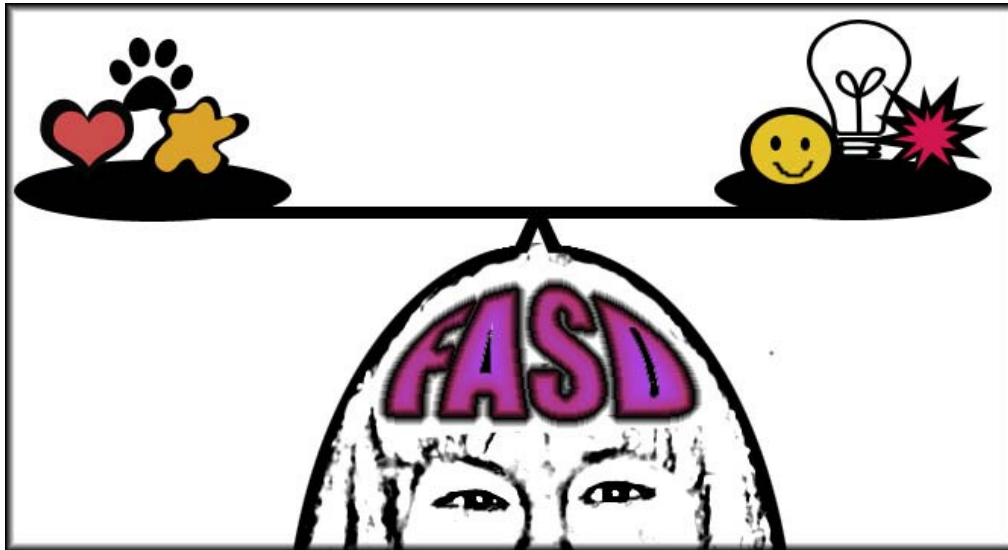


Fetal Alcohol Spectrum Disorders: Balanced Brain for Better Behaviors



presented by Teresa Kellerman, Director
Fetal Alcohol Resource Center

Fetal Alcohol Spectrum Disorder (FASD) are primarily brain damage caused by prenatal exposure to alcohol. The most common symptoms of FASD are behavior problems. Prenatal alcohol exposure interrupts brain development and impacts many brain systems, including the regulation and production of various neurotransmitters. Through a better understanding of how the brain functions, we can implement practical intervention strategies that can help the overall performance of the child's brain and hopefully improve outcomes and maximize success.

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

- Understand how prenatal alcohol 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

For more information, visit FAS Arizona www.fasarizona.com
Handout Packet Revised July 2016

Overlapping Behavioral Characteristics & Related Mental Health Diagnoses in Children

Overlapping Characteristics & Mental Health Diagnoses	FASD	ADD/ADHD	Sensory Int. Dys.	Autism	Bi-Polar	RAD	Depression	ODD	Trauma	Poverty
	Organic	Organic	Organic	Organic	Mood	Mood	Mood	Mood	Environ	Environ
Easily distracted by extraneous stimuli	X	X	X							
Developmental Dysmaturity	X			X						
Feel Different from other people	X				X					
Often does not follow through on instructions	X	X					X	X	X	X
Often interrupts/intrudes	X	X	X	X	X		X			X
Often engages in activities without considering possible consequences	X	X	X	X	X					X
Often has difficulty organizing tasks & activities	X	X		X	X		X			X
Difficulty with transitions	X		X	X	X					
No impulse controls, acts hyperactive	X	X	X		X	X				
Sleep Disturbance	X				X		X		X	
Indiscriminately affectionate with strangers	X		X		X	X				
Lack of eye contact	X		X	X		X	X			
Not cuddly	X			X		X	X			
Lying about the obvious	X				X	X				
No impulse controls, acts hyperactive	X		X		X	X			X	
Learning lags: "Won't learn, some can't learn"	X		X			X			X	X
Incessant chatter, or abnormal speech patterns	X		X	X	X	X				
Increased startle response	X		X						X	
Emotionally volatile, often exhibit wide mood swings	X	X	X	X	X	X	X	X	X	
Depression develops, often in teen years	X	X				X			X	
Problems with social interactions	X			X	X		X			
Defect in speech and language, delays	X			X						
Over/under-responsive to stimuli	X	X	X	X						
Perseveration, inflexibility	X			X	X					
Escalation in response to stress	X		X	X	X		X		X	
Poor problem solving	X			X	X		X			
Difficulty seeing cause & effect	X			X						
Exceptional abilities in one area	X			X						
Guess at what "normal" is	X			X						
Lie when it would be easy to tell the truth	X				X	X				
Difficulty initiating, following through	X	X			X		X			
Difficulty with relationships	X		X	X	X	X	X			
Manage time poorly/lack of comprehension of time	X	X			X		X			X
Information processing difficulties speech/language: receptive vs. expressive	X			X						
Often loses temper	X		X		X		X	X	X	
Often argues with adults	X				X			X		
Often actively defies or refuses to comply	X				X			X		
Often blames others for his or her mistakes	X	X			X		X	X		
Is often touchy or easily annoyed by others	X				X		X	X		
Is often angry and resentful	X						X	X		

What is FASD and FAS?



FASD stands for **Fetal Alcohol Spectrum Disorders**. This is not a diagnostic term, but is an umbrella term that encompasses all disabilities caused by prenatal exposure to alcohol. There are five diagnoses under the FASD umbrella:

- Fetal Alcohol Syndrome (FAS) with confirmed prenatal alcohol exposure
- Fetal Alcohol Syndrome (FAS) without confirmed prenatal alcohol exposure
- Partial Fetal Alcohol Syndrome (pFAS)
- Alcohol Related Neurodevelopmental Disorder (ARND)
- Alcohol Related Birth Defects (ARBD)

Fetal Alcohol Syndrome (FAS) is a group of symptoms seen in children who were exposed to alcohol before birth. Full FAS is characterized by:

- Growth deficiency, with height or weight below the 10th percentile
- Facial characteristics: small eyes, smooth philtrum, and thin upper lip
- Central nervous system damage (structural, neurological, and/or functional impairment).

Partial FAS (pFAS) is a diagnostic classification for patients who present with:

- Some but not all of the physiological symptoms of full FAS
- Central nervous system damage (structural, neurological, and/or functional impairment)
- Confirmed prenatal exposure to alcohol

Alcohol Related Neurodevelopmental Disorders (ARND) is a diagnostic classification for individuals who were prenatally exposed to alcohol and who do not have the facial characteristics of full FAS but who have symptoms of central nervous system damage associated with FAS. "ARND is indistinguishable from FAS except from the facial syndrome." [Claire D. Coles, PhD, National Task Force on FAS and FAE, September 20, 2002.]

Alcohol Related Birth Defects (ARBD) is a diagnostic classification for individuals who were prenatally exposed to alcohol and who have physical defects such as malformations of the heart, bone, kidney, vision, or hearing systems.

Fetal Alcohol Effects (FAE) is a term that is no longer used. FAE generally refers to diagnoses other than full FAS. The term Fetal Alcohol Effects means about the same as the term Alcohol Related Neurodevelopmental Disorders.

Research shows that alcohol damage to the developing baby can cause a wide range of disabilities. Damage varies due to volume of alcohol ingested, timing during pregnancy, blood alcohol levels, genetics and environmental factors. At the mild end, damage may be the loss of some intellectual functioning (IQ), attention deficit disorder, hearing and visual problems, and higher than normal pain tolerance.

At the severe end, damage may be severe loss of intellectual potential, severe vision problems, dyslexia, serious maxilo-facial deformities, dental abnormalities, heart defects, immune system malfunctioning, behavioral problems, attention deficit disorders, hyperactivity, extreme impulsiveness, poor judgment, difficulty with memory retention and retrieval, hearing disorders, little or no capacity for moral judgment or interpersonal empathy, sociopathic behavior, epilepsy, tremors, cerebral palsy, renal failure, heart failure, death.

Researchers have found a link between maternal alcohol use and sudden infant death syndrome.

The most problematic aspects of prenatal alcohol damage are:

- **Immature or inappropriate behavior**
- **Memory deficits**
- **Impulse control problems**
- **Poor judgment**

The affected person's ability to control behavior is erratic and inconsistent. One day they can function in a reasonable manner. The next day (or the next moment), they may be out of control, inappropriate, immature, forgetful, impulsive, and make unwise choices.

Important FASD Facts:

- The prevalence of full Fetal Alcohol Syndrome is estimated to be 2 per 1,000 live births (more prevalent than Down Syndrome).
- Each year in the U.S. more than 50,000 babies are born with Fetal Alcohol Spectrum Disorders
- The annual cost to U.S. taxpayers for treating FAS is \$5.8 billion.
- Prenatal exposure to alcohol is the leading known cause of mental retardation and developmental disabilities among babies born in North America and the Western World. [Drug and Alcohol Dependence 19: 51 70, 1987]
- Most individuals with FAS and ARND have normal intelligence. (Streissguth et al, 1996 Report on Secondary Disabilities)
- There is no safe level of drinking during pregnancy. (March of Dimes, American Academy of Pediatrics)
- Even one drinking binge can cause damage to the developing baby's brain. (Science News, Vol. 158, No. 2, July 8, 2000, p. 28)
- Half of all women of childbearing age are drinkers. Half of all pregnancies are unplanned.

FAS Community Resource Center
www.come-over.to/FASCRC
<http://www.fasstar.com>

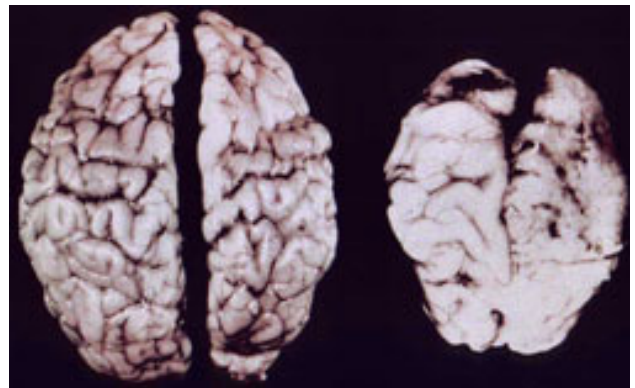
Prenatal Alcohol Exposure and the Brain

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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.

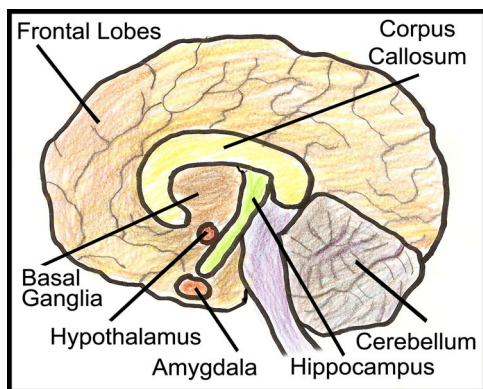
The brain is the organ most sensitive to prenatal alcohol damage.
[Dr. Edward P. Riley lecture, September 25, 2002]



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:
<ul style="list-style-type: none"> • inhibition • problem solving • sexual urges • planning • time perception • internal ordering • working memory • self-monitoring • verbal self-regulation • motor control • regulation of emotion • motivation • judgment 	<ul style="list-style-type: none"> • 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.

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?tool=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

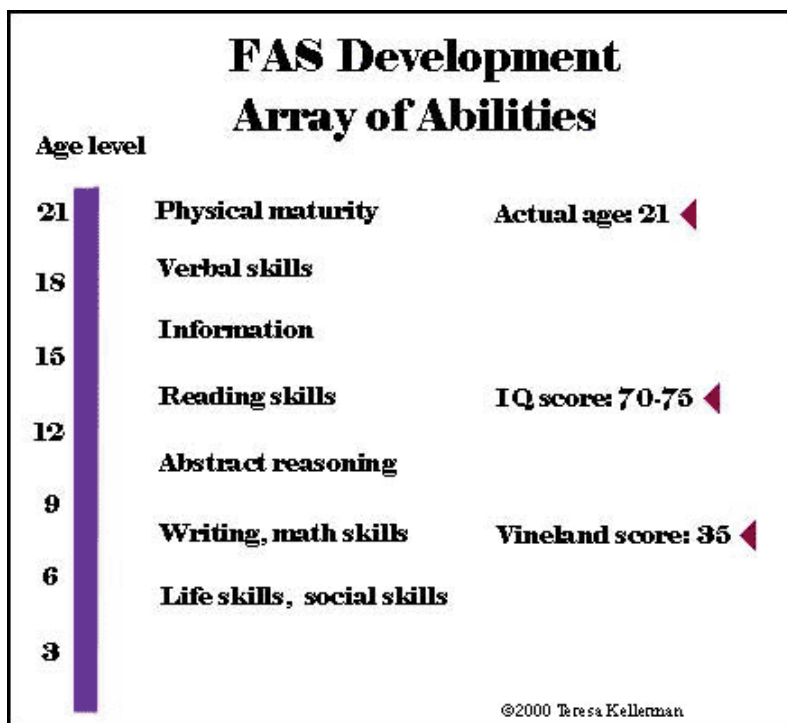
Ethanol can disrupt production of oxytocin later in life in females, interfering with bonding and maternal behaviors. Sexually Dimorphic Effects of Alcohol Exposure during Development on the Processing of Social Cues. Alcohol and Alcoholism. 2009 Nov-Dec;44(6):555-60.
<http://alcalc.oxfordjournals.org/cgi/content/abstract/agg061v1>

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.fasrc.com

ARRAY of ABILITIES

In a person with typical FAS symptoms



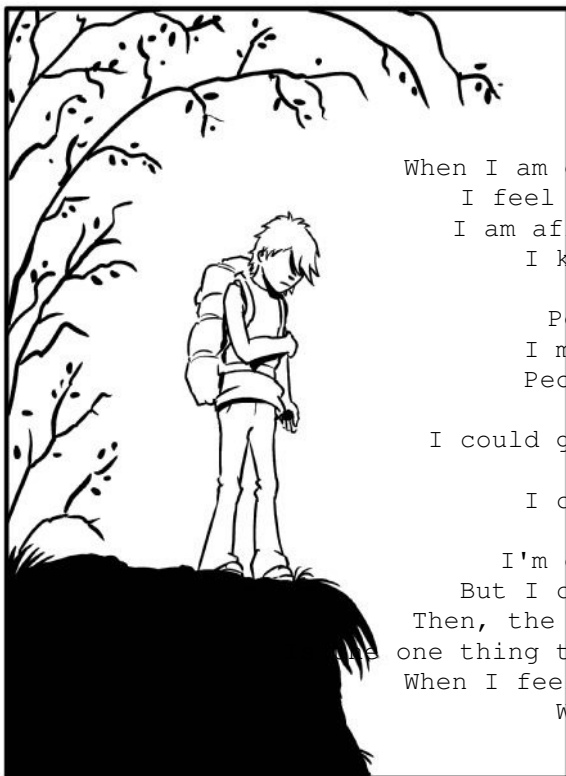
These different levels of development occur in one individual at the age of 21. The person has Fetal Alcohol Syndrome (FAS). These are actual results from a psychological evaluation that measures IQ, functional abilities, and adaptive behavior skills.

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”

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HELP!

by John Kellerman

When I am off track and out of control,
I feel like I am going to crash.
I am afraid of what might happen.
I know what will happen.

People won't like me.
I might lose privileges.
People won't respect me.
I could get fired.
I could get arrested and go to jail.
I could get hurt.
I could even get killed.

I'm on the right track now,
But I could lose it at any time.
Then, the thing that I need to do most
is one thing that I have a really hard time doing.
When I feel like I am going to lose it,
What I need to do is
Ask For Help!

When my brain is not working right,
I need to let someone I trust
Help me
To stay safe and get calm again.

When my brain is not working right,
I feel like I am on a FASD Train
Going downhill,
And the engineer is asleep
And I can't wake him up,
And I can't put on the brakes.

I watch myself go faster and faster,
And I can't stop.

In my head,
I want to yell for Help!
But the words that come out are full of
Anger and
Frustration and
Disrespect.
Bad, bad words.

When I slow down and finally stop,
I am okay again.
Then my mom and I have a "talk."
My mom is always there to help me.
But who is going to be there for me
When she is gone?

Help!

Secondary Disabilities in FASD

© 2000-2002 Teresa Kellerman
revised May 31, 2003

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).

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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

MED: Meds, exercise, and diet will have a profound effect on their ability to control their behavior

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.

MED: Meds, exercise, and diet. 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. Daily exercise and proper nutrition and hydration are critical for behavior and mood regulation.

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

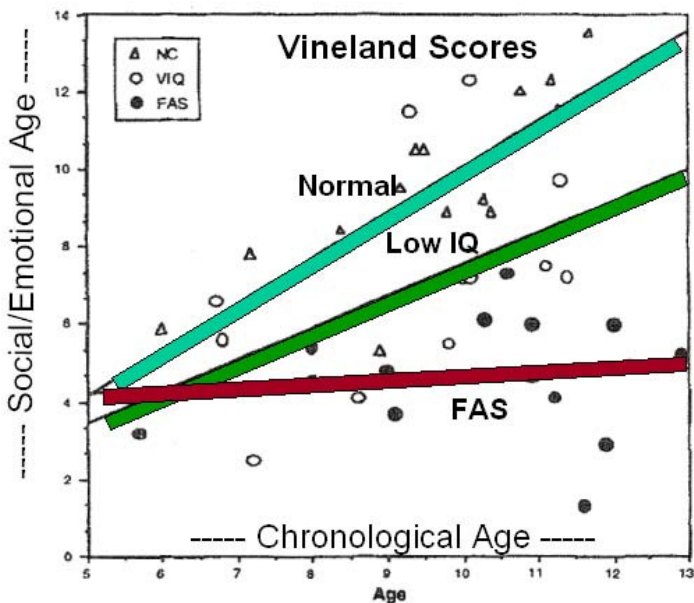
FASD and Social Development

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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.

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

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>

Balanced Brain for Better Behaviors

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Fetal Alcohol Spectrum Disorder (FASD) are primarily brain damage caused by prenatal exposure to alcohol. The most common symptoms of FASD behaviors are:

- Memory deficits (forgetting rules or consequences)
- Impulsivity (acting without thinking)
- Immaturity (stunted social/emotional/conscience development)
- Poor judgment (making decisions without regard to risk)

Prenatal alcohol exposure interrupts brain development and impacts many brain systems, including the regulation and production of various neurotransmitters, including:

- | | |
|--------------------------------------|-----------------|
| Dopamine (happy, excitement) | may be too low |
| Serotonin (happy, calm, contentment) | may be too low |
| Oxytocin (warm, trusting, loving) | may be too low |
| Testosterone (aggression, libido) | may be too high |
| Cortisol (stress, fight or flight) | may be too high |

FASD means the brain may not produce enough dopamine, serotonin and oxytocin, and may produce too much testosterone and cortisol. These levels fluctuate over the course of the day.

The child who demands constant attention, who pushes other people's buttons to get a reaction, who manipulates others, or who incites drama, may have too little dopamine. The child who seems sullen and depressed may have too little serotonin. The child who is hateful and mistrustful may have too little oxytocin. The child who is angry all the time, who intentionally breaks the rules, or who engages in self abuse, may have several neurotransmitters out of balance. There are ways we can help the brain produce a healthy balance of the neurochemicals so the brain can function better, giving the child more control over behavior.

We can help the overall performance and function of the brain by making sure the child gets adequate rest at night and lots of fluids throughout the day, and by eliminating artificial additives from the diet (no Red 40 and other colors with numbers, no MSG, no Nutrisweet/aspartame).

Dopamine can be increased with

- Lots of personal attention (5 minutes per hour)
- Reward systems that change every month
- Competition, games that can be won, prizes
- Thrilling activities (roller coasters, races)
- Vacation, party, day trips (zoo, park)

Adderall

- Vigorous daily exercise
- Humor and silly play
- Music and rhythm
- Video games
- Anticipation

Serotonin can be increased with

- Chocolate (dark or light, but no colors)
- Turkey, chicken, nuts, cheese, eggs, bananas

SSRIs (Paxil, Celexa, Prozac, etc.)

- Green tea, fish oil
- Mild exercise, a walk outside

Oxytocin can be increased with

- Hugs, massage, cuddling
- Pleasant sensory experiences

Cuddly pets with soft coats

- Playing with happy babies
- Generosity, gift giving

Testosterone levels and libido decrease with some medications, like SSRIs.

Cortisol can be decreased with relaxation exercises, calm music, a walk, positive self talk.

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	

Nutritional Recommendations for Individuals Exposed to Alcohol and Other Drugs

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Diet recommendations:

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

Recent research shows that these are highly toxic to the brain, and may impact the behavior of children with neurodevelopmental disorders.

Avoid hot dogs, pepperoni, Jell-O, Kool-Aid, popsicles, most colored candy, and Gatorade.

Avoid Red 2, Red 3, Red 40, Blue 1, Blue 2, Green 3, Orange B, Yellow 5, and Yellow 6.

Extra Nutrients:

Doctors and nutritionists recommend:

- Daily vitamin (no artificial colors)
- Vitamin E Omega 3 Fish Oil
- Lecithin –(gel cap or water soluble powder has **choline** to help repair the myelin sheath, improve neural connectivity, brain function)

Happy Foods: Chocolate, Turkey, Chicken, Potatoes, Green Vegetables, Berries, Red Grapes, Peanut Butter, and Bananas

These foods help boost serotonin and endorphins, reduce cravings, and are just plain healthy.

Wong, J. The Pursuit of Happiness. University of British Columbia, The Science Creative Quarterly, Issue 4, 2009

Hydrate with fluids throughout the day. Mild dehydration can cause irritability and increase impulsive and aggressive behavior. Always carry a water bottle!

Vigorous daily exercise will help increase dopamine and reduce behavior problems!

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 Splenda (no chocolate syrup)

Cheddar fish crackers (regular kind only)

Veggies with homemade dip: sour cream seasoned with garlic salt and dill weed.

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

Homemade ice cream with natural ingredients

Limit your child's access to alcohol!

Eliminate all temptations and opportunities for even one drink, and be a good role model for your child. Alcohol depletes dopamine in the brain. Alcohol lowers already low inhibitions, impairs already impaired judgment and increases risk of already risky behaviors. For individuals with FASD, alcohol can impair their ability to function, and may put them at risk of injury, arrest, and other negative consequences.

Nobody ever died from not drinking!

Note: This is not to be construed as medical advice. Consult with your doctor.

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.

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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

A Better Way to Discipline

Three strategies for disciplining your children with greater authority, less stress and better results.

By John Taylor, PhD

Like all kids, children with ADHD sometimes make bad choices regarding their own behavior. No surprise there. But to make matters worse, parents often err in the way they respond to misbehavior. Instead of using firm, compassionate discipline, they move into what I call the ignore-nag-yell-punish cycle.

First, the parent pretends not to notice the child's misbehavior, hoping that it will go away on its own. Of course, this seldom works, so the parent next tries to urge the child not to do such and such. Next, the parent starts yelling and scolding. When this doesn't produce the desired result, the parent becomes extremely angry and imposes harsh punishments. I think of this fourth stage as the parent's temper tantrum.

This four-part strategy (if you could call it that) isn't just ineffective. It makes life needlessly unpleasant for every member of the family. How can you avoid it? As with any other pitfall, simply being aware of it will help you steer clear of it. At the first sign of starting on the wrong path, you can stop what you're doing and make a conscious decision to try something else. Take an honest look at how you respond when your children misbehave. What specific situations are likely to cause you to go down this path? How far down the path do you typically proceed? How often?

Let's examine the ignore-nag-yell-punish strategy more closely to see why it doesn't work—and come up with some strategies that do.

Why ignoring doesn't work

By ignoring your child's misbehavior, you send the message that you neither condone nor support his misbehavior. At least that's the message you hope to send.

In fact, your child may read your silence as "I won't give you my attention or concern" or even "I reject you." That can wound a child. On the other hand, your child may assume that your silence means that you approve of his behavior or will at least tolerate it. "Mom hasn't said I can't do this," he thinks, "so it must be OK."

Even if your child correctly interprets the message that you're trying to send by ignoring him, he has no idea what you want him to do instead. In other words, ignoring your child doesn't define better behavior or provide guidance about how your child should behave next time.

Instead of ignoring him when he does something you disapprove of, I recommend another "i-word": interrupting. That is, quickly move people or objects so that your child is unable to misbehave.

For example, if Alex and Maria start quarreling over a toy, you might say, “Alex, sit over there. Maria, stand here. I’ll take this and put it up here.” Similarly, if your teen comes for supper with dirty hands, immediately take his plate off the table and silently point to his hands. If you feel the need to tell your child what you expect of him, tell him once, very clearly. Then stop talking.

Harsh punishments simply encourage a child to become sneaky so as to not get caught next time.

Don’t be a nag

Why is it important to keep words to a minimum when disciplining your child? Because, as I often remind parents, words are like tires. Each time they rotate against the pavement, they lose tread and become less efficient at starting, stopping, and steering. If you spin words out endlessly, they’ll become less efficient at starting, stopping, and steering your child. Eventually, your words will have no “traction” at all — as tires will eventually become bald.

If the chatterbox parent is ineffective, so is the parent who barks orders like a drill sergeant. To break the yelling habit, tell yourself that you won’t open your mouth until you’re calm enough to speak at a normal volume and in a cordial tone. Often, all it takes to calm down is to spend a few minutes alone — something as simple as excusing yourself to get a glass of water may do the trick.

Taking time to cool off will also help you avoid the last and most counterproductive element of ignore-nag-yell-punish.

Punishment vs. undoing and redoing

Parents often assume that by punishing a misbehaving child, they’re helping to build the child’s conscience. Not so. In most cases, harsh punishments, like spanking, simply encourage a child to become sneaky so as to not get caught next time. (They may even cause your child to doubt your love for her.)

A better approach is to impose consequences that are appropriate to the offense and respectful of your child. Ideally, the consequence you impose for a particular misbehavior will involve undoing or redoing the situation. The consequence for carelessly spilling milk, for example, might be that your child cleans up the mess (undoing), and then pours another glass and sets it in a safer place (redoing). No need to blame or yell. No need to impose harsh punishment (for example, withholding food).

If you’re careful to recognize your first steps down the ignore-nag-yell-punish path — and to substitute the strategies I’ve described — you’ll find yourself on a different path, one that leads to a more harmonious relationship with your child. It’s a trip I highly recommend.

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



How Are You Doing Today? Day _____ Date _____

Objective: I will respect myself and interact with others respectfully 75% of the time.

In each hour a point can be earned for each behavior. If earned, draw a heart, a happy face, a star or a check mark in the box. If not earned, make an X and explain in space at bottom.

	Respect	Compliance	Self-Care	Safety						
	= 100% respect explain disrespect	= 100% compliant Please explain NC (noncompliance)	= healthy explain any self harm	Stay in area/vehicle, don't leave area without permission	Overly Giddy Manic	Lovey Happy Sweet	Calm Okay Relaxed	Moody Grumpy Mumble	Angry Argue Yelling	
9 pm – 7 am										
7 am – 8 am										
8am – 9 am <input type="checkbox"/>										
9 am – 10 am <input type="checkbox"/>										
10 am– 1 am <input type="checkbox"/>										
11 am– 12 pm <input type="checkbox"/>										
12 pm– 1 pm <input type="checkbox"/>										
1 pm– 2 pm <input type="checkbox"/>										
2 pm– 3 pm <input type="checkbox"/>										
3 pm– 4 pm										
4 pm– 5 pm										
5 pm– 6 pm										
6 pm– 7 pm										
7 pm– 8 pm										
8 pm– 9 pm										

Remarks:







Objective: I will interact with others respectfully, be reasonable compliant, stay safe, and engage in healthy self care 75% of the time.

How Did You Do Today? Day _____ Date _____

Respect: Keep hands to yourself; use respectful language; close doors quietly

Compliance: Make bed; rinse sink after brushing, dirty clothes in laundry; car door cue; follow requests.

Self-Care: Brush teeth after breakfast and at bedtime, shower with soap all over; shampoo entire head.

	Respect	Compliance	Self-Care	Safety	Count Points
	 = 100% respect explain disrespect	 = 100% compliant explain noncompliance	 = Clean body, hair, and teeth	 = Stay in area/vehicle, don't leave without permission.	
10 pm - 7 am					
7 am – 8 am					
8am – 9 am					
9 am – 10 am					
10 am–11 am					
11 am–12 pm					
12 pm–1 pm					
1 pm–2 pm					
2 pm–3 pm					
3 pm–4 pm					
4 pm–5 pm					
5 pm–6 pm					
6 pm–7 pm					
7 pm–8 pm					
8 pm–9 pm					
9 pm–10 pm					
Total	Count check marks for hours today with no problems:				

Goal: John will achieve his daily goal five out of seven days a week to earn a reward.

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?
----------------	--------------------	-----------

1. _____	_____	_____
----------	-------	-------

Notes: _____

2. _____	_____	_____
----------	-------	-------

Notes: _____

3. _____	_____	_____
----------	-------	-------

Notes: _____

Attendees:

_____	_____
_____	_____
_____	_____

Comments:

ABC Rules

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Ask for help

Be respectful

Communicate your needs

Ask for help:

When you are starting to feel out of control, give the Time-Out signal.

When you are not sure what to do, say "Please help me."

When you are confused about a difficult situation, say, "Please help."

Be respectful:

Use nice words (no cussing)

Use nice names (no name calling)

Using nice gestures (no pushing, no blocking, no threatening)

Answer a question, even if the answer is "I don't want to talk right now."

Cooperate with others (no refusing to do things that are important)

Ask permission before hugging (don't stare, don't touch)

Give people their personal space (don't interrupt, don't stand too close)

Keep your body, hair, and teeth clean and smelling nice

Be nice to everyone, all the time, no matter what they do or say

Be good to yourself (healthy eating, exercise, take your meds)

Keep yourself safe (no running away, no getting out of a moving car)

Communicate your needs:

When you are feeling bad, try to identify how you are feeling

Use nice words to say how you feel ("I feel angry." or "I'm scared.")

When you're not sure how you feel, say "I'm not sure how I feel."

When you want attention, say "I would like to talk to you right now."

Accept when you can't get what you want. Say, "I feel sad about that."

*I promise to show respect to myself, to others,
and to my environment, at all times.*

Arizona Department of Economic Security
Division of Developmental Disabilities
Fetal Alcohol Resource Center
6740 S. Tucson Blvd.
Tucson, AZ 85756
cell: (520) 296-9172



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