

Arizona Department of Economic Security, Division of Developmental Disabilities
Fetal Alcohol Resource Center
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Fetal Alcohol Spectrum Disorders: Understanding Effects, Improving Outcomes

presented by Teresa Kellerman, Director
Fetal Alcohol Resource Center



As a result of this training participants will be able to:

- Understand how prenatal exposure affects the brain and impacts behavior
- Recognize physical and neurobehavioral symptoms of Fetal Alcohol Spectrum Disorders
- Identify intervention strategies that help affected individuals of all ages
- Apply new insights to existing program plans to improve outcomes
- Learn about new research on nutritional recommendations
- Implement protective factors to minimize or prevent secondary disabilities
- Be able to pre-screen for possible FASDs in children and adults and make appropriate referral

For more information, visit FAS Arizona www.fasarizona.com

What Are the Characteristics of FAS and FASD?

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Babies diagnosed with full Fetal Alcohol Syndrome (FAS) may have some but not necessarily all of the following physiological characteristics:

<ul style="list-style-type: none">• Low birth weight• Small head circumference• Small, widely spaced eyes	<ul style="list-style-type: none">• Short, upturned nose• Smooth, wide philtrum• Thin upper lip
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Note: Facial characteristics may not be as apparent immediately after birth or during adolescence or adulthood as they are between the ages of two and ten. Facial characteristics may not be present at all if the mother did not drink alcohol during the brief period that the midface was forming - around the 20th day of pregnancy.

If the facial characteristics are not visible, the child may not get a diagnosis of FAS, but may have the same neurological symptoms and behavior challenges as children with full FAS. Only about 20% of affected children receive a diagnosis of FAS. The other 80% have partial FAS or Fetal Alcohol Effects (FAE), also called Alcohol Related Neurological Disorder (ARND). Together FAS and FAE make up the broad category called Fetal Alcohol Spectrum Disorders (FASD).

Most infants with FASD are irritable, have trouble eating and sleeping, are sensitive to sensory stimulation, and have a strong startle reflex. They may hyperextend their heads or limbs with hypertonia (too much muscle tone) or hypotonia (too little muscle tone) or both. Some infants may have heart defects or suffer anomalies of the ears, eyes, liver, or joints.

Most children with FASD have developmental delays and some have lower than normal intelligence. Only 15% of children with FASD have an IQ under 70. Most children with FASD have IQ in the normal or above normal range.

The most serious characteristics of FASD are the invisible symptoms of neurological damage from prenatal exposure to alcohol. These symptoms persist into adulthood and include the following:

- Attention deficits
- Memory deficits
- Hyperactivity
- Difficulty with abstract concepts
- Inability to manage money
- Poor problem solving skills
- Difficulty learning from consequences
- Immature social behavior
- Inappropriately friendly to strangers
- Lack of control over emotions
- Poor impulse control
- Poor judgment

These symptoms are not just "behavior problems" but are "soft signs" - symptoms of permanent, unchanging damage to the brain (static encephalopathy) and are not within the child's control. Although psychological factors such as abuse and neglect can add to the intensity of the problems, the behaviors should be viewed first and foremost as a result of brain damage from alcohol.

Adults with FASD have difficulty maintaining successful independence. They have trouble staying in school, keeping jobs, or sustaining healthy relationships. They require long-term support and some degree of supervision in order to succeed.

Without appropriate support services, these individuals have a high risk of developing secondary disabilities such as mental health issues, getting into trouble with the law, abusing alcohol and other drugs, and unwanted pregnancies.

Children and adults with FASD are also quite vulnerable to physical, sexual, and emotional abuse.

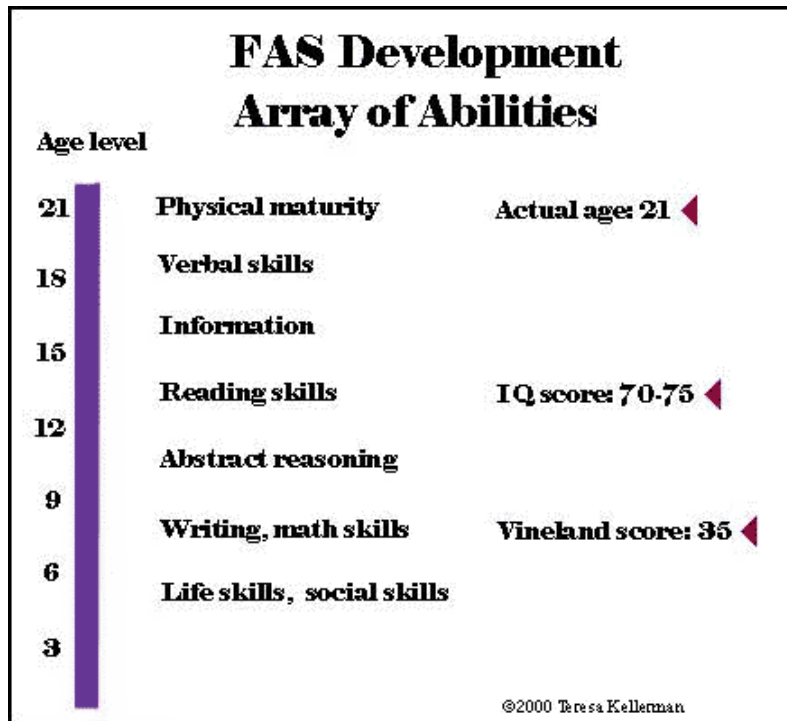
Fetal Alcohol Spectrum Disorders

Fact Sheet Prepared by Teresa Kellerman, Cofounder of FASworld FASD Awareness Day www.fasday.com



- Fetal Alcohol Syndrome (FAS) is the leading known cause of mental retardation in western civilization (NIAAA, Eighth Special Report NIH Publication No. 94-3699).
- Most individuals with alcohol related disorders have normal or above normal intelligence and normal physical appearance. (Streissguth et al, "Understanding the Occurrence of Secondary Disabilities in Clients with Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effects (FAE)," Final Report to the Centers for Disease Control and Prevention (CDC), August, 1996)
- Fetal Alcohol Spectrum Disorders (FASD) is a term that includes both FAS and FAE. Studies indicate that FASD may affect one out of one hundred babies in North America, making alcohol the leading cause of brain damage today. (Teratology 1997 Nov;56[5]:317-26)
- Children who grow up with Fetal Alcohol Syndrome (FAS) or Fetal Alcohol Effects (FAE) are at high risk of serious secondary problems, such as dropping out of school or getting expelled; getting into trouble with the law; abuse of alcohol and other drugs; inappropriate or risky sexual behavior; inability to maintain employment; and mental health issues such as clinical depression. (The Challenge of Fetal Alcohol Syndrome: Overcoming Secondary Disabilities, Ann Streissguth and Jonathan Kanter, 1997, University of Washington Press.)
- Fetal Alcohol Syndrome was first officially named as a medical disorder in 1973 by researchers from the University of Washington in Seattle. (Recognition of the Fetal Alcohol Syndrome in Early Infancy. Jones, K. L., Smith, D. W., The Lancet, Nov. 3, 1973, pgs. 999-1001.)
- Based on long-term research of cost and prevalence data in the states of Washington and North Dakota, it is estimated that there are almost 3 million individuals in the United States with FASD, and that care for these individuals costs the U.S. approximately \$7.5 billion each year. (Prevalence and Cost Calculator, Larry Burd, Ph.D., Director, North Dakota Fetal Alcohol Syndrome Center, <http://www.online-clinic.com/Content/Materials/calculator.asp>)
- The rate of drinking by women of childbearing age, including the riskier practices of frequent and binge drinking, increased dramatically from 1991 to 1995. (US Department of Health and Human Services. Summary of findings from the 1999 National Household Survey on Drug Abuse. Washington, DC: US Department of Health and Human Services, 2000.)
- The rates of binge drinking and frequent drinking reported by pregnant women in 1995 remained substantially unchanged by the year 2000. (Centers for Disease Control and Prevention MMWR Weekly April 25, 1997 / 46(16);346-350; MMWR Weekly, April 5, 2002 / 51(13);273-6)
- Fetal Alcohol Spectrum Disorders cause permanent damage to the developing brain, resulting in neurological impairment of the executive functions. Affected individuals often have difficulty functioning in everyday life and are not able to implement effective problem-solving strategies. (Journal of Pediatrics, 92(1):64-67; Ann Streissguth, Developmental Neuropsychology 2000; 18(3):331-54; National Institute on Alcohol Abuse and Alcoholism Press Release 301/443-3860, March 20, 2000)
- The effects of prenatal exposure to alcohol last a lifetime. There is no safe level of drinking during pregnancy. (Drinking Alcohol During Pregnancy, March of Dimes 2003)
- There is no cure, but Fetal Alcohol Spectrum Disorders are 100% preventable (Centers for Disease Control and Prevention 2003).

ARRAY of ABILITIES In a person with typical FAS symptoms



These different levels of development occur in one individual at the age of 21. The person has Fetal Alcohol Syndrome (FAS). These are actual results from a psychological evaluation that measures IQ, functional abilities, and adaptive behavior skills.

IQ score is about 70. Vineland (adaptive behavior scale) score is about 35. The person has good expressive language skills, which others use to judge intellectual abilities. For individuals with Fetal Alcohol Spectrum Disorders (FASD), the ability to function successfully in life is far below what is expected, based on appearances only. Teachers, law enforcement officials, and even parents may have higher expectations of the individual with FAS or FASD than the person can actually achieve.

The greatest obstacle individuals with FASD must overcome is the chronic frustration that results from the unreasonable expectations of others. This may contribute to the leading secondary condition associated with FASD: clinical depression with thoughts of suicide. Early recognition and understanding of FASD can help prevent the serious secondary effects associated with FAS and FASD.

“Think Young”

Effects of Ethanol (Alcohol) Exposure on the Embryo

Recent Animal Research Data
Compiled by Teresa Kellerman
Fasstar Enterprises www.fasstar.com

Ethanol induces cell death during the formation of new brain cells. Effects of gangliosides on ethanol-induced neurodegeneration in the developing mouse brain. Alcohol Clin Exp Res. 2007 Apr;31(4):665-74.

http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?db=pubmed&cmd=Retrieve&dopt=AbstractPlus&list_uids=17374046&query_hl=4&itool=pubmed_docsum

Ethanol disrupts the proliferation and differentiation of brain cells. Embryonic cerebral cortical progenitors are resistant to apoptosis, but increase expression of suicide receptor DISC-complex genes and suppress autophagy following ethanol exposure. Alcohol Clin Exp Res. 2007 Apr;31(4):694-703

http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?db=pubmed&cmd=Retrieve&dopt=AbstractPlus&list_uids=17374049&query_hl=4&itool=pubmed_docsum

Ethanol suppresses breathing movements during time before birth. Effects of ethanol exposure on the embryo-fetus: experimental considerations, mechanisms, and the role of prostaglandins. Can J Physiol Pharmacol. 1991 May;69(5):550-69.

http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=1863905&dopt=Abstract

Ethanol alters common signaling pathways causing shift in cell motion and metabolism. Reprogramming of genetic networks during initiation of the Fetal Alcohol Syndrome. Dev Dyn. 2007 Feb;236(2):613-31

http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?itool=abstractplus&db=pubmed&cmd=Retrieve&dopt=abstractplus&list_uids=17200951

Ethanol alters expression of certain genes involved in cell proliferation, differentiation, tissue growth, brain cell growth and survival. Gene-expression analysis after alcohol exposure in the developing mouse.

J Lab Clin Med. 2005 Jan;145(1):47-54.

http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?db=pubmed&cmd=Retrieve&dopt=AbstractPlus&list_uids=17200951&query_hl=4&itool=pubmed_DocSum

Ethanol yields ocular and forebrain abnormalities after early exposure. Maternal oral intake mouse model for fetal alcohol spectrum disorders: ocular defects as a measure of effect. Alcohol Clin Exp Res 2006 Oct;30(10):1791-8

http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?itool=abstractplus&db=pubmed&cmd=Retrieve&dopt=abstractplus&list_uids=17010146

Ethanol alters genetic expression of tissue in craniofacial areas resulting in smaller face, eyes, nose, and jaw, and underdevelopment or cleft in lip or palate. Differential gene profiles in developing embryo and fetus after in utero exposure to ethanol. J Toxicol Environ Health A. 2004 Dec;67(23-24):2073-84

http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?itool=abstractplus&db=pubmed&cmd=Retrieve&dopt=abstractplus&list_uids=15513904

Ethanol changes the expression of certain genes in the developing neural tube during early stages of development that results in damage to the central nervous system. Identity and neuroanatomical localization of messenger RNAs that change expression in the neural tube of mouse embryos within 1 h after ethanol exposure.

Brain Res Dev Brain Res. 2003 Aug 12;144(1):9-23

http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?itool=abstractplus&db=pubmed&cmd=Retrieve&dopt=abstractplus&list_uids=12888214

Ethanol compromises development of the midline neural tube and forebrain. Neurotox Res 2002 Jun; 4 (4) 337-42 Developmental Brain Research 144 (2003) 43–55.
<http://anatomy.iupui.edu/anatfaculty/zhoupub/2003-FAS-Midline.pdf>

Ethanol alters dopamine levels that affect behavior and disrupt the reward cycle in the brain. Moderate-level prenatal alcohol exposure alters striatal dopamine system function in rhesus monkeys. Alcohol Clin Exp Res. 2005 Sep;29(9):1685-97
http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?db=pubmed&list_uids=16205369&cmd=Retrieve&indexed=google

Ethanol slows the migration and reduces the development of serotonin neurons by 20%-30%. Prenatal alcohol exposure retards the migration and development of serotonin neurons in fetal C57BL mice. Developmental Brain Research, Volume 126, Issue 2, 28 February 2001, pp 147-155
<http://www.ncbi.nlm.nih.gov/pubmed/11248348>

Ethanol impacts the limbic system and reduces capacity to adapt to maternal separation and other stress. Moderate level alcohol during pregnancy, prenatal stress, or both and limbic-hypothalamic-pituitary-adrenocortical axis response to stress in rhesus monkeys. Child Dev. 2004 Jan-Feb;75(1):96-109.
<http://www.ncbi.nlm.nih.gov/pubmed/15015677>

Ethanol oxidizes proteins in the hippocampus resulting in long-lasting behavioral alterations. Difluoromethylornithine decreases long-lasting protein oxidation induced by neonatal ethanol exposure in the hippocampus of adolescent rats. Alcohol Clin Exp Res. 2007 May;31(5):887-94. Epub 2007 Mar 26
http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?db=pubmed&cmd=Retrieve&dopt=AbstractPlus&list_uids=17386069&itool=iconabstr&query_hl=51&itool=pubmed_DocSum

Ethanol may cause alterations in GABA(A) receptor expression in the hippocampus, thus contributing to behavioral disorders and difficulties with spatial learning. Chronic prenatal ethanol exposure alters hippocampal GABA(A) receptors and impairs spatial learning in the guinea pig. Behav Brain Res. 2004 Apr 2;150(1-2):117-25
http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?itool=abstractplus&db=pubmed&cmd=Retrieve&dopt=abstractplus&list_uids=15033285

Ethanol increases levels of maternal cortisol (stress hormone) that can have negative impact on fetal brain development. Chronic prenatal ethanol exposure alters glucocorticoid signaling in the hippocampus of the postnatal Guinea pig. J Neuroendocrinol. 2005 Sep;17(9):600-8
http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?db=pubmed&cmd=Retrieve&dopt=AbstractPlus&list_uids=16101899&query_hl=38&itool=pubmed_docsum

Ethanol can disrupt production of oxytocin later in life in females, interfering with bonding and maternal behaviors. Sexually Dimorphic Effects of Alcohol Exposure during Development on the Processing of Social Cues. Alcohol and Alcoholism. 2009 Nov-Dec;44(6):555-60.
<http://alcalc.oxfordjournals.org/cgi/content/abstract/agp061v1>

Ethanol causes long-term disruption in regulation of vasopressin, a neurotransmitter associated with social behaviors, bonding and mating, as well as recognition of facial cues. Arginine vasopressin and body fluid homeostasis in the fetal alcohol exposed rat. Alcohol. 1989 May-Jun;6(3):193-8
<http://www.ncbi.nlm.nih.gov/pubmed/2736078>

For more information on Fetal Alcohol Spectrum Disorders, visit www.fasrcr.com

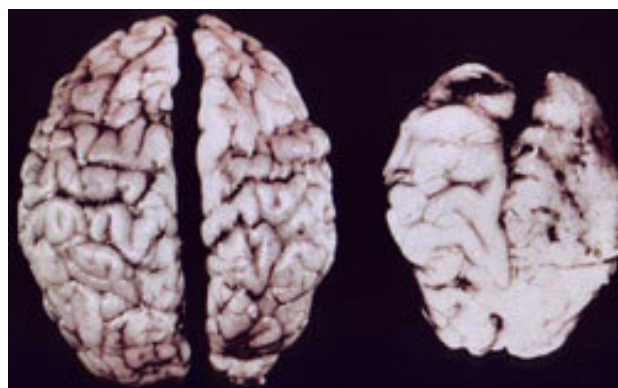
Prenatal Alcohol Exposure and the Brain

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Alcohol is a "teratogen" - an environmental substance that can harm the developing baby. Damage can occur in various regions of the brain. The areas that might be affected by alcohol exposure 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.

Not all damage from alcohol exposure is seen on brain scans, as lesions are sometimes too small to be detected with current technology, yet large enough to cause significant disabilities.

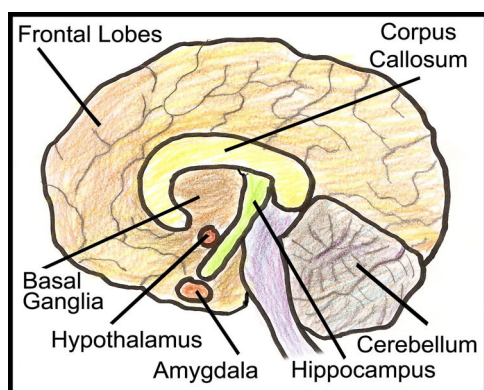
The brain is the organ most sensitive to prenatal alcohol damage.
[Dr. Edward P. Riley lecture, September 25, 2002]



Brain of baby with no alcohol exposure Brain of baby with heavy prenatal alcohol exposure
(Photo courtesy of Sterling Clarren, MD)

Alcohol Exposure During Stages of Pregnancy:

1. During the first trimester, as shown by the research of Drs. Clarren and Streissguth, alcohol interferes with the migration and organization of brain cells. [Journal of Pediatrics, 92(1):64-67]
2. Heavy drinking during the second trimester, particularly from the 10th to 20th week after conception, seems to cause more clinical features of FAS 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, 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]



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

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

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

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

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

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

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

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

The hypothalamus, amygdala, and hippocampus are part of the limbic system, which regulates emotions, social and sexual behavior, the “fight or flight” response, and empathy, all areas of concern for individuals with prenatal alcohol exposure.

The term Fetal Alcohol Spectrum Disorders (FASD) includes Fetal Alcohol Syndrome (FAS) and Alcohol Related Neurodevelopmental Disorder (ARND). Individuals with FASD often have symptoms or behavior issues that are a direct result of damage to the prefrontal cortex, which is the part of the brain that controls “executive functions.”

Executive Functions	
Executive functions of the prefrontal cortex:	Effects of alcohol exposure on behaviors related to executive functions:
inhibition problem solving sexual urges planning time perception internal ordering working memory self-monitoring verbal self-regulation motor control regulation of emotion motivation judgment	socially inappropriate behavior, as if inebriated inability to figure out solutions spontaneously inability to control sexual impulse, esp. in social situations inability to apply consequences from past actions difficulty with abstract concepts of time and money like files out of order, difficulty processing information problems with storing and retrieving information needs frequent cues, requires “policing” by others needs to talk to self out loud, needs feedback fine motor skills more affected than gross motor moody “roller coaster” emotions, exaggerated apparent lack of remorse, needs external motivators inability to weigh pros and cons when making decisions

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]

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

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

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



Birth Moms and FAS Q&A

Prepared by Teresa Kellerman

The following data is based on the keynote address given by Dr. Sterling Clarren at the 2002 Yukon FAS Conference in Whitehorse regarding his studies of FAS and clinical practice in the state of Washington.

Part 1: Understanding why women are still having babies with FAS after 25 years of public knowledge about the dangers of drinking during pregnancy

Q: What percentage of children with FAS are being raised by their birth mothers?

A: Only 10%

Q: What percentage of these birth mothers also have FAS related conditions themselves?

A: Approximately 50%

Q: What percentage of these birth mothers were victims of serious physical and/or sexual abuse?

A: 100% were victims of serious abuse, and 90% have Post Traumatic Stress Disorder.

Q: What percentage of these birth mothers had alcoholism?

A: 100%, but 5% had not been previously diagnosed.

Q: What percentage of these birth mothers suffer from major depression?

A: 90% have depression, and many have a mental health disorder such as phobia, anxiety, mania, bulimia and schizophrenia.

Q: What is the treatment preferred by the birth mothers to ease the pain of the mental health disorders?

A: Self medication with alcohol.

Q: Why did the birth mothers not get treatment for their substance abuse problem?

A: They didn't have anyone to leave their kids with. They were afraid they would lose their kids. Their partner wasn't supportive. It was too expensive. They didn't have insurance.

Q: What percentage of the birth mothers sought substance abuse treatment when they got pregnant?

A: About 95%. They get support while they are pregnant and in treatment. But they end up having their children taken away from them. And then they get no support or treatment until they get pregnant again.

Q: Over the long term, what percentage of these birth mothers will be able to achieve recovery?

A: About half.

Q: What did the mothers who found recovery have that the other mothers did not have?

A: The mothers with successful recovery had a higher IQ and a strong social support network.

Q: What is most helpful to the birth mother in finding and maintaining recovery and preventing a subsequent alcohol-exposed pregnancy?

A: There is a program that seems to work well called the "new best friend" program that provides daily personal support by a mentor for three years.

Birth Moms and FAS Q&A Part 2: Understanding FAS as a starting point to finding the right interventions

Q: What is FAS?

A: FAS is permanent brain damage.

Q: What percentage of children with FAS have a small head circumference or seizures?

A: Only 25% have small head or seizures. But 100% have brain damage. But the brain damage only shows up in brain imaging tests in 50% of cases of full FAS.

Q: What facial features are criteria for a diagnosis of FAS?

A: Small eyes, smooth philtrum, thin upper lip.

Q: When during pregnancy does alcohol cause damage that results in these facial features?

A: The mother's drinking on the 20th day of pregnancy will result in the facial features of FAS. If the mother does not drink on the 20th day, the child may not have the features, and therefore will not get a diagnosis of FAS, but will still sustain permanent brain damage from drinking after the 20th day.

Q: What does alcohol do to the brain of the developing baby?

A: Anything it wants.

Q: What systems can alcohol disrupt in the developing baby?

A: All of them.

Q: In a child with FAS who has a brain of normal size and structure, what causes the brain dysfunction?

A: The brain dysfunction is caused by abnormal neurochemicals.

Q: How can we test the neurochemicals in these children?

A: We can't. But we see it in the child's behaviors. Alcohol is a behavioral teratogen.

Q: What percent of children with FAS have suffered from physical abuse?

A: Of children with FAS, 75% are victims of physical abuse.

Q: How can we determine that alcohol is the specific cause of certain behavioral maladies?

A: We can't, because of the presence of other determining factors such as genetics and environmental factors such as abuse and neglect and multiple home placements.

Q: What percent of children with FAS have suffered from physical abuse?

A: Of children with FAS, 75% are victims of physical abuse.

Q: What diagnosis is more important for the child than the diagnosis of FAS?

A: The diagnosis of brain damage, because that is what will get appropriate intervention.

ase example: Mother tells the child, "Don't run in the street, or you might get hit by a car." This lesson is repeated and learned. The child goes out the door, and runs into the street. Why? We cannot jump from the **Case example:** Mother tells the child, "Don't run in the street, or you might get hit by a car." This lesson is repeated and learned. The child goes out the door, and runs into the street. Why? We cannot jump from the behavior to FAS. There could be several reasons. For example, he could have misunderstood his mother and taken the direction literally. In his concrete thinking, he ran ACROSS the street but didn't run IN (down the middle of) the street. Or he might have forgotten the rule. Or he may have had a moment of poor judgment and didn't know how to apply the rule. Or it could have been his attention deficit disorder, or he was just oppositional and did it intentionally. Or he might have been depressed and thought that it would be a good idea to get hit by a car. A diagnosis of FAS is a starting point to getting a needs assessment to determine proper treatment.

Dr. Sterling K. Clarren is the Robert A. Aldrich Professor of Pediatrics and past Head of the Division of Congenital Defects at the University of Washington School of Medicine in Seattle, Washington. He is currently the medical doctor for the University of Washington FAS Diagnostic and Prevention Network clinic. He has published over 100 research articles and has received research funding from the National Institute on Alcohol Abuse and Alcoholism, the Centers for Disease Control, the Glaser Foundation, and the March of Dimes.

Q: What diagnosis is more important for the child than the diagnosis of FAS?

A: The diagnosis of brain damage, because that is what will get appropriate intervention.

FASD and the Child Protective Services System

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Director, FAS Community Resource Center, Tucson, Arizona

There are many significant misunderstandings about Fetal Alcohol Spectrum Disorders (FASD) in the service provider arena, including child protective services, that pose obstacles to effective intervention.

Most experts in various areas that are connected to the Child Protective Services system lack a thorough education about Fetal Alcohol Syndrome (FAS) and related disorders and their ignorance of the nature of FASD renders much of their advice useless for a large number of families needing support services as they come through the system.

The child protective services system may provide the first contact within the system and the first opportunity for effective intervention for a family trying unsuccessfully to cope with a child who is affected by prenatal exposure to alcohol and other drugs. But most social workers do not understand enough to be helpful to the families who need help the most.

Parents of children with FASD report that their difficulties dealing with professionals who do not understand FASD is more stressful than coping with the child's behavior problems.

Fetal Alcohol Syndrome and related disorders are probably the most common but least recognized problem among families in the child protective services system. The mistaken belief that only alcoholic women have babies with FASD closes our eyes to recognizing the many affected children who do not have obvious physical symptoms. The mistaken belief that "milder" Fetal Alcohol Effects (FAE) is less serious than full FAS closes our eyes to helping the children who are at highest risk, those with normal intelligence and no physical symptoms but who carry the label "difficult child" and who are at high risk of abuse and neglect.

The lack of recognition that many of the parents in abuse/neglect cases might be alcohol affected themselves (but with no obvious physical symptoms) renders typical treatment programs or court orders ineffective in helping them attain success in parenting.

Research that I have studied indicates that alcohol is a major factor in most cases of child abuse and neglect, as well as cases of domestic violence. Research also indicates that when the father in the family is a heavy drinker, the mother tends to increase her drinking to match his drinking behavior. According to government surveys, mothers who abuse alcohol when their children are young were likely to have engaged in excessive drinking years before it became an obvious problem, years when she may have been pregnant with the children we see today. Women who drink during pregnancy almost always deny that they drank during pregnancy, saying they quit when they found out they were pregnant, when in reality they didn't realize they were pregnant until damage was already done, they cut down but still drank enough to cause brain damage, or they were just in denial and can't report their drinking behavior honestly. More mothers in the system were drinking during pregnancy than we realize. More children are affected than we recognize. It is estimated that 1 out of every 100 babies born today are significantly affected by prenatal exposure to alcohol in ways that will interfere with their ability to function successfully in life. Most of these children are not recognized as alcohol exposed, but they may be diagnosed as ADHD or learning disabled, or just as "problem children." These children are at high risk of being abused physically and sexually, of dropping out of school later, of getting in trouble with the law, and are at extremely high risk of having alcohol/substance abuse problems as adults. They are at risk of having clinical depression as adults, with a suicide attempt rate of 23%. One of the primary protective factors from these secondary problems is a stable home environment and early recognition of alcohol-affected children and effective intervention through appropriate support services.

FASD is probably our number one health issue, the number one social problem that our society is facing today. But no one realizes it. There is so much denial and misunderstanding that progress in the area of prevention is extremely slow. It is crucial that child protective service agencies recognize the scope of the problem and educate themselves and train their staff and volunteers so that efforts to protect children at risk can be successful.

For more information, visit Fasstar Enterprises www.fasstar.com

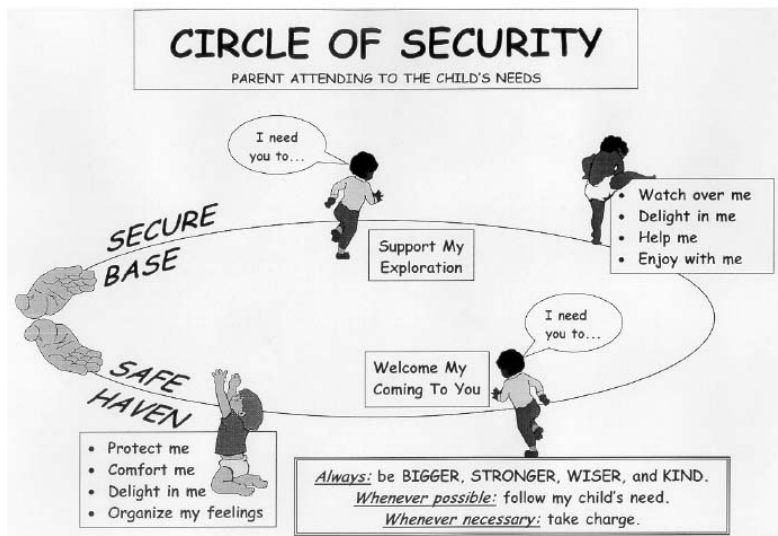
- Of families in the Arizona dependency system, 90% have parents who abuse alcohol and other drugs (William Stanton, Governor's Administrative Office of the Courts)
- Of women of childbearing age, over half drink alcohol (SAMHSA's national survey on drug use and health)
- Of all pregnancies, half are unplanned (Alan Guttmacher Institute)
- Of those mothers who drink alcohol one year after the birth of a child, almost all were drinking at the same rate at the time they got pregnant. (SAMHSA's national survey on drug use and health)
- Of all mothers in Arizona who are asked after they give birth whether they drank alcohol during pregnancy, only 1 in 100 admit that they did. (Arizona Department of Health)
- Of all women in their first trimester who were asked if they drank alcohol during the past month, 23% admitted that they had. (SAMHSA's national survey on drug use and health)
- Foster parents who are familiar with symptoms of FASD report that they suspect at least 75% of their foster children may have FASD. (FasAdopt support group survey)
- Most children with FASD appear to be normal at birth and in the early years.
- Only 11% of children with FASD have symptoms that will warrant a diagnosis by age six. (Ann Streissguth 1996 study on FASD and secondary disabilities)
- Only 15% of children with FASD have mental retardation. (Ann Streissguth 1996 study on FASD and secondary disabilities)
- Twice as many babies are born with full FAS than with Down Syndrome. (National Organization on Fetal Alcohol Syndrome)
- Ten times as many babies are born with an alcohol related disorder. (National Organization on Fetal Alcohol Syndrome)
- Half of all mothers who give birth to a baby with FAS are alcohol affected themselves.
- Children of parents who abuse alcohol are at high risk of abuse and neglect. (Bays, J. "The care of Alcohol- and Drug-Affected Infants". *Pediatric Annals*, Vol. 21, Aug. 1992, pp. 485-495.)
- Children with the less visible forms of FASD are at higher risk of becoming victims of abuse, neglect, injury, SIDS, and early death. (FASD Center for Excellence)

Understanding the Dynamics of Attachment and FASD

by Julia Wellwood

What comes to mind when you think about attachment? Maybe you picture how your child likes to cuddle up with you or how they look over their shoulder for you as they venture away from your side to explore at the playground, how they run to you with a scraped knee and how your kiss seems to make it all better. Or maybe you think of how they cling to you when you need to go out or how you can't go to the bathroom without a little shadow!

We know from research on attachment that out of all the roles that a parent plays, such as playmate, teacher and nurturer, it is the role of attachment figure that is critically important and lays the foundation for all else. This means that how we respond when our child is emotionally upset, such as feeling scared, sad or mad, or when they are physically hurt or ill determines whether our child will feel safe and secure or insecure, anxious or even confused (disorganized).



When a child is in this kind of distress, we say that their attachment system is activated. This means that we can observe, through their behaviour at this time, how they have learned to cope based on repeated past experiences with distress. Infants are “hard-wired” to seek the attention of their primary caregiver to have their needs addressed.

This typically includes behaviours such as crying, lifting up their arms to be held or running to the parent. Re-search shows that the strategies that a child uses are reflective of their experience of caregiving and they will develop either a secure attachment style or perhaps an anxious or avoidant style.

This means that if these hard-wired behaviours elicit an effective response from their parent that settles them and helps them to cope, the child will feel safe and secure and will use these strategies again. If a parent finds it difficult to tolerate distress in a child, they may respond by directing the child away from themselves and by offering toys or a soother for comfort. The child learns to minimize their expression of emotional distress and to calm themselves with objects. If a parent responds to a child in an inconsistent and variable way, the child will learn to heighten their signals of distress. They will cry harder and longer, and may be generally fussy and clingy to ensure contact with their parent.

Keeping in mind that attachment is best understood in the context of relationship, it is therefore important to recognize what is happening for the parent as well as for the child.

As parents, we are all doing the best we know how. A big part of how we parent is based on our own experiences of being parented as children. Some-times we have had experiences that leave us vulnerable to aspects of our child's behaviour, which can lead us to misread their cues. The experiences that influence our parenting have been coined “ghosts in the nursery.” Sometimes we have big worries about food, shelter or safety that can understandably lead us to miss cues altogether. At other times, we might be sending contradictory signals to our child without being aware of it. All of this, along with what the child brings to the relationship, becomes part of the attachment experience for both parent and child.

Children with FASD

While these comments apply to all children and parents, at the FASD Outreach Program we are specifically interested in the dynamics of attachment theory and practice as it applies to the child with FASD and their parents. Children with FASD seem to be more vulnerable and therefore more at risk for developing insecure attachment patterns. This vulnerability is related to neurological factors as well as to environmental factors and quite often is a combination of both.

Neurological issues such as symptoms of withdrawal after birth, immature nervous systems, sensory processing difficulties, and in the older child, impulsive and hyperactive tendencies and cognitive differences place great demands on a parent. Perhaps you've experienced the helplessness of trying to comfort an infant who is inconsolable or holding a child who arches away from you or avoids your eye contact. Maybe you are weary from the constant supervision of your child's activity level and constant repeating, or maybe you worry because it seems like your child would go with anyone. The stress of daily care, in addition to possible grief issues, beliefs about the disability, and the individual strengths and vulnerabilities of the parent discussed earlier all influence the parent-child relationship.

Interestingly, many characteristics of FASD such as sleep issues, avoidance of physical contact or clinginess, picky eating, frenetic activity and indiscriminate friendliness can also describe attachment issues and reflect instead environmental factors in the child's life. All too often children with FASD have experienced relationship disruption due to multiple placements or other types of trauma, which makes attachment a very prevalent issue and a difficult one to sort out.

Of all the scenarios, it is the child who has no coherent strategy for coping with distress that is the most concerning. This is the child who, when upset, wants up and then down, approaches but then turns away, accepts a hug but then holds their body stiff, or who approaches but in a slow, apprehensive way. In the research literature, this child is classified as "disorganized." It is an extremely problematic classification given its high correlation with later mental health issues and significant behaviour problems. Based on the findings of the Secondary Disabilities Study by Anne Streissguth, notably the high rate of mental health issues in the population with FASD and the protective qualities associated with stability and longevity of placement, this is an important issue for these children.

Most of us have heard at one time or another that "children with FASD don't attach." Our work with families is showing us that attachment theory seems to be equally applicable to children with FASD and that, in fact, it provides a critically important framework for understanding their needs and a context for guiding intervention.

Exciting research

There is exciting work happening in the field of attachment, both in research and intervention. Modified Interaction Guidance (MIG) is an example of an intervention that has particular relevance here in Manitoba. The FASD Outreach Team has had the good fortune of participating in training in this intervention this past year, along with a group of people from the community and from the Child Development Clinic.

Dr. Diane Benoit, an Infant Psychiatrist with the Toronto Sick Children's Hospital, developed Modified Interaction Guidance as a short-term, play-based therapy for parents who want to improve the way they and their children interact together. They learn to watch more closely for their child's signals and to respond in more accurate and targeted ways. In addition, they can learn to recognize in themselves signals that they might be unintentionally sending to their child and that they may wish to change.

Modified Interaction Guidance sessions include goal-setting by the parent, specific information provided to the family that is tailored to their needs, weekly review of progress and the weekly video-taping of a 10-minute playtime for feedback by the parent and by the therapist. Videotaping allows the parent to observe their interactions and to evaluate their progress. Weekly homework is based on the feedback session. During feedback, the parent learns to recognize which of their responses worked really well and which new responses they can try. These are then practiced at home. Success is measured by how the child responds when in distress and by the reduction of problematic behaviours.

The research on this and other interventions is showing that it provides a very important process for change. Those of us with the FASD Outreach Team feel that we finally have an intervention that helps to address the attachment issues that have concerned us for many years. Above all, we want to say how appreciative we are of the work that families do and what a privilege it is to be part of that!

Julia Wellwood is part of the FASD Outreach Team, Children's Special Services, Manitoba Family Services and Housing. Reprinted by permission from Manitoba F.A.S.D. News - Spring 2006

Secondary Disabilities in FASD

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Based on the Final Report from Research on Secondary Disabilities by Ann Streissguth, presented to the FAS Conference in Seattle in September of 1996

Primary Disabilities refer to the brain damage that results in impaired mental function of persons with Fetal Alcohol Spectrum Disorders (FASD). Primary Disabilities are measured by general intelligence, mastery of reading, spelling, math, and level of adaptive functioning, representing the CNS manifestations of FASD. The sample of 473 individuals in the study included 178 with Fetal Alcohol Syndrome (FAS) and 295 with Fetal Alcohol Effects (FAE). The range of IQ of individuals with FAS was from 29 to 120, with mean IQ of 79. Range of IQ of individuals with FAE was from 42 to 142, with mean IQ of 90. Only 16% of all the individuals with FASD in this study legally qualify as having mental retardation. This means that 86% of the individuals with FASD have an IQ in the "normal" range and do not qualify for services for developmental disabilities. They nevertheless have impaired mental functioning caused by brain damage that is permanent and incurable.

The academic abilities of individuals with FASD are below their IQ level, and their living skills, communication skills and adaptive behavior levels are even further below IQ levels. For example, a person with FAS with an IQ of 80 may have a reading IQ of 78, a spelling IQ of 75, a math IQ of 70, daily living skills IQ of 68, socialization skills IQ of 65, communication IQ of 62 and adaptive behavior IQ of 60. This indicates that when a person with FAS/FAE is evaluated, a battery of tests be done that include a test of level of functional abilities and daily living skills.

Secondary Disabilities are those not present at birth but occur as a result of the primary disabilities. Secondary disabilities can presumably be prevented or lessened by better understanding and appropriate interventions. Secondary disabilities were ascertained from life history interviews of 415 individuals with FASD using 450 questions. Six main categories are defined:

* **Mental Health Problems**, the most prevalent secondary disability, experienced by 94% of the full sample. During childhood, 60% of children with FASD have ADHD. During adulthood, most adults with FASD have clinical depression. The study revealed that 23% of the adults had attempted suicide, and 43% had threatened to commit suicide.

* **Disrupted School Experience** (suspension or expulsion or drop out), was experienced by 43% of children of school age. By the time students with FAE reach adulthood, the rate of disrupted school experience peaks at 70%. Common school problems include: not paying attention; incomplete homework; can't get along with peers; disruptive in class; disobeying school rules; talking back to the teacher; fighting; and truancy.

* **Trouble with the Law** (involvement with police, charged or convicted of crime), was experienced by 42% of those in the study, and by about 60% of those age 12 and over. The most common first criminal behavior reported was shoplifting. The most common crimes committed (by almost half of individuals with FASD age 12-20) were crimes against persons (theft, burglary, assault, murder, domestic violence, child molestation, running away), followed by property damage; possession/selling; sexual assault; and vehicular crimes.

* **Confinement** (inpatient treatment for mental health, alcohol/drug problems, or incarceration for crime), experienced by 60% of those age 12 and over. Over 40% of adults with FASD had been incarcerated; about 30% of adults with FASD were confined to a mental institution; and about 20% had been confined for substance abuse treatment.

* **Inappropriate Sexual Behavior** was reported in 45% of the those age 12 and over, and 65% of adult males with FAE. This includes only sexual behaviors that had been repeatedly problematic or for which the individual had been incarcerated or treated. It is thought that the actual incidence of inappropriate sexual behavior is much higher, and not always reported by the individual or the family due to embarrassment or fear of being reported to authorities. Problem sexual behaviors most common with FASD include: sexual advances; sexual touching; promiscuity; exposure; compulsions; voyeurism; masturbation in public; incest; sex with animals; and obscene phone calls.

* **Alcohol/Drug Problems** were experienced by 30% of individuals age 12 and over. Of the adults with FAE, 53% of males and 70% of females experienced substance abuse problems. This is more than 5 times that of the general population. To determine levels of independence in adulthood, two additional categories were identified for individuals 21 years of age and older (median age 26):

* **Dependent Living** was the situation for about 80% of adults with FASD.

* **Problems with Employment** were indicated in 80% of adults with FASD.

Only 8% of the individuals in the study had no problem with independent living or employment.

Risk Factors: The greatest risk factors associated with secondary disabilities in FASD are shown by the studies to be:

* **IQ over 70** (those with lower IQ's are likely to get more services and intervention)

This means that individuals with FAE are at greater risk than those with FAS.

* **Exposure to violence** (sexual and/or physical abuse), which occurs at rate of 72% of individuals with FASD. Those exposed to violence are four times as likely to exhibit inappropriate sexual behavior.

Problems With Parenting: Of the 100 females of childbearing age, 30 had given birth; 40% drank during pregnancy, more than half no longer had the child in their care. Of their children, 30% have been diagnosed with or suspected of having FASD.

Protective Factors:

* **Early diagnosis** is a universal protective indicator for all secondary disabilities. Only 11% of individuals with FASD were diagnosed by age 6. Every effort must be made to attain early diagnoses for children with FAS and FAE.

* **Eligibility for services** from DD division of state is another strong protective factor. These services are needed by most individuals with FASD, yet most do not qualify.

* **Living in stable home** with nurturing parents and minimum of changes in household.

* **Protection from violence**, from witnessing or being victimized by violence.

Recommendations:

* Develop statewide diagnostic clinic.

* Parent/citizen education centers re intervention/services for persons with FASD.

* Agency representative in fields of Mental health, education, criminal justice system, alcohol/drug abuse treatment, health department.

* Fund further research.

* Modify eligibility criteria for DD services, and provide adequate services for those with FASD.

* Fund and implement long-term residential/job training programs for persons with FASD.

* Promote prevention programs (education, alcohol abuse treatment, advocacy, birth control).

Citation: Streissguth, A.P., Barr, H.M., Kogan, J. & Bookstein, F. L., "Understanding the Occurrence of Secondary Disabilities in Clients with Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effects (FAE)," Final Report to the Centers for Disease Control and Prevention (CDC), August, 1996, Seattle: University of Washington, Fetal Alcohol & Drug Unit, Tech. Rep. No. 96-06, (1996).

SCREAMS – The Sweet Sound of Success

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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 Fetal Alcohol Syndrome (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 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 Fetal Alcohol Spectrum Disorders (FASD), 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 FASD – 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 having FASD, 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, television shows and movies that show healthy behavior and life styles

Environment: minimized chaos, low sensory stimulation, modified to meet individual needs

Attitude: understanding by everyone 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 lifetime due to poor judgment and lack of impulse control

Structure: Most people who know about FASD are aware of the need for structure, but sometimes this is confused with control. While providing structure as a foundation, we need to help them learn simple and concrete rules, and offer them choices they can handle, remain flexible, and remember KISS – Keep It Simple Sweetie!
ABC Rules: Ask for help – Be respectful – Communicate your needs.

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.

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.

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 their limitations and the need for protective restrictions.

Medications: Meds are usually initially prescribed for ADHD, but medications can help more than just reduce hyperactivity. The right meds or combination of meds 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. Brain chemicals can also be better balanced with daily vitamin, extra B vitamins, and a diet that is free of artificial additives and preservatives.

Supervision 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.

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!



Read more articles by Teresa at www.fasstar.com

How to Talk to Your Child With FASD About FASD

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How one explains FASD to the child depends on the extent of their disabilities, their level of understanding, their past experiences, the relationship you have with them, etc. There is no one right way to do it. I do have some suggestions though, of what is important, based on consultation with experts, other parents, and my own personal experience.

First of all, the earlier you start, the easier it is. Some parents wait too long, and then they do not have the courage to discuss it with the teen, who eventually gets into serious trouble. Start young!

What I suggest is to take advantage of the many teaching moments that happen to pop up on a daily basis - the forgetting, the impulsive action, the bad judgment, the immaturity. Since children with FASD become frustrated with themselves and others and difficult situations, there are always opportunities to explain why they are having a hard time.

John would say, "Oh I'm so stupid!" I would say, "You're not stupid, John, it's just that your brain is not working right now. Maybe later or tomorrow your brain will work better again. For now, let's take a break, and do something easy or fun."

When he was feeling a little better, we would talk about how he feels when his brain doesn't work, and I would explain in simple terms how the alcohol messed up his brain when he was a little baby still inside his birth mom. I talk about his birth mom's alcoholism, her inability to control her drinking, her wish for him to be adopted by a family who could care for him. I talk about FASD in a matter of fact way. I talk about his birth mother without judgment. John had no shame or embarrassment about having FAS because I did not have any shame or embarrassment about it.

My attitude of acceptance is reflected in John's attitude of acceptance. I was always truthful with John. This is important in establishing a strong trust relationship. Later John would need to trust me to help him make decisions that would keep him safe. Trust would later help him accept the restrictions that keep him from getting into serious trouble. Having this relationship of trust made it easier for him to come to me when others would tease or bully him. These were just more teaching moments where I could help lift his self esteem while I help him recognize and understand his strengths and needs.

When he would get frustrated with making so many mistakes and having so many difficulties, he would say, "Why do I have to have FAS? It's not fair."

I let him be angry about having FAS, then I explained to him that EVERYBODY has problems or disabilities of some sort, and the few that don't have any, will have eventually. I talked to him about hidden disabilities, that other people might have that he may not be aware of. I talk about the friends or neighbors or family members who have cancer, or diabetes, or migraines, or arthritis, and how that affects their life and we don't even notice.

When he says he feels different from others, I let him know that he is different from non-disabled people. But I also tell him there are thousands, of other people with FASD who experience the

same frustrations, who also need extra help and guidance and supervision. Belonging to a local support group will not only help parents cope, but can give the children a valuable chance to learn that they are not alone, and that others have similar struggles - and success. It's not the worse thing in the world to have FASD.

I tell him that everyone has talents too, and we talk about what natural gifts he has, and how everyone has some special talents, and how nice it is to do well in these special areas, and how good it feels to have that success. We talk about how we can make the most of these gifts and talents.

Then we might get back to all those people with invisible disorders. The person with cancer might have to go through chemo, not fun. A person with diabetes has to be on a strict diet and might have to get injections every day, not fun. A person with arthritis might be in constant pain, not fun.

At some point in his maturity, he became angry with his birth mother. He realized that if she had not consumed alcohol when she was pregnant with him, he would not have all these problems now. That was okay for him to be angry. I let him talk about how he felt and we talked about his birth mother's experience and difficulties. Since I had worked through my grief about this years ago, I was able to help him through his grief without my own anger getting in the way.

If the birth mother is raising her child, then I suggest some counseling for the birth mother before she talks to her child, so she can work through her own guilt first. The fear and anger and guilt experienced by birth parents and adoptive parents can become obstacles to the child's success. I firmly believe in the importance of parents resolving all their past grief issues.

Eventually John came to terms with having FASD. He is comfortable with who he is. He is appreciated and valued as a human being, a son, a brother, a friend, a musician, a member of the community. He helps to educate others about FASD. He told me that he believes his mission in life is to help everyone learn about the dangers of drinking during pregnancy so that other children might be born free of the problems of FASD.

There have been times when John and I have been out in the community, when John has engaged in some socially unacceptable conversation or behavior, such as inappropriately flirting with a store clerk. With a gentle cue from me, John would stop himself, then would apologize to the clerk, and explain why he has difficulty with social interactions, always warning her, "Don't drink when you are pregnant, so your child does not have to deal with all these problems like I do!." Some people chuckle with amusement or perhaps with discomfort in the face of such self honest statements. But everybody learns, and maybe another case of FASD is prevented.

When children get older, we can explain FASD in more detail. There is an article that I wrote for people who need a simple explanation of FASD, called The ABCs of FASD:

<http://fasteen.com/ABCFASD.htm>

IEP 123 Conflict Resolution Plan

Take a piece of paper and at the top write the student's name and the date of the IEP meeting. Then draw three columns and head them like this, spacing out the numbers on the page:

IEP ISSUES & OUTCOMES

Name: _____ School: _____ Date: _____

Student Needs:	School's Response:	Resolved?
----------------	--------------------	-----------

- 1.
- 2.
- 3.

Persons attending:

1. Before the IEP meeting, under "Student Needs" list the three most important issues or needs that are of highest priority, like constant supervision at all times, a communication log, FAS training for the teacher and her staff, an OT assessment for Sensory Integration Disorder, etc.

2. During the meeting, with the paper in front of you, when it is your turn to speak, say you have a few questions too. Be sweet and pleasant. Ask about one need at a time. If your request is ignored, say "I'll just take that as a 'no,' then, okay?" and write down "No." This will catch them off guard because you are not arguing, you are just asking and taking notes. If they talk around the issue and don't exactly give you an answer, say "I'll just take that as a 'no' since you didn't say 'yes,' okay?" If they actually say "no" to an item, then ask for their reasons, and write down their exact words, check with them to make sure you get it down right.

3. Before you leave the meeting, read your notes to them and ask if they agree with what you have written. IF they don't, ask very politely if they could send you a letter about what it is they don't agree with and their justification or documentation used to make that decision. You can even ask them to initial the items on which they do agree.

Using this plan increasing your chances of getting what your child needs. In cases where there is no resolution, you have good notes with which to write a letter to the school principal or special ed director, with copies sent to all interested parties, including your Protection and Advocacy agency, which is familiar with special ed law. If the school was not responsive, your notes will show that you were not treated as an equal participant in the IEP process. Good luck!

Based on IEP Conflict Resolution Chart by <http://www.kerrlaw.com> and
Suggestions from <http://at-advocacy.phillynews.com/data/iepchart.html>
More on special ed advocacy at www.wrightslaw.com and www.reedmartin.com

IEP ISSUES & OUTCOMES

Name: _____ **School:** _____ **Date:** _____

Student Needs:	School's Response:	Resolved?
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1. _____

Notes: _____

2. _____

Notes: _____

3. _____

Notes: _____

Attendees:

Comments:

Cognitive Behavior Therapy as a Treatment for Fetal Alcohol Spectrum Disorders

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Thirty years ago, I found myself raising two little ones with challenging behaviors. Typical behavior modification techniques just did not seem to work well with my children. I could accept this, because I knew that my children's behavior problems were not typical "naughty" behavior that one would expect from young children. One child has Prader-Willi Syndrome (PWS) and one child has Fetal Alcohol Syndrome (FAS). Both of these disorders are physiological disabilities that involve brain dysfunction and impair the person's ability to control their behavior.

While my children were growing up, I was constantly researching their disabilities and intervention strategies for challenging behaviors. At one point, I felt desperate enough to consult the help of a professional. After shopping around, interviewing several psychologists, I found one who not only understood my children's behaviors, but understood the stress and grief I was experiencing as a mother.

This wonderful psychologist helped me understand the neurological explanations for the behaviors that frustrated me the most. Research on these two disabilities over the years has helped me to focus on the brain's role in their behaviors.

By studying all the research on the neurobehavioral disorders associated with Fetal Alcohol Spectrum Disorders (FASDs), I have developed a keen interest in figuring out solutions to the various behavior problems that I have observed in both my children and in hundreds of other children with FASDs whose parents I have mentored over the years.

Some of the most helpful ideas have come from Dr. Wonderful (not his real name, of course). Each week he would give me a new tool or trick to try, and almost always it was effective. One week he gave me a book to read on the subject of cognitive behavior therapy (CBT). I was enthralled. To realize that we can change our behavior by changing our thoughts was an amazing discovery for me. This awareness gave me the freedom to change my own feelings and behaviors, as well as insights into having a positive effect on my children's behaviors. I finally believed what Abraham Lincoln said: "Most folks are as happy as they make up their minds to be." I tested that theory, and it worked for me. Maybe it would work for my children.

Now, of course, I cannot directly change my children's thoughts, but I know that I can have some influence over what they think, especially in the case of my son with FAS. He is so easily influenced by others, it would be funny if it were not so sad. I can ask him a question one way and get one answer, and ask the same question a different way and get the opposite answer, just by changing the tone of my voice. I can talk him into just about anything. That's scary, because anyone can talk him into anything.

Everyone who works with or has raised a child with an FASD knows that they are very easily influenced. They take on the morals and attitude of whomever they happen to be around. We know that we must be very careful about their choice of friends, as they will pick up the behaviors of those with whom they associate. This is a very high-risk aspect of FASD, and along with poor judgment and immature social development, being easily influenced by others is what gets them into so much trouble. How exciting to think we can use this to help them stay out of trouble. We just need to fill their heads with the right thoughts.

Cognitive behavior therapy is based on the theory that one can effect a change in one's own behavior by purposefully engaging in self-talk. Can we use cognitive behavior therapy to help a child with challenging behaviors? I think so. It certainly worked for my children. Can it work for other children?

One family consulted me recently who has a son with a diagnosis of Alcohol Related Neurodevelopmental Disorder (ARND), which is a type of FASD without the facial features. The boy is intelligent, gifted actually, but has ADHD, is very impulsive and is socially and emotionally immature, and has some difficulty controlling his tendency to react physically to frustration and anger. His aggression issues are causing serious problems at school and at home. And now he has developed a disregard for authority, both at school and at home. My first thought was this: Could we try cognitive behavior therapy to help this boy?

My first search led me to a 15-year study that looked at school-aged children with ADHD and aggression (Robinson 1999). The authors of this study concluded that CBT may be very helpful in reducing incidents of impulsivity and aggression and other disruptive behaviors in school, and CBT interventions might be effective beyond the term of treatment in reducing inappropriate and maladaptive behaviors in the students by giving them more self-control.

I don't pretend to be a psychologist. But having been coached by one of the wisest psychologists I know, and having such positive results from applying CBT in my own family, I think it would be wise for parents and teachers of children with FASDs who exhibit problem behaviors to consult with specialists who have been trained in both FASD and CBT. You can also look it up on the Internet or at the library and educate yourself about it. I learned that I can help my child have positive self-talk by providing the words verbally and by modeling positive self-talk out loud. Here are a few examples:

- "When I get frustrated, I stop and take a deep breath."
- "If I feel angry, I can say that I am angry."
- "If someone makes me mad, I can turn around and walk away."
- "When I feel out of control, I ask for help."

By planting the seeds of positive self-talk, and by providing healthy influences in the child's social environment, perhaps we can help the child with FASD have healthier thoughts that lead to better outcomes in school, at home, and in the world.

Robinson T R, Smith S W, Miller M D, Brownell M T. Cognitive Behavior Modification of Hyperactivity-Impulsivity and Aggression: A Meta-Analysis of School-Based Studies, *Journal of Educational Psychology* 1999; 91(2): 195-203

Reasonable Plan for Supporting Adults with FASD

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What do we need in our community in order to care for adults with FASD?

There are two very obvious needs. We need adequate services and we need funding to provide those services.

But let's get reasonable. We cannot just tell our legislators we need programs A, B, and C, and we need X amount of dollars to fund them.

This is just not going to happen until we "get over it." As a society we need to get over our love affair with alcohol. As responsible consumers we need to recognize the power that the alcohol industry has over our attitudes and beliefs and behaviors and the influence this mighty entity has over our legislators and policymakers and our families.

We as a society need to remove our blinders of denial about alcohol as a dangerous drug. We don't need to be anti-alcohol, we just need to tell the truth about alcohol. We break down denial by raising awareness about alcohol and FASD, and not just on September 9th. We need to talk more about the danger alcohol consumption poses to women of childbearing age and about the high rate of birth control failure. Half of all women of childbearing age drink alcohol, and that rate is increasing year after year. We need to ask ourselves "Why?" Half of all pregnancies are unplanned, so women are exposing their babies to alcohol without even knowing they are pregnant. Again, we need to ask ourselves "Why?" Is the alcohol industry targeting young women? Are there more young women for whom prevention, education, or treatment is just not going to be effective? We need to keep asking ourselves "Why" until we find the core answers.

But let's jump forward in time and say that we have the money and the resources to provide services to adults with FASD. What would that look like?

First of all, for a group's needs to be met in the community, the community needs to know about and understand the group's needs. If FASD is mostly invisible and to a great extent misunderstood, then we have to begin by educating the entire community: government leaders, service providers, educators, and the general public.

We need to recognize individuals with FASD at all ages. A diagnosis would be ideal; documentation would be helpful. But this is seldom going to be the case. So we should do what we can to verify suspicions of possible FASD.

We would identify adults using assessments, such as a good psychological evaluation, or a questionnaire or checklist, or maybe a functional assessment like the Vineland, or perhaps just a thorough journal by the parent or caregiver. Based on the data collected, we would put together a good needs assessment, an individual personal plan.

Then we would educate everyone in that person's life: the team, the family, and the individual himself or herself, about that person's specific disability, how FASD affects his or her ability to

function in life. An important component of educating the family and the individual would include guidance through the grief process to accept the reality of FASD, to let go of the dream, and to find a new dream toward which to work.

Then, and only then, can we begin to provide quality services. That means providing the individual with an “external brain” as noted by Drs. Sterling Clarren and Susan Doctor. That external brain will look different for each individual, based on their unique needs. It might look like 24/7 supervision, or daily mentoring. How much guidance is given will depend on the individual’s past record, their present level of functioning, and the future risk of serious secondary disabilities based on reasonable expectations.

We will set reasonable goals for the individual, based on this priority: Safety first, then health, and then freedom. We will resist the temptation (peer pressure) to give the adult with FASD (who may have the functional ability of a 6 year old) the same independence we give to nondisabled adults. Giving them too much freedom puts them at serious risk of becoming arrested, addicted, injured, or killed. Then they will have no freedom. If we protect their right to a safe environment and a healthy lifestyle, we maximize their chances to have a relatively high level of freedom.

So it boils down to providing the individual with the “external brain” as determined by sound assessments to allow the person the best chance to live a quality of life that encourages them to find their dreams and attain success.

Being a compulsive acronym seeker, I found a way to put all of this into bullets that spell out a word that we need to remember: REASONABLE. We need to be reasonable in our expectations of individuals with FASD, of their families, and of the professionals who are entrusted with providing what they need.

- R** is for Remove invisible barriers, such as denial, stigma, blame.
- E** is for Educate everyone at all levels about the nature of FASD.
- A** is for Assessments, such as IQ, Vineland, questionnaire, journal.
- S** is for Service plan based on individual needs, capabilities, and talents.
- O** is for Objectives with reasonable expectations for success.
- N** is for New definition of “success” and new dream for the future.
- A** is for Acceptance by everyone of the reality of FASD disabilities.
- B** is for Build a Circle of Support to nurture, guide, and mentor.
- L** is for Life-long plan for sustaining that support in a safe environment.
- E** is for Everyone is responsible for FASD, it’s prevention and intervention.

I believe that one of these bullets is more important than all the others. If all but this one is in place, but this one is missing, then all is for nothing. Can you figure out which one is most important? Hint: It has to do with the individual with FASD.

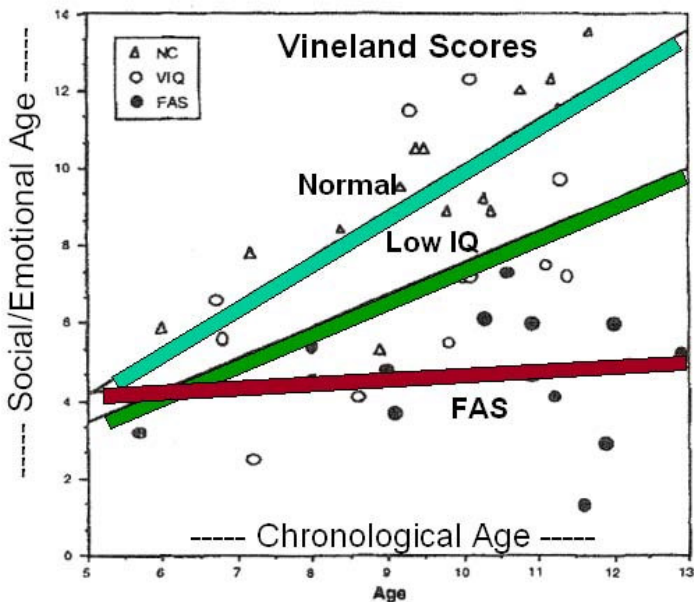
FASD and Social Development

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Research conducted by Dr. Ed Riley and associates made a comparison of social abilities among:

- Children with FAS
- Children with same IQ (no FAS)
- Control group (normal children)

Riley utilized the Vineland Adaptive Behavior Scales “VABS II” (parent version) to determine the level of social skills in these three groups. The results show that children with FAS have social skills stunted at the 4 to 6 year old level, regardless of age or intellectual abilities.



Citation: Comparison of social abilities of children with fetal alcohol syndrome to those of children with similar IQ scores and normal controls. Thomas SE, Kelly SJ, Mattson SN, Riley EP.. Alcohol Clin Exp Res 22:528–533, 1998.

<http://ncbi.nlm.nih.gov/pubmed/9581664?dopt=Abstract>

Social developmental age is reflected in emotional regulation and conscience development. The 18-21 year old with FAS may be functioning intellectually at the level of a 12-16 year old but socially and emotionally at the level of a 4-6 year old.

In another research report, Riley explains “arrested social development”:

Adaptive and Social Skills. Studies have suggested that alcohol-exposed children are at high risk for problem behaviors that can interfere with their participation in home, school, and social environments. For example, these children are more likely than non-exposed children to be rated as hyperactive, disruptive, impulsive, or delinquent. Furthermore, based on parent ratings of their child’s behavior, children with histories of prenatal alcohol exposure had significant and profound impairment, with particular difficulties in social, attention, and aggressive domains. Results from a recent study suggest that social deficits in children with FAS are beyond what can be explained by low IQ scores and indicate that they may be arrested, and not simply delayed.

Citation: Fetal Alcohol Spectrum Disorders: An Overview with Emphasis on Changes in Brain and Behavior. Edward P. Riley¹ and Christie L. McGee, *Experimental Biology and Medicine* 230:357-365 (2005)

Requests for reprints should be addressed to Center for Behavioral Teratology, 6363 Alvarado Court, 209, San Diego, CA 92120.

E-mail: eriley@mail.sdsu.edu

What is the Vineland Test?

The Vineland Adaptive Behavior Scales, Second Edition (Vineland-II) measures the personal and social skills of individuals from birth through adulthood. Because adaptive behavior refers to an individual's typical performance of the day-to-day activities required for personal and social sufficiency, these scales assess what a person actually does, rather than what he or she is able to do.

FASD experts agree that the Vineland II (parent version) is the best assessment to determine the functional abilities of individuals with diagnosed or suspected Fetal Alcohol Spectrum Disorders.

In order to determine the level of an individual's adaptive behavior, someone who is familiar with that individual, such as a parent or caregiver, is asked to describe his activities. Those activities are then compared to those of other people the same age to determine which areas are average, above average, or in need of special help.

Learning about an individual's adaptive behavior helps us to gain a total picture of that individual. When adaptive behavior information is combined with information about an individual's intelligence, school achievement, and physical health, plans can be made to address any special needs that person may have at home or in school.

There is a teacher version and a parent version. The parent questionnaire can be processed either as an interview or a parent survey. The parent version will address a wider variety of adaptive behaviors than the teacher version, which only addresses behaviors observed in the classroom.

The Vineland-II assesses adaptive behavior in four domains: Communication, Daily Living Skills, Socialization, and Motor Skills. It also provides a composite score that summarizes the individual's performance across all four domains.

Domains & Index	Subdomain
Communication	Receptive Expressive Written
Daily Living Skills	Personal Domestic Community
Socialization	Interpersonal Relationships Play and Leisure Time Coping Skills
Motor Skills	Fine Gross
Maladaptive Behavior Index (Optional)	Internalizing Externalizing Other

Information about the Vineland assessment is provided by AGS publishing:
<http://ags.pearsonassessments.com/group.asp?nGroupInfoID=aVineland>

For a sample letter requesting a school to administer the Vineland test, see this link:
<http://www.come-over.to/FAS/VinelandRationale.htm>

Finding Factors That Affect Behaviors In Children with Fetal Alcohol Spectrum Disorders

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Tommy is a 10-year-old boy with FAS. He has no other disorders other than the typical attention deficits. Poor judgment and lack of impulse control are ongoing problems. Tommy lives in a stable home, is on medications that help balance his brain chemicals to optimize control over his behavior. His parents have good parenting skills and Tommy has a healthy attachment to his family.

But... every so often, he just loses it! Tantrums might occur over small issues. A meltdown might occur unexpectedly, without any obvious reasons.

How many factors can you identify that might have an adverse effect on Tommy's behavior?

Hint: some are internal and some are external.

Internal Factors:	External Factors:
Missed meds	Clothing (elastic, labels, too scratchy, too much, too little)
Hunger (too long between meals)	Wind, weather, temperature, air pressure
Dehydration (very important to avoid)	Noises: television, radio, people
Nutrition/Diet (MSG, artificial food coloring, nitrates, Nutrisweet)	Lighting (fluorescent)
Frustration, anger	Visual distractions that are "busy"
Fear, anxiety	Chaotic household or classroom
Unrecognized symptoms of illness	Role models acting out with rudeness or aggression
Fatigue, disrupted sleep cycle	Being yelled at, blamed, put down
Hormones	

How to Access FAS Diagnostic Guidelines

Go to the FAS Community Resource Center web site www.fascrc.com

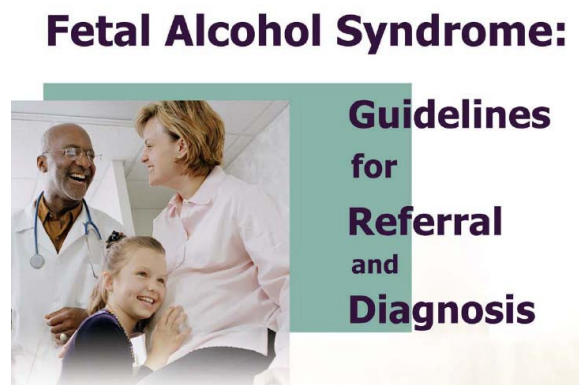
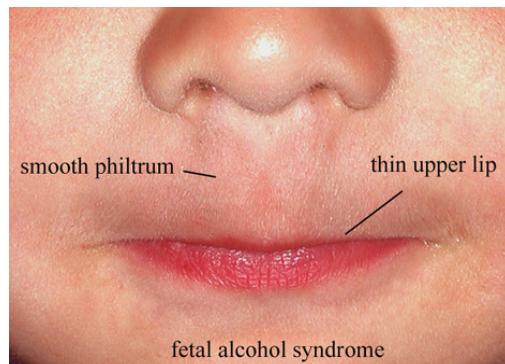
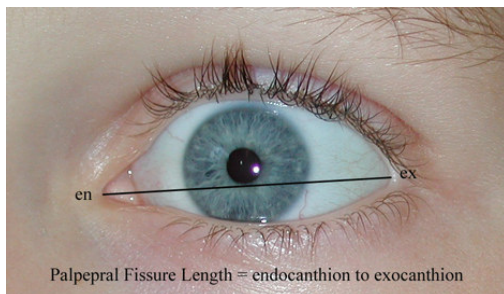
Scroll down about half way to "The Doctor's Office. See "New Diagnostic Guidelines" <http://pediatrics.aappublications.org/cgi/reprint/115/1/39> A Practical Clinical Approach to Diagnosis of Fetal Alcohol Spectrum Disorders: Clarification of the 1996 Institute of Medicine Criteria - *Pediatrics* 2005;115:39-47 by H. Eugene Hoyme, MD, Philip A. May, PhD, Kenneth Lyons Jones, MD,¶ and Luther K. Robinson, MD et al This one covers the entire spectrum from full FAS to invisible ARND.

See the link for **FAS Guidelines for Referral and Diagnosis** published by the U.S. Department of Health and Human Services

http://www.cdc.gov/ncbddd/fas/documents/FAS_guidelines_accessible.pdf

These guidelines are intended to assist physicians and allied health professionals in the timely identification, referral, and diagnosis of persons with fetal alcohol syndrome.

You can also find a link to the **Astley-Clarren 4-digit code** diagnostic criteria (available on CD-Rom from March of Dimes) <http://depts.washington.edu/fasdpc/htmls/4-digit-code.htm>



Lip-Philtrum Guide I

Nutritional Recommendations for Children Exposed to Alcohol and Other Drugs

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Fasstar Enterprises www.fasstar.com

Diet recommendations:

- No aspartame (Nutrisweet)
- No artificial food colors (with numbers)
- No MSG (monosodium glutamate)

These three ingredients are the worst ones. Recent research shows that these are highly toxic to all of us, but those who have neurodevelopmental disorders may be even more affected by these additives.

Extra Nutrients:

Scientists have reported that children with FASD may not be able to absorb adequate nutrients even when they eat healthy foods. Doctors and nutritionists recommend:

- Daily vitamin (no artificial colors)
- Extra B6
- Extra B12
- Extra E: Omega 3 (fish or flax oil)
- Lecithin – in gel cap or water soluble powder (has **choline** to help repair the myelin sheath for improved neural connectivity and brain function)

No access to alcohol!

Eliminate all temptations and opportunities for even one drink, because alcohol lowers already low inhibitions, impairs already impaired judgment and increases risk of already risky behaviors and situations. Beer, wine, and mixed drinks are not food, they are drugs. Just because alcohol is legal does not mean it is healthy. For individuals with FASD, alcohol can be detrimental to their ability to function, and presents a much greater risk for them.

Don't forget to be a good role model!

Three Basic Rules:

- Read the labels
- Cook from scratch when possible
- Watch out for prescribed and over-the-counter medications that have additives

Snack ideas:

Banana pops: cut banana into four pieces, roll in sweetened lemon juice, put a Popsicle stick in each piece, freeze.

Milk shake: in blender put ½ cup low-fat milk, ½ cup water, sweetener or fruit, 6-8 ice cubes.

Cocoa made with milk, cocoa powder and sugar or safe sweetener (no chocolate syrup)

Veggie sticks (like carrots and zucchini) in a baggie flavored with pickle juice

Veggies and fresh dip made from scratch

Cheddar fish crackers (regular kind only)

Freshly made cheese pizza (with carefully chosen toppings, no pepperoni)

Sun Drops candy (like m&ms, found in health food markets)

Homemade ice cream with natural ingredients

Neurotransmitter Boosters:

Chocolate every day boosts serotonin.

Turkey, potatoes, and bananas boost dopamine.

Avoid dehydration, provide plenty of water

Impact of Food Additives on Children's Behavior

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Aspartame (Nutrisweet) * Artificial food colors * MSG (monosodium glutamate)

These three ingredients are the worst ones. Recent studies show that these three substances are highly toxic to all of us, but those who have neurodevelopmental disorders may be even more affected by these additives. Take a look at the research:

Way back in 1982, the National Institute of Health (NIH) determined that some children with hyperactivity had an increase in behavior problems when on a diet that included moderate amounts of additives, and there was no increase with the placebo. It was this NIH report that initiated legal mandates to include a list of ingredients on packaged food items.

In 2004, to determine whether artificial colorings and preservatives had an effect on children's hyperactivity, John Warner and colleagues assessed nearly 2,000 preschoolers for symptoms of ADHD. The effects were substantial. "We were surprised by the results," Warner said, "because the effect was not just in one group. We showed there was an effect on perfectly normal children. If that is confirmed by further research then there is a public health issue."

A meta-analysis in 2004 of previous research supported evidence that neurobehavioral symptoms may be adversely affected by a variety of additives commonly found in packaged and prepared foods.

A doubleblind study by Karen Lau in 2006 shows that Aspartame and MSG can be "highly toxic to brain cells" when combined with certain artificial food colors. The mouse-model study showed that the combination of additives, in an amount equivalent to that found in a typical snack and soft drink. The synergistic effects could be profound. "Cell proliferation, migration, differentiation and synapse formation progress in a tightly programmed and orderly fashion," the researchers note. "Interference with any stage of this cascade of events may alter normal progression of subsequent stages and short-term disruptions may have long-term effects later in life."

References:

Bateman B, Warner JO, Hutchinson E, Dean T, Rowlandson P, Gant C, Grundy J, Fitzgerald C, Stevenson J. The effects of a double blind, placebo controlled, artificial food colourings and benzoate preservative challenge on hyperactivity in a general population sample of preschool children. *Arch Dis Child*. 2004 Jun;89(6):506-11.

Lau K, McLean WG, Williams DP, Howard CV. Synergistic interactions between commonly used food additives in a developmental neurotoxicity test. *Toxicol Sci*. 2006 Mar;90(1):178-87.

National Institutes of Health (1982) Defined Diets and Childhood Hyperactivity. Consensus Development Conference Summary, Volume 4, Number 3

Schab DW and Trinh NH (2004) Do artificial food colors promote hyperactivity in children with hyperactive syndromes? A meta-analysis of double-blind placebo-controlled trials. *Journal of Developmental & Behavioral Pediatrics* 25(6): 423-434

Resources in Arizona for Families and Individuals with Fetal Alcohol Spectrum Disorders

www.fasarizona.com February 2, 2010

Addiction Recovery

Alcoholics Anonymous 24-hour hotline: (520) 624-4183

Advocacy

Arizona Center for Disability Law (800) 927-2260

Community Referral Services

Fetal Alcohol Resource Center in Tucson (520) 745-5588x2625

Community Information and Referral throughout Arizona (800) 352-3792

Developmental Disabilities

If your child has an IQ under 70, he/she may qualify for disability services. Call the Arizona Department of Developmental Disabilities (602) 542-0419 or toll-free (886) 229-5553. If your child does not meet eligibility criteria, you can still get support and information through participation in The Arc of Arizona (602) 243-1787 - (800) 252-9054. They have chapters throughout the state.

Diagnosis

Children's Health Center at St. Joseph's Hospital (602) 406-3543

Phoenix Children's Hospital (602) 546-0970

St. Joseph's Hospital and Medical Center (602) 406-3611 or (800) 392-2222

University of Arizona Health Sciences Center in Tucson (520) 626-5175

Flagstaff Medical Center (520) 773-2054 or (800) 232-1018

Yuma Regional Medical Center (928) 336-7095 or (800) 837-7309

Early Intervention

Arizona Early Intervention Program (800) 392-2222

Education, Special Education

Exceptional Student Services, AZ Department of Education (800) 352-4558

Arizona Center for Disability Law Special Ed Hotline (602) 274-6287 or (800) 927-2260

Family Support

Fetal Alcohol Resource Center in Tucson (520) 745-5588x2625

Other areas, see FAS Arizona www.fasarizona.com, click on Resources

Health Services

Arizona Department of Health, Office of Women's & Children's Health (602) 364-1400

Native American Support Services

Phoenix Area Indian Health Services (602) 364-5039

Tucson Area Indian Health Services (520) 295-2405

Navajo Area Indian Health Services (928) 871-5811

Window Rock - Navajo Country: Louise Ashkie louise.ashkie@nndoh.org 928-871-6237

Legal Assistance

Arizona Center for Disability Law, (602) 274-6287 in Phoenix, (800) 927-2260 in other areas

Mental Health and Substance Abuse Services

Graham, Greenlee, Santa Cruz, Cochise: CPSA (800) 771-9889

Maricopa: Magellan Health Services (800) 564-5465

Mohave, Coconino, Apache, Navajo and Yavapai: NARBHA (800) 640-2123

Pima: CPSA (800) 771-9889

Pinal and Gila: PGBHA (800) 982-1317

Yuma and La Paz: EXCEL Group (800) 880-8901

Post Adoption Resources

Fetal Alcohol Resource Center in Tucson (520) 745-5588 x2625

K.A.R.E. Kinship and Adoption Resources and Education (520) 323-4476

Prevention

Fetal Alcohol Resource Center in Tucson (520) 745-5588x2625

Arizona Prevention Resource Center (800) 432-2772

Printed Materials

Fetal Alcohol Resource Center in Tucson (520) 745-5588x2625

FAS Arizona www.fasarizona.com click on Resources

“Damaged Angels” by Bonnie Buxton www.damagedangels.com

“A Crime of Alcohol” by Kathy Norgard www.fasarizona.com

Recreation

Special Olympics in Arizona: (800) 289-IWIN

Screening Services

Free screening for FASD is available through the Fetal Alcohol Resource Center (520) 745-5588 x2625

Services for Individuals With Fetal Alcohol Spectrum Disorders

Except for Early Intervention, there are no services for which individuals would qualify based solely on a diagnosis of Fetal Alcohol Syndrome or Alcohol Related Neurodevelopmental Disorder. The only services specific to FASD are screening, support, training, and consultation available through the Fetal Alcohol Resource Center. Call Teresa Kellerman in Tucson at (520) 296-9172 or Dr. Cindy Beckett in Flagstaff at (928) 773-2307.

Task Force

Arizona Task Force on Preventing Prenatal Exposure to Alcohol and Other Drugs. Contact Senator Linda Lopez (602) 926-4089 or Dr. Cindy Beckett (928) 773-2307

Training Workshops on FASD

Arc of Arizona Prevention Committee, Fetal Alcohol Resource Center in Tucson (520) 745-5588x2625

Vocational Rehabilitation

Arizona DES Rehabilitation Services Administration (602) 542-2209 or (800) 563-1221

www.fasstar.com

Arizona Department of Economic Security
Division of Developmental Disabilities
Fetal Alcohol Resource Center
4710 E. 29th St.
Tucson, AZ 85711
(520) 745-5588 ext. 2625



www.fasarizona.com

For more information on Fetal Alcohol Spectrum Disorders visit www.fascrc.com
For information on training and workshops on FASD issues visit www.fasstar.com