The next day I sat her down and told her. When I finished, she didn't do what I was expecting her to do. She looked at me and started laughing! When I asked her why she was laughing, she simply looked at me and said, "So do I. It's nothing to freak about." I was so glad she told me that, because I had the courage to tell my other friends. I found out that half my friends had FAS. I knew when I met them that there was something that made us all click with each other.

When I began high school, I decided to work hard and try to make friends. I went to each class, worked hard, and tried to talk to anyone. Finally a girl named Crystal came up to me, and we started talking. We became friends instantly. I was so happy, and we had all our classes together.

Each year in high school, it got easier to make friends, and I became less shy. I even had a couple boyfriends. Things were finally going good.

So with that behind me, I was able to make it through high school and graduate and be the woman I am today. I am 18 now, and I'm learning to be a dog trainer.

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I'll never forget the day that I first realized the success I had achieved as a mother of a young adult with FAS. When the light of awareness went on in my mind, it was bright in contrast to the darkness I had been carrying for years. I had been somewhat depressed over the hopelessness of the idea that FAS is permanent brain damage for which there is no cure. What made this concept so devastating is that it is 100% preventable - theoretically speaking anyway.

My son John had just turned 18, that magical age when a person legally becomes an adult. But I knew that he really was and always would be a boy in a man's body, never able to function independently in the true sense of the word. He would always need supervision and support services. I had tried so hard all his life, worked so diligently, to help him achieve his potential, and it was hard for me to accept that, in spite of all my efforts, he would always need to be in the care of others to stay safe and well and living with a decent quality of life.

When I started my journey as John's mother, I was a foster parent for special needs babies, and John came to me a scrawny little thing a few weeks after his birth, only 4 pounds, with a diagnosis of FAS. As delighted as I was to have a diagnosis, it was not long until I learned that there was almost no information available regarding prognosis or intervention. His future was a big question mark, and I realized I might have to rely on my "whatever works" philosophy of intervention. After I adopted John, I followed Ann Streissguth's continuing studies on children and adolescents with FAS, and that helped me to know what behaviors to expect and what problems to try to prevent. As other parents know, day to day life was challenging, sometimes joyful, sometimes frustrating. And as John reached adulthood without the abilities to live as an adult, I felt discouraged that nothing I could do for him would reverse the physiological damage of FAS. Until my "awakening" to a new reality.

It was that September day in 1996 that Dr. Ann Streissguth revealed the results of her long-term studies on secondary disabilities associated with FAS disorders. I was sitting in the auditorium in Seattle with other conference attendees. Streissguth noted the primary disabilities associated with FAS - the delayed growth, the facial characteristics, the physiological anomalies, and the dysfunction of the central nervous system. I recognized that John had just about every primary disability that was mentioned. Then Streissguth talked about the secondary disabilities that the individuals in her study developed: mental health issues such as clinical depression that in 23% of adults led to suicide attempts; dropping out or getting kicked out of school, getting in trouble with the law, sexual assault, abuse of alcohol and other drugs. These are among the secondary disabilities that can result from of having FAS disorders, more devastating than the primary disabilities, and all preventable! It was at that moment that I realized that John had reached the legal adult age of 18 without having incurred any of the secondary disabilities! Streissguth reported that the protective factors include early diagnosis, stable home environment, and appropriate support services. John came to me with the first, and I provided the others. The joy I felt, the pride that I must have done something right in raising John to have helped him get at least this far in his life with absolute success!
The strategies I had been using all the years John was growing up were not just haphazard ideas applied blindly, they were carefully thought out strategies based on what I had learned from Streissguth and other FASD experts. There was a method to my madness, and that method was something I decided to record and distribute for other parents to use as guidelines in helping their children achieve success as well. My model for intervention has been used by many other families with great success, according to the feedback I have received.

There are seven basic components that I apply, and they happen to form the acronym SCREAMS.

- **Structure**: a regular routine with simple rules and concrete, one-step instructions
- **Cues**: verbal, visual, or symbolic reminders can counter the memory deficits
- **Role models**: family, friends, TV shows, movies that show healthy behavior and life styles
- **Environment**: minimized chaos, low sensory stimulation, modified to meet individual needs
- **Attitude**: understanding that behavior problems are primarily due to brain dysfunction
- **Meds & Diet**: most individuals can increase control over behavior with the right medications and good diet
- **Supervision**: 24/7 monitoring may be needed for life due to poor judgment, impulse control

**Structure**: Most people who know about Fetal Alcohol Spectrum Disorders are aware of the need for structure, but sometimes this is confused with control. While providing structure as a foundation, we need to offer choices they can handle, remain flexible, and remember KISS - Keep It Simple Sweetie! Here is a simple, concrete explanation of FASD that a parent can read with an affected child: **SCREAMS Article** There are three simple, concrete rules at the end of this article that every parent and child can discuss and memorize. The most important rule is the "B" rule: Be Respectful!

**Cues**: Giving cues can be tricky, as we tend to only give verbal reminders. I call it cueing; John calls it nagging. Kids with FAS respond well to visual cues, to symbols and signs, to music and rhythm. Check out **Do2Learn** for printable picture cards.

**Role models**: Children with FAS disorders learn behavior primarily by mimicking the behavior of others. This makes healthy role models extremely important. I am reminded of this saying: "Children learn by example; unfortunately they can't tell a good example from a bad one." We need to provide positive examples for dealing with frustration and anger, for appropriate social interactions, and for life styles that are healthy. Our kids need to be shown how to act in ways that will keep them out of trouble. John learned to walk away from being shoved or hit. He learned to express his anger with words that explain what he is feeling rather than words or actions that might hurt others. When we have observed unhealthy behavior, like inebriation or violence or disrespect, we talk about it and we play act healthy reactions to difficult situations that are likely to occur.
**Environment:** Behavior modification is not on my list, because it has not been reported to be very effective when dealing with FAS behaviors. Our kids might understand consequences, but they usually aren't able to learn from them. Time-out may not teach them to change their behavior either, but quiet time can be used when they are overwhelmed or over-stimulated as an opportunity to self-calm before rejoining a group. Behavior mod implies changing the child. What works better for our kids is to change the environment. Avoid noisy, crowded places; reduce the chaos; and prepare in advance some coping strategies for unavoidable situations that might be too stimulating. One overlooked factor in environment is diet - avoid all artificial additives (preservatives, coloring agents, aspartame, etc.), which may increase behavior issues. Here are some guidelines for healthy discipline.

**Attitude:** Understanding the nature of FAS as a neurological disability helps to minimize unrealistic expectations. Dr. Calvin Sumner stated that the greatest obstacle our kids must overcome is chronic frustration from unreasonable expectations of others. I believe this attitude of understanding by all who are in the individual's life could reduce the risk of depression and suicide tendencies later. The parents whose children experience the most success are those who have achieved an attitude of acceptance that their child may not fulfill their dream of "normalcy."
Again, unrealistic expectations for full independence might set the teen up to fail. The teens and young adults who enjoy the most success are those who have accepted the limitations of their disability and the need for protective restrictions. FASD and the Brain explains alcohol's impact on the developing brain that affects behavior later.

**Meds & Diet:** The right combination of medications can normalize the balance of brain chemicals, and can somewhat restore function and give the individual more control over behavior, increase memory and learning, and enable the individual to function more appropriately in social interactions. The individual can also function better with daily vitamin, extra B vitamins, Lecithin, and a diet that is free of artificial additives (read online article here) and preservatives. Here is a list of medications that parents and doctors have reported as helpful.

**Supervision:** Close monitoring is difficult to impose, especially as the child reaches the teen years and wants the same independence as they think their peers are given. Unfortunately, giving privileges due to an 18-year-old to a person with the judgment, conscience, and impulse control of a 6-year-old could result in total loss of freedom, if they end up in the hospital, on the streets, in jail, or in the morgue. Here is an explanation of the "External Brain" concept.

I have overcome criticisms of being overprotective and of not letting go. But my son is healthy and happy and productive, and I am proud of the success he has achieved. His quality of life is better than that of most non-disabled people. The only screams in our family are screams of excitement and joy. Especially now that John is pursuing a romantic relationship with a new female friend. But that's another story!

Once you get the hang of these SCREAMS strategies, you will be more likely to refer to them as the SMILES strategies!
INDEPENDENT LIVING FOR PEOPLE WITH FETAL ALCOHOL SPECTRUM DISORDERS

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

¹ Source: SAMHSA Fetal Alcohol Spectrum Disorders Center for Excellence
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%

**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/rsai/index.html?src=mr
- National Council on Independent Living, 703-525-3406, ncil@ncil.org, www.ncil.org

**Reference**


**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.
FASD Circle of Support
Finger Game

Directions:
1. Cut out the large square along outer edge. Place face down.
2. Fold opposite corners together diagonally (big triangle).
3. Crease and unfold. Repeat in the other direction.
4. Fold each corner almost to the center, along the gray lines.
5. Flip it over. Fold each corner to the center. 6. Fold in half.
7. Write the name of each of four people in your circle of support under each corner figure. Example: Mom, Dad, Counselor, etc.
8. Color each person/corner square a different color (four colors).
9. Put your thumbs and index fingers in the four corner pockets.
10. Ask a friend to pick a Circle of Support person's name.
11. Spell the person's name: open and close as you spell.
12. Ask the friend to choose a number from the inside.
13. Count the number (open, close). Choose a category.
14. Lift the flap and read 5 ways to be smart about FASD!

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HELPING FAMILIES DEAL WITH FASD: Suggested Readings

PUBLICATIONS


Text for kids and teens living with FAS/E. Also contains tips for advocating for services for children.

This book chronicles the life of the author’s son, Adam who was born with FAS. It received the 1989 National Book Critics Circle Award and the 1989 Christopher Award.

Damaged Angels: A Mother Discovers the Terrible Cost of Alcohol in Pregnancy by Bonnie Buxton 2004 Toronto: Alfred A. Knopf Canada
An adoptive mother welcomes a little girl not knowing she struggled with Fetal Alcohol Spectrum Disorder.

Dear World: We Have Fetal Alcohol Syndrome – Experiences of Young Adults
FASNET Information Series, 1997, FAS/E Support Network of B.C.
This booklet was written with the help of a group of young people with FAS/E. It is meant to be a guide to help young people with FAS/E understand what FAS/E is and what it means to them.

Faces of FAS: Putting a Personal Face on FAS by Beth McKechnie 2001. Winnipeg, MB: Manitoba Association for Community Living (MACL)
This booklet provides a personal perspective on the daily challenges and situations that families and parents face in raising their children with FASD. Contact: MACL, #210-500 Portage Ave, Winnipeg, MB R3C 3X1, Phone (204) 786-1607

or Email: aclmb@mb.sympatico.ca and Website: www.aclmb.ca

Fantastic Antone Grows Up: Adolescents and Adults with Fetal Alcohol Syndrome by Judith Kleinfeldm, Barbara Morse and Siobhan Wescott (eds.) 2000. University of Alaska Press
This is a guide to life with a teen or young adult with FAS or pFAS. The first section discusses the meaning of success for teens and adults with FAS. The second section discusses strategies that work in areas such as counseling, education, sexuality, trouble with the law, and independent living. Section three covers what families need from the community, including innovative programs that help individuals with FAS and how to get a diagnosis at adolescence. The book also contains important resources, organizations to contact, and Internet addresses.

FASD Strategies not Solutions by Stephanie Jones and Laura Cunningham, 2004, Region 6 Edmonton and Area Child and Youth. This Booklet is designed for caregivers and professionals who, in their everyday lives, encounter children and youth affected by Fetal Alcohol Spectrum Disorder. Readers should be aware that this Booklet provides strategies and suggestions for people who already have a base understanding of FASD. Available for on-line viewing and download at www.faslink.org/strategies_not_solutions.pdf

Fetal Alcohol Spectrum Disorder: A message to Police Officers about FASD. The Pas Family Resource Centre Inc. & RCMP 'D' Division 2003. Pas, MB
Developed for police officers, this pamphlet on Fetal Alcohol Spectrum Disorder (FASD) is a sample of materials being developed for a policy and community training initiative. With information on the physical and mental defects caused by alcohol use during pregnancy, this pamphlet outlines: key terminology, ways to identify those who may be affected by FASD; and ideas for working more effectively with FASD individuals in emergency situations.


Fetal Alcohol Syndrome: A Parents Guide to Caring for a Child Diagnosed with FAS Wake Forest University Health Services, 2004, Wake Forest University, School of Medicine.

This booklet is aimed at helping families with a child diagnosed with fetal alcohol syndrome (FAS). It explains what causes FAS, the symptoms of FAS, statistics, and how you can help your child with FAS reach his or her potential. Available at www.otispregnancy.org/readResource.php?r=108654


Presents parent-driven guidelines evolved from the first hand experience of those living with FASD and those that care for them and responds to a community need for tips, techniques and strategies that are empirically proven by parents themselves. Available for on-line viewing and download at www.von.ca/fasd/_fasdtool_fullproof_final.pdf

Letters To Our Children, Letters From Our Children: Living with Fetal Alcohol Syndrome and Alcohol Related Effects by Dorothy Badry and Liz Lawryk 2000. Alberta Association for Community Living

This is not a clinical textbook but a collection of stories written from the heart by parents, relatives, and caregivers who love their children and children who know they live life with a difference.


A book for young children with FAS/E. The booklet is about Amanda and her brother Jason who both have FAS/E. It explains in a very simple way what FAS/E is and how children are affected by it.


The story of a young teen diagnosed with FAE - permanent neurological brain damage due to prenatal exposure to alcohol. The book includes creative approaches in reaching and loving children with attachment issues; understand how alcohol affects the growing brains of children and become familiar with brain terminology; uncover ideas to help a child nutritionally; and wade through school and behavior issues with tears, laughter and strategies you may not have tried.


This parent/caregiver guide outlines the challenges faced by parents of children affected with FAS/E. It contains many easy to implement strategies.


Offers practical advice on dealing with FAS's lifelong effects on behavior and learning. It covers the historical, medical, and social aspects of FAS, and details common behavioral characteristics associated with the condition. Taking a developmental approach, the guide offers specific behavioral management techniques to be used with children with FAS from infancy through late adolescence. The author's own case studies are used to clarify psychological concepts and personalize FAS for the novice.

What Early Childhood Educators, Caregivers and Doctors -- Need To Know About Fetal Alcohol Syndrome (FAS) Manitoba Child Care Association and the Manitoba Healthy Child Initiative, Manitoba Education and Training. 2000 Winnipeg, MB: Manitoba Child Care Association; Manitoba Healthy Child Initiative, Manitoba Education and Training

This guide provides an overview of the characteristics and behaviors of children affected by prenatal alcohol exposure and highlights
general and specific guidelines to use in caring for infants, toddlers, and children.

- What Educators Need to Know About FAS audio cassette and manual
- What Early Childhood Educators Need to Know About FAS audio cassette and manual
- What Doctors Need to Know About FAS - CD and laminated FAS resource guide

Contact: Healthy Child Manitoba, 219 - 114 Garry St., Winnipeg MB R3C 4V6, Phone (204) 945-2266 Email: healthychild@gov.mb.ca
Website: www.gov.mb.ca/healthychild/fasd/fasdearly_en.pdf

WEBSITES

Advocating for the Student with FASD
www.come-over.to/FAS/schooladvocacy.htm
2001 Teresa Kellerman

Behavior Environmental Adaptation Model (BEAM)
www.come-over.to/FAS/BEAM.htm
The 15 BEAM Rules of FASD Behavior Management (Also known as the Fasstar Trek Model) by Teresa Kellerman 2004.

FAS Community Resource Center (FAS-CRC)
www.come-over.to/FASCRC
The website offers 164 articles written by Teresa Kellerman (FAS Consultant/parent and Coordinator of FAS Community Resource Centre) about FASD issues, both intervention and prevention. In addition to these, there are various non-article items such as an online quiz, an online simulation of FASD disabilities, an online store for FAS books, posters, handouts, brochures, guidelines for FAS Awareness Day, a collection of news reports and research abstracts, a collection of FASD resources, a list of online support groups, conference reports, collection of parents’ poems, a collection of families’ stories, and several photo galleries.
Contact: FAS Community Resource Centre Contact: FAS-CRC, 4710 E. 29th St. #7, Tucson AZ 85711.

The FAS Online Video Training Website:
www1.dshs.wa.gov/ca/fosterparents/videoFAS.asp

FASaholics Anonymous
www.come-over.to/FasaholicsAnonymous
Support site for parents/caregivers of children with FAS.

FASD Connections: Serving Adolescents and Adults with FASD
www.fasdconnections.ca
The website has a resource listing of FASD key documents on numerous subjects concerning adolescents and adults with FASD. Email: info@fasdconnections.ca

Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Related Conditions with Carolyn Harntess and Julie Gelo
These Internet online training videos on FAS are produced by Washington State Department of Social Services and are part of the Foster Parent Webcast Archive. Carolyn Harntess and Julie Gelo are the presenters and they provide an overview of FAS/FAE and intervention strategies that are helpful for the care of children or adults with FASD. The training consists of 2 separate sessions consisting of 3-45 min lectures.

SAMHSA Fetal Alcohol Spectrum Disorders Center for Excellence
Download the What You Need To Know Series by SAMHA:
- Independent Living for People with Fetal Alcohol Spectrum Disorders
  www.fasdcenter.samhsa.gov/documents/WYNKLIndLivin
- Understanding Fetal Alcohol Spectrum Disorders: Getting a Diagnosis
  www.fasdcenter.samhsa.gov/documents/WYNKDiagnosis_5_colorJA_new.pdf
- The Language of Fetal Alcohol Spectrum Disorders
  www.fasdcenter.samhsa.gov/documents/WYNKLanguageFASD2.pdf
- Tips for Elementary School Teachers
  fasdcenter.samhsa.gov/documents/WYNKTechersTips2.pdf
Contact: SAMHSA FASD Center for Excellence, 1700 Research Boulevard, Suite 400, Rockville, MD 20850; Phone 1-866-786-7327 or Email: fascenter@samhsa.gov

SCREAMS Model
www.come-over.to/FAS/ScreamsArticle.htm
How to minimize screaming, yours, not theirs by Teresa Kellerman.
Social Behavioral Challenges in Children with FAS/E
www.fasalaska.com/behavior.html

Staying Alive with the FASD Survival Plan
www.come-over.to/FAS/StayingAlive.htm
Sponsored by Teresa Kellerman

VIDEOS

FAS: When the Children Grow Up 2002. Knowledge Network B.C & Magic Lantern. This program tells the stories of adults living with FAS and FAE – some who were diagnosed early and others who were not – and the events, programs, and people who made a difference in their lives. 40 min

Fetal Alcohol and Other Drug Effects: A Four-Part Training Series for Parents and Professionals 2000. Fetal Alcohol Syndrome Consultation, Education and Training Services, Inc. (FASCETS) Set of 4 hour-long videos were developed to provide accessible, practical information and training to help parents, families, professionals, and to support program development. Part 1: Diagnostic Criteria: Effects of Prenatal Exposure, Part 2: Common Learning and Behavioral Characteristics, Part 3: Behaviors and Overlapping Diagnoses, and Part 4: Barriers to Identification: Historical, Cultural, Professional and Personal. Contact: FASCETS, PO Box 83175 Portland, OR 97283 Phone (503) 621-1271 or Email: dma@fascets.org.
EDUCATION OF THOSE WITH FASD
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.¹ 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.
**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.
7. Provide structure. Structure helps students with FASD make sense of their world.
8. Supervise. Students with FASD can be naïve 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
- Resources for Educators, depts.washington.edu/fadu

**REFERENCES**


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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 or call 866-STOPFAS.

06/04
This is a general outline to follow, step by step, to advocate in the U.S. education system for the child who has or may have Fetal Alcohol Syndrome (FAS) or Fetal Alcohol Effects (FAE), collectively referred to as Fetal Alcohol Spectrum Disorders (FASD). Before an actual IEP is written up, there are several actions to take in preparation for that step.

I. Gather Information. When asking for services for children with FASD, some school personnel may view the problems as ordinary behavior problems due to poor parenting, and may perceive the child as "lazy" and the parents as either "too lenient" or "overprotective." In cases where the school might be reluctant to evaluate the child for special ed, it is helpful to have some record of problems in the recent past that you have seen with your child that would have an adverse affect on the child's ability to learn. Collect all information from past testing or appointments and keep them in one place, and start an advocacy file.

A. Journal. Keep a journal and record all incidents and situations you observe. Write the date and time of each incident or behavior. Use the "ABC" method, listing the antecedent (a trigger to behavior, or what happened before the incident, or what might have contributed to it), the behavior, and the consequence, whether natural or imposed. Here is a pdf form you can use to chart behavior: http://www.dbpeds.org/pdf/abcform.pdf. Use this worksheet to identify behaviors: http://come-over.to/FAS/FBAworksheet.pdf

B. Documentation. Keep a log of every conversation you have with school personnel regarding your child.

C. Identify your concerns. Make a list of all your concerns. Pick out the most important ones that you want to deal with first. Besides areas of need that will be revealed by evaluations (below), areas of concern regarding a child's needs in a school setting include the following issues, which should be written into the IEP:

- **Training** of all staff on FASD issues
- **Communication** log for sharing information between home and school
- **Supervision** at all times, including on the bus, before school, on the playground, in the cafeteria, in the locker room, and all other times in and out of the classroom.

II. Educate yourself. Know your rights. Check up on current law regarding special education. Sometimes parents know more about IDEA law than the school, and this can work in your favor because no one will try to get away with sidestepping the law with regard to your child’s IEP, and they will be less likely to intimidate you at IEP meetings.

A. IDEA stands for Individuals with Disabilities Education Act Amendments. Here are some links that can be helpful:

- [http://www.reedmartin.com/](http://www.reedmartin.com/) - Reed Martin is a lawyer with practical suggestions, articles, and a newsletter.

B. Protection and Advocacy. Every state has a Protection and Advocacy agency, paid for by your tax dollars, that can provide you with answers to questions, quotations of the law, training workshops, handouts and booklets, legal advice, and even legal representation in certain cases they
may choose to take and fight on your child's behalf. It is good to be familiar with your local P&A. Sign up for a class, or talk to a lawyer or volunteer, just to have a contact. Here is where to find your local P&A office: http://www.napas.org/aboutus/PA_CAP.htm. At the very least, ask them for a copy of your rights as a parent of a child with special needs.

C. FASD Information. Educate yourself well about FASD and be ready to offer information on FASD to the school personnel. Rather than hand them a stack of papers that you have downloaded off the Internet, which is too overwhelming to read and might end up in the waste basket, give them each a copy of the brochures on FASD that are available here: http://come-over.to/FAS/brochures/ Find someone locally who knows what FASD is and who understands how it can impact a child's ability to learn, and ask that person to advocate with you. Although you as the parent are THE expert on your child, and probably know more about FASD than anyone else on the team, your credibility might be questioned, and they are more likely to listen to an outside party that you bring in as an expert, even though you know just as much as they do.

D. Disability Groups. If your child is developmentally disabled (IQ under 70), join The Arc. If your child has normal IQ but has an attention deficit like ADD or ADHD, join CHADD. If your child has co-occurring mental health issues, join NAMI. You will learn more about how to access local services from other parents than from any other source.

III. Assessments and Evaluations. Sometimes parents or others only suspect that the child may have FASD. In most cases, the effects of prenatal alcohol exposure are not recognized early and often a diagnosis has not been made before the child enters the school system.

A. Medical Assessments. Concerns and suspicions should be taken to the child's primary care physician, who can either make a diagnosis or make a referral to a geneticist or neurologist who is trained in making a diagnosis of FASD. Sometimes a geneticist will suggest DNA tests to rule out genetic disorders. If there is any documentation of alcohol exposure during pregnancy, that will be helpful to provide. This can be an admission by the birth mother or it can be a report from a family member or physician or other reliable witness. Having anything in writing that suggests there was alcohol consumption during pregnancy, such as a social worker's report, might be valuable. The IEP must consider all outside reports from private sources that you submit.

B. Psychological Evaluation. A psych eval can and should be done by the school system. A parent can request that an evaluation be performed. Call the principal and tell him/her of your concerns. Follow up with a written request for an evaluation of your child. If the school refuses, they must provide a written explanation. Although most children with alcohol related disorders test in the normal range, they may have areas of high ability and areas of difficulty, and these problem areas are not reflected in an IQ score. There are areas of concern that should be assessed, including fine motor skills, social skills, visual-spatial skills, adaptive behaviors, and functional ability. Be sure to include this information in your written request.

a. IQ test. Schools most frequently use the Wechsler test, known as the WISC-III. Other IQ tests may show similar results in children with FASD. The WISC-III gives a composite score of 10 subtests, with a composite score for Verbal IQ and a composite score for Performance IQ. A "normal" IQ score does not actually mean a child has normal cognitive function. Most often, children with FASD will have an composite score in the normal range, but a composite score will not show scatter scores of highs and lows in specific subtests, such as auditory processing or short term memory. In some states, a child's eligibility for DD services (services for individuals with developmental disabilities) could depend on getting a score under 70. These services are separate from educational services, but the tests administered at school now could assist in getting other services later, such as respite care and medical services. To understand test scores, see the link under "Reports" below.
b. **Visual-spatial test.** The Bender Visual Motor Gestalt (BVMGT) can determine visual processing ability, and the Human Figure Drawing (HFD) can be administered to assess ability to conceptualize visually.

c. **Social skills test.** Functional abilities, communication skills, and social skills can be measured best using the Vineland Adaptive Behavior Scales (VABS). There is a test being developed called the FAS Adaptive Behavior Scales (FABS), but until it is released, we can rely on the Vineland to show problems in functional abilities. This is a questionnaire with several hundred questions about the child's ability to perform tasks, communicate, and participate in typical daily living activities. There is a version for parents and a version for teachers. It is recommended that the version for parents be administered to get a more thorough idea of how the child performs over-all. The score of the Vineland for a child with FAS or FAE is expected to be much lower than the child's IQ, sometimes by 20 or 30 points. Parents should answer the questions honestly, in a way that truly reflects the child's ability. If the question asks if the child can brush his own teeth, a parent might want to answer "yes" but if the child forgets to use toothpaste unless reminded, and needs to be watched to be sure he brushes adequately or can't really do a thorough job without help, then the correct answer should be "no, not by himself, he needs assistance." This is not the time to "brag" about the child's one-time or infrequent accomplishments. How the question is answered could determine how the psychologist scores the points on the test. Here is a sample letter requesting a school to administer the Vineland: http://www.come-over.to/FAS/VinelandRationale.htm

**C. Reports.** Every test or evaluation should have a report written by the professional who administered the test and should be given to the parent, with an opportunity to explain the results. Sometimes parents can request "raw data" from the testing, which will show subtests such as those on the Woodcock-Johnson or the Vineland that will be helpful to understand and use for planning to meet the child's needs when writing the IEP. Be sure to request copies of these reports and any data to which you might legally be entitled. Here is a site that will show you how to interpret the scores: http://www.wrightslaw.com/advoc/articles/tests_measurements.html

**IV. M.E.T.** The M.E.T. stands for Multidisciplinary Evaluation Team. This team is formed before an IEP is written to determine if the child qualifies for special ed and what evaluations will be performed. Typically, the team includes the school psychologist, the child’s teacher, and a special education teacher. If the child has a suspected or confirmed disability, then an expert in the field of the disability should be on the team. Often the parent is more of an expert than anyone else, but to find someone in your area that can act as the FASD expert, look in the USA FAS Resource Directory: http://www.nofas.org/resource/directory.aspx It is important to have an FASD expert give input to the team to ensure that all the proper assessments are done. If the team decides that your child is not eligible for an IEP, refer to the following article on how to resolve an eligibility dispute: http://www.wrightslaw.com/advoc/ltrs/eric_eligibility_disputes.htm.

**V. Individualized Education Planning Team** The IEP team includes the regular teacher, a special ed representative, and a member of the MET. By law, parents must be invited to be active participants in the meeting. An explanation of the IEP team can be read here: http://www.resa.net/sped/parent/iept.htm

**A. Labels.** There are many labels for classification of special ed, including but not limited to: MR (mental retardation), LD (learning disabled), EH (emotional handicap), MH (multiple handicaps), and OHI (other health impaired). If your child has an IQ low enough to qualify for the MR label, that is an appropriate classification. If your child's disabilities are mild, then the LD label could be helpful. If your child has mental retardation and physical disabilities, then MH would be appropriate. The least favorable label for the child with FASD is EH because placement in the EH
classroom is not the best environment for a child with FASD to learn, and the approach to behaviors is based more on psychological basis than on a neurological basis. The best classification for the child with FASD is OHI, Other Health Impaired. This is appropriate because FASD is a neurological impairment of a physiological nature.

B. Objectives. Goals and objectives for your child should be based on the results of the assessments made earlier. Goals and objectives for a child with FASD should include social skills, and expectations should be reasonable and based on the child's level of development as noted in the Vineland test results. Here is a game plan for writing goals and objectives: http://www.wrightslaw.com/advoc/articles/plan_iep_goals.html

C. Placement. Become familiar with the legal meaning of the term "least restrictive environment." Sometimes, for children with FASD, restrictions offer needed structure and reduce factors that contribute to some of the problems. In most cases the "least restrictive environment" for a child with FASD is one with many environmental controls. Just because your child has an IEP does not necessarily mean your child will be placed in a special ed classroom. The classroom and classification that is right for your child depends on your child's unique needs, on the environment of the classroom, and on the education and attitude of the teacher.

1. Regular Classroom. Inclusion in the regular classroom might work, if the teachers and aides are educated about the nature of alcohol related disorders and if adequate one-on-one is provided. However, the regular classroom is usually to chaotic and the child with FASD is likely to become frequently overwhelmed from sensory overload due to the level of noise. Regular teachers are seldom trained to work with children with FASD, and conventional behavior management might not only be less effective but could make the problems even worse.

2. EH Classroom. Many children with FASD are placed in a classroom with children who have serious behavior problems. This may or may not be the best placement for the child with FASD. If the other children's inappropriate behavior is a model for your child to imitate, or if the teachers approach your child's behavior problems solely from a psychological perspective, then the EH classroom will probably not work well. But if the teacher is knowledgeable about the nature of FASD and knows and practices the techniques that are known to work well with children with alcohol related disorders, then this placement could work.

3. Special Ed Classroom. Other classrooms, such as those for children with MR (mental retardation) or MH (multiple handicaps) classifications, can be an option for the child with FASD, as a full time placement or as a "pull out" for special assistance. Some experts believe that the ideal classroom for the child with FASD is the one designed for students with autism, because that provides for a quiet environment with adequate structure and favorable staff ratio.

4. Homeschool. Some parents do not wish to go through the struggles of changing the school system to meet their child's needs, and choose to homeschool. After having suffered from chronic frustration of unrealistic expectations and feelings of failure in the school system, children with FASD seem to do very well when homeschooled. Some parents would like to homeschool but fear they will not have the information or stamina to do so, but most who try it wish they had not waited so long to pull their child out of regular school. Here is how to get an idea if homeschooling is for you: http://www.come-over.to/homeschool/

D. Conflict Resolution. Here is a simple plan to help you resolve IEP conflicts easily: http://www.come-over.to/FAS/IEP123Plan.htm Print it out and take it with you to every IEP meeting. Even if you don't have a conflict, this will help prevent any conflicts from occurring.

VI. Teresa's Tips
- **Know where to go for help.** Bookmark this page so you can find it when you need it. Ask a friend to go with you to the IEP meeting. Talk to someone at one of the organizations mentioned above.

- **Do your homework.** Think of this as a class you are taking. Give yourself time to study the information on the links provided, and take notes to put in your folder or notebook.

- **Avoid becoming an adversary.** When it's you against them, they usually win. Think "team work" and remind everyone that we all have the same goal, to set up a program that will help your child succeed in school. Everyone wants your child to succeed. It's okay to get angry, but vent your emotions with a trusted friend or family member, and go into the IEP meeting with a cool head, armed with facts. It is much easier to work WITH the team than to work against the team.

- **Think positive.** When making a complaint, be ready to propose some possible solutions. When you go in to discuss a problem, begin the conversation with a few issues you are pleased with to balance your attitude and defuse the need for defensiveness. Visualize how the situation will look when your child's needs are being met in school.

- **Stay healthy.** Protect yourself and your child by following these important Dietary Recommendations: [http://come-over.to/FAS/DietRecommendations.pdf](http://come-over.to/FAS/DietRecommendations.pdf)

- **Give yourself a pat on the back.** You deserve credit for having read this article all the way through. You also deserve credit for seeking ways to make your child's life easier. FASD issues are difficult enough to cope with on a daily basis, but struggling with educators and professionals who don't understand FASD is even more difficult. Know that you are not alone, and that you can do it. Now go take a break and do something nice for yourself.
EDUCATION OF THOSE WITH FASD: Suggested Readings

PUBLICATIONS

Challenges and Opportunities: A Handbook for Teachers of Special Needs with a Focus on Fetal Alcohol Syndrome (FAS) and Partial Fetal Alcohol Syndrome (pFAS) by P. Lasser 1999. Vancouver, BC: Vancouver School Board
Written by a teacher and reviewed by teachers, parents, and advocates of students with FAS/E, this handbook puts a “human face” on FAS/E by providing pictures and quotes of students who live with FAS/E and vignettes from their lives. It contains 200+ teaching strategies.

This book is a field guide to life with an adolescent or young adult with FAS/E. Chapters include information on how prenatal alcohol exposure affects children and their families; parenting approaches and strategies that work (i.e. education, counseling, sexuality, trouble with the law, & living skills); and what families need from the community.

This booklet was written to help parents of children with FAS/E advocate for services within the school system. It outlines steps to follow in keeping records about their child, explains the IEP (individual education plan) and how to work with the teacher. Various cognitive, behavioral and language assessment scales are described. Contact FAS/E Support Network of B.C. #108, 17767- 64th Avenue, Surrey, BC V3S 1Z2, or Phone (604) 576-9911 Email: info@fetalalcohol.com

This manual has four main purposes: 1. It is a resource that educators can use to make a difference in the lives of their students. 2. It offers hope in cases where educators may feel their efforts are failing to help students grow to their full potential. 3. It provides guidelines for establishing relationships with individuals afflicted by FASD, as well as with their families and communities. 4. It provides educators with easy access to information that can be used in their classrooms to help students with FASD. Available on-line at www.education.gov.yk.ca/pdf/fasd_manual_2007.pdf

Reach to Teach: Educating Elementary and Middle School Children with Fetal Alcohol Spectrum Disorders, DHHS Pub. No. SMA-4222. Rockville, MD: Center for Substance Abuse Prevention, Substance Abuse and Mental Health Services Administration, 2007.
Reach to Teach is a resource for parents and teachers to use in educating elementary and middle school children with fetal alcohol spectrum disorders (FASD). It provides a basic introduction to FASD, which results from prenatal alcohol exposure and can cause physical, mental, behavioral, and/or learning disabilities, and provides tools to enhance communication between parents and teachers. Available on-line at www.fasdcenter.samhsa.gov/documents/Reach_To_Teach_Final_011107.pdf

This resource includes: background and terminology that will help educators understand the current diagnostic definition of FASD. It also explains the diagnostic process, primary and secondary disabilities, and the strengths and protective factors often seen in students with FASD; key considerations for planning effective education programs; suggestions for how to build a positive classroom climate and maintain a supportive learning environment; overarching strategies on how to structure the learning environment, develop effective routines, build skills for whole class instruction, teach social and adaptive skills, and help students generalize new skills and concepts. Available on-line at education.alberta.ca/media/377037/fasd.pdf

This resource guide is organized around areas of concern identified by experienced classroom and integration support teachers. Its goal is to provide teachers with a clear understanding of the needs of students with FAS/E. Includes section on social skills and how to teach them. Many of the strategies are general and may be appropriate for use with students who are not diagnosed with FAS/E, but who do share some of the learning needs of students with FAS/E. Download the resource: www.bced.gov.bc.ca/specialed/fas/ or contact: BC Government Publication Services, 563 Superior Street PO Box 9452 Stn Prov Govt Victoria, BC V8W 9V7 Phone: (250) 387-6409

A guiding principle of the authors was that, although all children have the capacity to learn, they do not all learn in the same way. These suggestions are intended for teaching children with ARD.


This is a planning resource intended to provide support to student service administrators, principals, classroom teachers, resource teachers, school counselors, clinicians, and other community professionals who will help in assisting schools in developing approaches for students who are alcohol-affected. Specifically, the planning resource will provide: • processes and systems that can be used by a school/division to address the needs of students who are alcohol-affected
  • strategies and interventions for individual students
  • sample tools including forms and support materials

Download the resource: www.edu.gov.mb.ca/ks4/specedu/fas or contact: Program and Student Services Branch: Manitoba Education, Citizenship and Youth, W110-1970 Ness Ave., Winnipeg, MB R3J 0Y9 or Phone (204) 945-2070 or Email: lmclean@gov.mb.ca .

Your Victory: A Happy Child…Supportive Strategies for the Staff of Children’s Summer Camps and Recreation Programs by R. deBree, 2001, Duncan, B.C.

This booklet provides basic information on FAS and strategies for staff who will be coordinating or working with children in recreational and summer programs.

VIDEOS

Learning Disabilities and Social Skills with Richard Lavoie PBS Home Video 1994 62 min Subtitle is Last One Picked On.

Parent’s guide on helping children who have learning disabilities address social problems. Theses children often encounter and the video helps explain why this happens and what parents can do to help with practical solutions.


http://www.edu.gov.mb.ca/ks4/specedu/fas
**Students Like Me**  Vida Health Communications, Inc. 1996. 49 min

Students Like Me was created to help elementary and special educators understand what Fetal Alcohol Syndrome is and provide teaching methods to help children affected by fetal alcohol reach their full potential. Includes:

- How to recognize a child with FAS in the classroom
- How to modify the class environment and adjust teaching methods
- How to communicate clearly and plan transitions and unstructured time

Contact Vida Health Communications toll free phone: 1-800-550-7047.
FASD AND THE COMMUNITY
Ain’t Misbehavin’

Without an understanding of the physically-based cognitive challenges faced by people with Fetal Alcohol Related Conditions, typical, normal behaviors can be misinterpreted as willful misconduct or deliberate disobedience, when it is often just the opposite.

Information Processing Differences

Due to the way the brain was developmentally affected, people with Fetal Alcohol Related Conditions have difficulty with the following:

- Input, or taking in of information
- Integration of new information with previous learning
- Memory, especially short-term memory
- Output, or ability to use information

Children and adolescents prenatally exposed to alcohol have difficulty with:

- Abstract Reasoning – Abstract concepts are the invisible foundation that structures our world.
- Cause and Effect Reasoning – People with Fetal Alcohol Related Conditions often can’t imagine something they haven’t experienced.
- Generalization – They can’t make parts of the thinking process; so, when you change a piece of the routine for a child, you’ve created an entirely new routine.
- Time – Telling time, feeling the passage of time, associating specific activities to numbers or a clock, cyclical nature of events.
- Memory – Especially short-term memory.

They have difficulty with socialization and skills of independence.

Fetal Alcohol Syndrome is a lifelong disability, but “Secondary Characteristics” may occur, such as:

- Fatigue, tantrums
- Irritability, frustration, anger, aggression
- Fear, anxiety, avoidance, withdrawal, shutdown, lying, running away.
- Trouble at home and/or school
- Legal trouble, drug/alcohol abuse
- Mental health problems

These secondary conditions are preventable when parents and professionals understand the cognitive challenges associated with a child’s history of prenatal exposure to alcohol.

Behavioral Expectations of Children and Adolescents with FAS/E:

Age-appropriate vs. developmental age-appropriate expectations:

Typical 5-year olds...
- Go to school
- Follow 3 instructions
- Interactive, cooperative play
- Share
- Take turns

Typical 10 year olds...
- answer abstract questions
- get along with others, solve problems
- learn inferentially
- academic and social
- physical stamina
- generalize information learned from worksheets

Developmental age with FAS/E: 10 years going on 6 years...
- learn by doing, experientially
- mirror and echo words, behaviors
- supervised play, structured play
- learn from modeled problem solving
- easily fatigued by mental work

Typical 18 year olds...
- on the verge of independence
- maintain a job and graduate from school
- have a plan for life
- budget own money
- organize

Developmental age with FAS/E: 18 years going on 10 years...
- needs structure and guidance
- limited choices of activities
- in the “here and how,” little projection
- giggles, curiosity, frustration
- gets an allowance
- gets organized with help of adults

“My way or no way”

www.fasstar.com

They often talk better than they think.
They can “talk the talk”
but can’t “walk the walk.”
Fetal Alcohol Syndrome

Fetal Alcohol Syndrome (FAS) and other alcohol related birth defects refer to a group of physical and mental birth defects resulting from a woman drinking alcohol during pregnancy.

Four primary diagnostic criteria indicate full Fetal Alcohol Syndrome:

- Growth deficiencies – stunted prenatal and/or postnatal growth.
- Permanent brain damage resulting in neurological abnormalities, delay in development, intellectual impairment, learning/behavior disorders.
- Abnormal facial features: short eye openings, short nose, flat mid-face, thin upper lip, small chin.
- Maternal alcohol use during pregnancy.

Some but not all of the primary diagnostic criteria for FAS can lead to such diagnoses as:

- Fetal Alcohol Effect (FAE)
- Alcohol Related Neurodevelopmental Disorder (ARND)
- Fetal Alcohol Related Conditions (FARC)
- Alcohol Related Birth Defects (ARBD)

Alcohol is a teratogen that affects whatever is developing in her fetus when a pregnant woman drinks. Whether or not her child has the specific physical characteristics of FAS simply depends on when and how much the other drank alcohol. However, the brain is developing throughout gestation, and prenatal exposure to alcohol at any time during pregnancy can alter the development of the baby’s brain.

Prenatal exposure to alcohol causes an “invisible disability” that manifests behaviorally. Many children have the brain damage without all of the physical dysmorphology of full FAS, which remains others of their disability.

“We see what we look for, and we look for what we know.”
Goethe

FAS in a Nutshell

- FAS is the leading known cause of mental retardation.
- Most individuals with FAS have normal intelligence.
- FAS causes serious social and behavior problems.
- Each year in the US 5,000 babies are born with FAS.
- Ten times as many are born with alcohol related disorders.
- No amount of alcohol is known to be safe during pregnancy.
- Alcohol causes more damage to baby than any other drug.
- Fas and related conditions are 100% preventable.

www.fasstar.com

Ain’t Misbehavin’

Understanding the Behaviors of Children and Adolescents with Fetal Alcohol Syndrome

By Deb Evensen
dbeevensen@alaska.net

For more information on Fetal Alcohol Syndrome And related conditions Please visit: www.fasstar.com
PSYCHOSOCIAL NEEDS ASSOCIATED WITH FAS & FAE
Prepared by Robin LaDue, Ph.D., Fetal Alcohol & Drug Unit, Dept.of Psychiatry & Behavioral Sciences, University of Washington School of Medicine, Seattle, Washington
(Reprinted with permission)

General Issues
· Early and adequate identification and diagnosis
· Safe, stable and structured home or residential placement
· Unrealistic expectations of persons with FAS/E due to the outward appearance and verbal, gregarious manner
· Appropriate academics, vocational and living skills training programs

Infancy & Early childhood: Ages 0-5 Years

Problems and Concerns
· Poor habituation
· Sleep disturbances; poor sleep/wake cycle
· Poor sucking responses
· Failure to thrive
· Delays in walking and talking
· Delayed toilet training
· Difficulty following directions
· Temper tantrums and disobedience
· Distractibility

Recommendations
· Early identification
· Intervention with birth and/or foster parents
· Education of parents regarding physical and psychosocial needs of an infant or child with FAS/E
· Careful monitoring of physical development and health
· Safe, stable and structured home
· Assignment of a case manager for coordination of services and support to parents
· Placement of the child in preschool
· Respite care for caretakers

Latency Period: Age 6-11 Years

Problems and Concerns
· Easily influenced and difficulty predicting and/or understanding consequences
· Give an appearance of capability without actual abilities
· Difficulty separating fact from fiction
· Temper tantrums, lying stealing, disobedience and defiance of authority
· Delayed physical and cognitive development
· Poor comprehension of social rules and expectations

Recommendations
· Safe, stable and structured home or residential placement
· Careful and continued monitoring of health issues and existing problems
· Appropriate education and daily living skills placement
· Help caretakers establish realistic expectations and goals
· Caretakers establish realistic expectations and goals
· Caretaker support group
· Psychological, educational and adaptive evaluations on a regular basis
· Use of clear, concrete and immediate consequences for behavior
· Respite care for caretakers
· Case manager role expands to include liaison between parents, school, health care providers and social service agents
Adolescence: Ages 12-17 Years

Problems and Concerns
- Lying, stealing and passivity in responding to requests
- Faulty logic
- Egocentric; has difficulty comprehending and/or responding appropriately to other people's feelings, needs, and desires
- Low motivation
- Low self-esteem
- Academic ceiling, which is usually around grade 4 for reading and grade 3 for spelling and arithmetic

Recommendations
- Education of caretakers and patients regarding sexual development, birth control options and protection from sexually transmitted diseases
- Planning and implementation of adult residential and vocational training and placement
- Appropriate and mental health interventions as needed
- Respite care for caretakers
- Caretakers support group
- Safe, stable and structured home or other residential placement
- Shifting of focus from academic skills to daily living and vocational skills
- Careful monitoring of social activities and structuring of leisure time
- Working towards increased independence by teaching to make healthy choices (taught at the child's level)

Adulthood: Ages 18+ Years

Problems and Concerns
- Residential placement
- Economic support and protection
- Job training and placement
- Depression and suicidal ideation
- Pregnancy or fathering of a child
- Social and sexual exploitation, or inappropriate behavior
- Increased expectations of the patient by other people
- Increased dissatisfaction towards the patient by others
- Withdrawal and isolation
- Unpredictable behavior

Recommendations
- Guardianship for funds
- Specialized residential and/or subsidized living
- Specialized vocational and job placements
- Medical coupons
- Acceptance of the patient's "world"
- Acknowledgement of the patient's skills limitations
- Patient advocates to ensure the above occurs
Social Behavioral Challenges in Children with FAS/E

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Understanding the cognitive differences associated with a history of prenatal exposure to alcohol is crucial in supporting a child with FAS/E from infancy through adulthood. With this knowledge comes the ability to provide positive behavioral and academic support so that the child does not develop secondary disabilities (i.e., emotional problems, trouble in school, addictions) and is able to develop according to full potential.

มากกว่าInformation Processing Deficits(105,603),(999,641)

Difficulty with input, integration, memory and output of information results in an inability to understand cause and effect. This means that, although a child is able to communicate a surface understanding of expectations he/she may be unable (not unwilling) to perform as expected. Developmentally, social and emotional functioning is far below the child’s chronological age. For example, a teenager with FAS could be described as a "stretch toddler" in understanding of social situations. Typically, a child with FAS/E will need consistent management and structure from childhood into adulthood.

(105,724),(999,765)(105,765),(999,807)

Lack of Generalization Skills

The inability to generalize information learned puts a child with FAS/E at high risk for getting into trouble during childhood, adolescent, and adulthood years. Because of this lack of generalization skills, a child/adolescent/adult who experiences FAS may be unable (not unwilling) to "see the whole picture," and has difficulty linking ideas together or taking what is learned in one setting and putting it into practice in another.

Concrete vs. Abstract Understanding

A common characteristic of people with FAS/E is the inability to understand the abstract meanings of the concepts which structure our social world. Many are able to "talk the talk, but not walk the walk," and this incongruity leads to misinterpretation of their behaviors/intent by those not understanding the disability. People with FAS/E need a nurturing, stress-free, simple environment with few changes from day to day where lifelong habit patterns of behavior can be learned.
Socialization and Skills of Independence

The emotional/social understanding of a child with FAS/E is far below chronological age. Due to the way his/her brain processes information and remembers what has been learned, it is essential that education be based on daily life.

Anxiety/Frustration Levels

Due to the difficulty a child/adolescent/adult with FAS has understanding expectations and combining ideas to make a whole, he/she can easily be over-stimulated and frustrated. Anxiety can lead to the inability to make sense of a situation or to think things through or "FAS Shutdown". People with FAS/E need a stress-free environment to in order to learn.

developed by Deb Evensen and Jan Lutke
FASD AND THE COMMUNITY: Suggested Readings

PUBLICATIONS

This report includes excerpts of life stories of individuals with FAS as well as a discussion of a number of issues and experiences that participants have told about day-to-day living with FAS/E. These issues and experiences have been divided into different topic areas (e.g. accomplishments, employment, education, parenting with FAS/E, independence, justice.). The Implications section outlines directions for advocacy, supportive policies and effective practices for adults living with FAS/E as identified through this research.

FASD Strategies not Solutions by Stephanie Jones and Laura Cunningham, 2004, Region 6 Edmonton and Area Child and Youth. This Booklet is designed for caregivers and professionals who, in their everyday lives, encounter children and youth affected by Fetal Alcohol Spectrum Disorder. Readers should be aware that this Booklet provides strategies and suggestions for people who already have a base understanding of FASD. Available for on-line viewing and download at www.faslink.org/strategies_not_solutions.pdf

Topics covered in this book include: an overview of FAS and diagnostic process, teratology and brain damage, physical and behavioral manifestations, a model for advocacy, guidelines for employment and education, effective services for high risk mothers, and addressing public policy.

This book provides information about people with FAS/E in the criminal justice system. Judges, Lawyers, probation, and parole officers, those working in the legal system with find this tool an excellent resource. Available from the Asante Centre Tel: (604)467-7101 Email: info@asantecentre.org

Fetal Alcohol Spectrum Disorder (FAS) and the Role of Family Court Judges in Improving Outcomes for Children and Families by Diane Malbin, Juvenile and Family Court Journal, 55(2): 53-63, Spring 2004

Fetal Alcohol Syndrome: Implications for Correctional Service by Correctional Service of Canada 1998. Corrections Canada: Ottawa, ON
This report reviews the literature on Fetal Alcohol Syndrome from the perspective of the implications this condition might have for the criminal justice system and for Correctional Service Canada. The report is presented in three parts. Part 1 provides a basic background about the disorder. Part 11 traces the course and consequences of this condition, including the connection to delinquency and crime. Part 111 considers the possibility of identifying fetal alcohol syndrome and related effects in individuals who come in contact with the criminal justice system, and how institutional and post-release programs might best fit their needs. Download the resource: www.csc-scc.gc.ca/text/rsrch/reports/r71/r71_e.pdf

The goal of this resource is to raise awareness of the effects and characteristics of fetal alcohol spectrum disorder (FASD) through learning activities that teachers can incorporate into the health and life skills, and Career and Life Management programs. It provides strategies, activities and student information sheets focusing on the prevention of alcohol use and abuse during pregnancy. A handout for community resource people offers tips for working with students and outlines the specific goals and learning outcomes for the health program. Contact: Learning Resources Centre, 12360 - 142 Street, NW Edmonton, AB T5L 4X9; Phone (780) 427-2767 or toll free 1-888-310-7777; Email:
This drug awareness program targeted to “tough kids” provides educators and other youth community professionals with practical strategies related to educating this group about alcohol, inhalant and other drug issues.

Trying Differently: A Guide for Daily Living And Working With FAS And Other Brain Differences by Debbie Trudeau (ed.) and the Fetal Alcohol Syndrome Society Yukon (FASSY), 2002, Whitehorse, YT: FASSY. Provides a general overview of FAS and offers advice for individuals affected by prenatal alcohol exposure. It provides strategies and suggestions to help them manage in a number of areas including daily routines and structure, life skills, and community issues. It also stresses self-care for parents and caregivers.

WEBSITES

FAS Community Resource Center (FAS-CRC)
www.come-over.to/FASCRC
The website offers 164 articles written by Teresa Kellerman (FAS Consultant/parent and Coordinator of FAS Community Resource Centre) about FASD issues, both intervention and prevention. In addition to these, there are various non-article items such as an online quiz, an online simulation of FASD disabilities, an online store for FAS books, posters, handouts, brochures, guidelines for FAS Awareness Day, a collection of news reports and research abstracts, a collection of FASD resources, a list of online support groups, conference reports, collection of parents’ poems, a collection of families’ stories, and several photo galleries.
Contact: FAS Community Resource Centre
Contact: FAS-CRC, 4710 E. 29th St. #7, Tucson AZ 85711.

FASD and the Justice System
fasdjustice.on.ca/
This site is designed for justice system professionals and others who want to understand more about FASD. It provides information and resources about Fetal Alcohol Spectrum Disorder (FASD), including background information, case law, legal resources and strategies for effective intervention.

VIDEOS

Fetal Alcohol Syndrome and the Criminal Justice System - Understanding the Offender with FAS 2000. Asante Centre, Vancouver, BC
Set of 3 videos Talking With Victor 43 min, A Judge's Perspective 56 min, and Mistakes I Have Made 28 min. Based on the publication ‘FAS and the Criminal Justice System by Conry and Fast, this series of videos explores the unique considerations facing individuals with FAS that come in contact with the criminal justice system such as: The implications of FASD in the Canadian Charter of Rights and Freedoms; The concept of “Not Criminally Responsible by Reason of a Mental Disorder; The tendency for clients with FASD to be impressionable, suggestible and easily mislead; Examples of assumptions that may seem reasonable for a typical client, but would not be appropriate for a client with FASD; and The importance of obtaining an FASD assessment.
FINDING FASD
INFORMATION, WORKSHOPS
AND CONFERENCES
FINDING FASD INFORMATION, WORKSHOPS AND CONFERENCES

FASCETS: Fetal Alcohol Syndrome Consultation, Education and Training Services
www.fascets.org/

FASD Information & Consultation Service: Canadian Centre on Substance Abuse (CCSA)
www.ccsa.ca

FASlink: Canadian Fetal Alcohol Syndrome Internet Information and Support Communications Link.
www.acbr.com/fas/faslink.htm
FASlink maintains both an extensive FAS information website and a discussion listserve. FASlink's website and the FAS InfoDisk/CD ROM (resource list for purchase) are updated regularly along with other electronic publishing projects. FASlink also publishes brochures and electronic media for distribution. Contact: FASlink, 2445 Old Lakeshore Road, Bright's Grove, ON N0N 1C0; Phone (519) 869-8026 or Email: FASlink@acbr.com

Fetal Alcohol Spectrum Disorders (FASD) Center for Excellence Website. US Department of Health and Human Services Substance Abuse and Mental Health Services Administration (SAMHSA)
www.fascenter.samhsa.gov
SAMHSA is a US Federal initiative devoted to preventing and treating FASD. The website provides information and resources about FASD. The site offers information on training, technical assistance and materials you can use to raise awareness about FASD. The website provides many resources including a searchable online FASD Resource library; events calendar; and resource list of what experts recommend as a starting point for caregivers and parents to begin understanding FASD. Contact: SAMHSA FASD Center for Excellence, 1700 Research Boulevard, Suite 400, Rockville, MD 20850; Phone 1-866-786-7327 or Email: fascenter@samhsa.gov

Fetal Alcohol and Drug Unit Department of Psychiatry and Behavioral Sciences, University of Washington School of Medicine
www.depts.washington.edu/fadu
A source of technical and academic material, most of it taken from research undertaken or supervised by the psychology professor, and FASD researcher, Dr. Ann Streissguth at University of Washington Faculty of Medicine in Seattle. Fetal Alcohol And Drug Unit, University of Washington School of Medicine, 180 Nickerson St., Suite 309, Seattle, WA 98109; Phone (206) 543-7155.

National Organization on Fetal Alcohol Syndrome (NOFAS)
www.nofas.org
NOFAS is a national US nonprofit organization that addresses alcohol use during pregnancy and improving the quality of life those individuals and families affected by FASD. The website hosts numerous health, educational, and advocacy resources on FASD, including a national directory of services and links to affiliated programs and services of NOFAS online. Contact: NOFAS 900 17th Street, NW, Suite 910, Washington, DC 20006; Phone (202) 785-4585.

Project FACTS: Fetal Alcohol Consultation and Training Services
www.fasalaska.com
This website provides information on FASD, with a focus on intervention techniques for educators. The site has handouts to download on the following: 8 Magic Keys: Developing Successful Interventions for Students with FAS, Links to Other FAS Sites (home schooling, family, and sites on resources in Alaska, US, and International), Social/Behavioral Challenges/Schedule, Biological Basis of FAS, Common Misinterpretations, Developmental Characteristics and FAS Frequently Asked Questions. Contact: FACTS, PO Box 1092, Homer, Alaska 99603; Phone (907) 235-2544 or Email: debevensen@alaska.net