

# Self-Study Course

## Fetal Alcohol Spectrum Disorder: An Introduction for Foster Parents

Updated 9/2017

3.0 Hours Credit

This self-study is based on a variety of sources that are cited throughout the course. This self-study draws heavily on the work of Diane B. Malbin, Debbie Evensen, Patricia Tanner-Halverson, Barbara Morse, Sterling Clarren, Ann P. Streissguth and the collection of papers that make up the book Fantastic Antone Succeeds: Experiences in Educating Children with Fetal Alcohol Syndrome. Other sources include the Office of FAS, the Centers for Disease Control; Fetal Alcohol Syndrome: A Guide For Families and Communities by Ann Streissguth; FAS: A Guide for Daily Living published by the Society of Special Needs Adoptive Parents in British Columbia; and the many publications of Theresa Kellerman's FAS Community Resource Center at <http://come-over.to/FASCRC/>.

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# **FETAL ALCOHOL SPECTRUM DISORDER**

## *Part One: An Introduction For Foster Parents*

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### **Introduction**

In the last four decades, awareness has risen about the dangers of drinking during pregnancy. Alcohol is the most used and abused drug in America. Up to 20% of American women drink enough during pregnancy to put their unborn child at risk.<sup>1</sup> When a pregnant woman drinks, her unborn child also “drinks”. That is, the fetus absorbs alcohol into its system, posing risk of permanent damage. Fetal Alcohol Spectrum Disorders (FASD) is the term used to describe the continuum of disorders associated with prenatal exposure to alcohol. While children with alcohol effects can thrive and build skills to live in the world, many face a lifelong struggle with possible physical delays and abnormalities, learning disabilities and brain dysfunction. Children and youth also make up a significant portion of the foster care population and their birth parents also often struggle from alcohol exposure..

#### ***How Many Children Are Affected?***

More American babies are born with FAS than with Down Syndrome, Muscular Dystrophy, and HIV combined. FAS is the leading cause of mental retardation in western civilization. The CDC (Centers for Disease Control and Prevention) released a fact sheet on February 2, 2016 stating that “up to 1 in 20 US school children may have FASDs.” (<https://www.cdc.gov/vitalsigns/fasd/>). Based on the best available data, it can be estimated that **2-5%** of children in the United States have an FASD. The [CDC website](#) states that “experts estimate that the full range of FASDs in the United States and some Western European countries might number as high as 2 to 5 per 100 school children (or 2% to 5% of the population).” The State of Alaska Fetal Alcohol Syndrome Surveillance Project has determined that approximately 126 infants born each year in Alaska are identified as having been affected by maternal alcohol use during pregnancy. During 1995 through 1998, an average of 14 Alaskan infants were born with Fetal Alcohol Syndrome (1.4 per 1000 live births). During the same time, the FAS prevalence findings for Alaska Native were 4.8 per 1000 live births.<sup>2</sup> During 1996-2002, Alaska experienced a 32% decrease in FAS birth prevalence from 19.9 to 13.5 per 10,000 live births FASD. Most of this decline in identified FAS cases were in the Alaska Native populations, Cases of identified FAS increased slightly during that time among non-Natives. However, is not a problem of any one racial group. FASD occurs in all races and all economic groups.

#### ***Foster And Adoptive Care Is Impacted By Alcohol Effects***

Children with alcohol effects are also born into a family affected by alcohol and addiction. Many of these children enter the foster care system due to neglect or inability of the parent to care for them. Parents may die as a result of their drinking, may be unable to care for their children, may be neglectful or abusive, or may expose their children to high risk situations. Other birth parents may keep their families intact, but struggle to deal with the challenging behavior an alcohol affected child may show. Parents themselves may have been prenatally exposed and have the dual challenge of raising children while struggling to function in the world themselves. Foster and adoptive parents benefit from fully understanding fetal alcohol spectrum disorders.

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<sup>1</sup> Institute of Medicine, National Academy Press, Washington, D.C. “FAS; Diagnosis, Epidemiology, Prevention and Treatment (1996)

<sup>2</sup> FAMILY HEALTHY DATALINE, June 2002, Newsletter of the State of Alaska DHSS Division of Public Health.



# FETAL ALCOHOL SPECTRUM DISORDER

## Part One: An Introduction For Foster Parents

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### Unit One: What Is Prenatal Alcohol Exposure?

When a pregnant woman drinks, the blood alcohol level of her developing child reaches the same concentration as her own. It takes approximately 48 hours for a woman's body to detoxify after alcohol ingestion. It takes nearly twice this time for the alcohol to be completely eliminated from the fetal surroundings.<sup>3</sup> The long term effect of alcohol on the fetus is more powerful than any other drug, including cocaine. This is because alcohol has a very small molecule that can get into the developing parts of the brain tissue throughout the period of gestation. Alcohol may damage different parts of the brain and causing varying levels of damage to individual fetuses.

No level of drinking during pregnancy is considered safe. Some mothers drink heavily yet their children seem to have no apparent affects. Different women metabolize alcohol differently -- smaller women may absorb drinks much more quickly than larger women. Fetuses also have different resistant levels to alcohol. Twin studies have shown that even fetuses in the same physical environment who were exposed to the same level of alcohol will have different levels of damage. Because of all the variants that affect the possibility of damage to the fetus, it is recommended that all pregnant women abstain from drinking during pregnancy and breastfeeding.

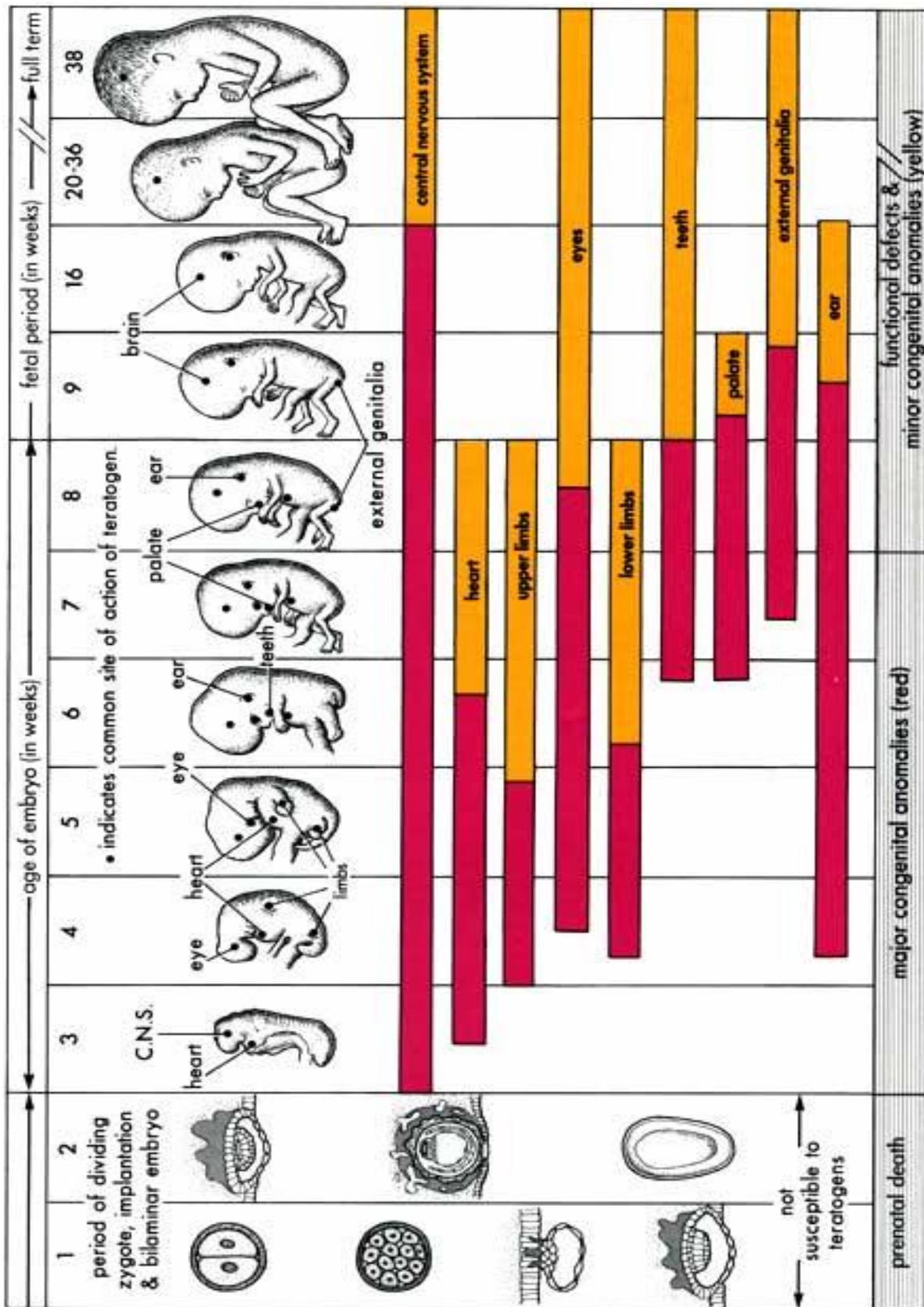
Alcohol can have a wide range of effects on a fetus depending on the frequency and the intensity that it is used during pregnancy. How the fetus is affected depends on *how much* alcohol is drunk but it is also dependent upon when the alcohol is consumed. Drinking during the first trimester may interfere with the migration and organization of brain cells and major organ development. Drinking during late stage pregnancy may cause fewer physical abnormalities, but cause more functional defects, such as damage to the central nervous system and parts of the brains such as the hippocampus, which leads to problems with visual and auditory functions. The effect of alcohol and drugs will have on a developing fetus depends on what organs or bodily functions are developing at the time of contact.

Alcohol is a teratogen. A *teratogen* is a chemical that can cause toxic effects in developing human embryos. Alcohol is considered a neurobehavioral teratogen. That means alcohol can damage the brain and change behavior. This damage to the brain is a central feature of fetal alcohol disorders. **Graphic #1** shows fetal development and suggests possible effects of toxic substance on development such as alcohol, cocaine, prescription drugs, illegal drugs and tobacco.<sup>4</sup>

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<sup>3</sup> From "Fetal Alcohol Syndrome: Fact Paper" by Lisa Pieper written for the Alaska Council on Prevention of Alcohol and Drug Abuse, March 1989.

<sup>4</sup> Adapted from Keith Moore, The Developing Human, Philadelphia 1988. Taken from the Alaska Children's Services manual of FAS/FAE.



**GRAPHIC 1: Impact of Alcohol on the Developing Fetus**

<http://www.faslink.org/Graphics/teratogens.jpg>

## ***FETAL ALCOHOL SPECTRUM DISORDERS***

*Fetal Alcohol Spectrum Disorders* (FASD) refer to the wide continuum of effects that result from prenatal exposure to alcohol. FASD is not a diagnosis. The term is an umbrella term that includes the many disorders that are caused by prenatal alcohol exposure. There can be different words and diagnosis terms that are favored in different parts of the country. In the Western United States and in Alaska, we use the language established by the University of Washington because that is where most of our diagnostic teams received their training. These disorders related to prenatal alcohol exposure include four diagnosable conditions: *fetal alcohol syndrome* (FAS); *partial FAS*; and *neurobehavioral disorder/alcohol exposed*; *static encephalopathy/alcohol exposed*. The terms helps us remember that alcohol is a teratogen, which means it can cause lifelong birth defects, but that individuals will be impacted in many different ways.

**Fetal Alcohol Syndrome** Fetal Alcohol Syndrome (FAS) is a medical diagnosis which refers to a cluster of symptoms making up the full syndrome. The definition of FAS has not changed much in the past 40 years since the syndrome was defined and named. FAS is a medical diagnosis of a birth defect syndrome. A syndrome is a cluster of symptoms that indicate a disease or a disorder. A teacher, social worker, a judge, or a parent cannot give a diagnosis of FAS. This can only come from a medical professional.

FAS is characterized by:

- growth deficiency (height or weight < 10th percentile).
- a unique cluster of minor facial anomalies (small eyes, smooth philtrum, thin upper lip).
- severe CNS abnormalities (structural, neurological, and/or functional abnormalities).
- prenatal alcohol exposure (confirmed or unknown).

The following graphic show the facial features or *dysmorphology* of a child with Fetal Alcohol Syndrome. Some of the characteristics are discriminating or a central feature; other are associated, which means they are often seen, but not a defining feature of FAS. Any one or two of the characteristics shown may be normal, given genetic predetermination. It is the collection or constellation of characteristics which begin to present the probability of a FAS diagnosis.

Children with FAS have many (but not always all) of the following characteristics:

### *Discriminating features*

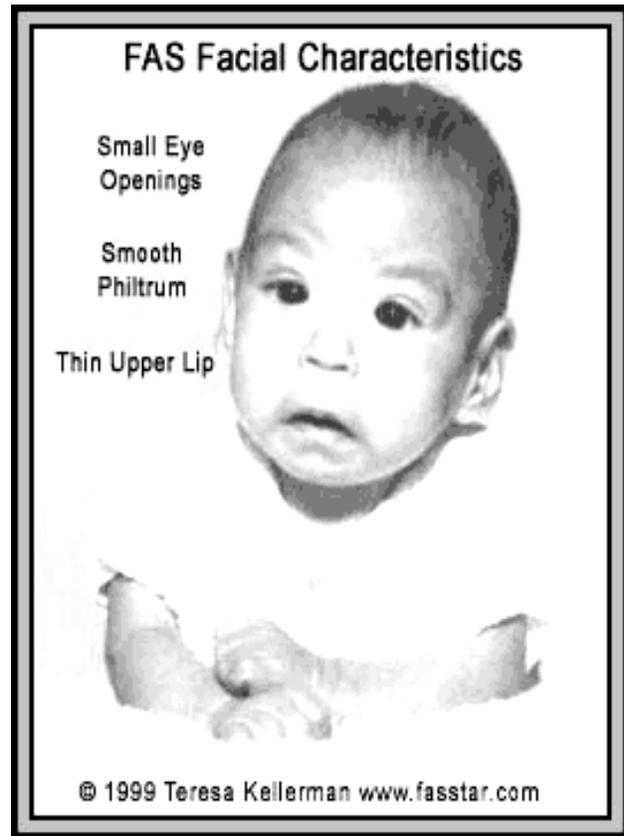
- Small birth weight
- Small head circumference
- Short, upturned nose
- Smooth, wide philtrum
- Thin upper lip

### *Associated features*

- Epicanthal folds
- Small, widely spaced eyes
- Flat midface
- Minor ear anomalies
- Underdeveloped jaw

**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.

Graphic from [www.fasstars.com](http://www.fasstars.com). Used here with Permission. Characteristics from *Identification and Care of Fetal Alcohol Exposed Children: A Guide for Primary Care Providers from the National Institute on Alcohol Abuse and Alcoholism.*)



### **The Rest Of The FASD Spectrum**

Children can still be profoundly affected by prenatal exposure to alcohol, but not have the fully syndrome. Full Fetal Alcohol Syndrome makes up just 10% of the continuum of Fetal Alcohol Spectrum Disorders. The other 90% may have fewer physical and facial symptoms but are still impacted by the impact on the developing brain. Children with FASD are also at greater risk for developing serious secondary conditions later. (Streissguth, 1997)

There are other terms that classify individuals who do not have FAS (sharing the full four diagnostic categories) but share characteristics associated with prenatal alcohol exposure (especially central nervous system dysfunction and other cognitive abnormalities). These terms help define the particular impact on an individual with more specific terms to describe their condition. But it is important to realize, that even if an individual does not have fully diagnosable Fetal Alcohol Syndrome, it does not necessarily mean that the individual is not as fully impacted. Again, these terms are used in the diagnostic process and clarify the nature of the disorder more clearly. Let's look at what these terms mean:

**Partial FAS** is a diagnostic classification for patients who present with:

- Most, but not all, of the growth deficiency and/or facial features of FAS.
- Severe CNS abnormalities (structural, neurological, and/or functional abnormalities).
- Prenatal alcohol exposure (confirmed).

**Static Encephalopathy/Alcohol Exposed (SE/AE).** The term "*encephalopathy*" refers to "any significant abnormal condition of the structure or function of brain tissues" (Anderson, 2002). The term "*static*" means the abnormality in the brain is unchanging; neither progressing nor regressing. This diagnostic classification is for patients who present with:

- Severe CNS abnormalities (structural, neurological, and/or severe functional abnormalities).

- Prenatal alcohol exposure (confirmed).

**Neurobehavioral Disorder/Alcohol Exposed (ND/AE)** is a diagnostic outcome classification for patients who present with:

- Moderate CNS dysfunction.
- Prenatal alcohol exposure (confirmed).

The prevalence of SE/AE and ND/AE are 5 to 10 fold higher than the prevalence of FAS/PFAS. The severity of brain dysfunction increases as one advances from ND/AE to SE/AE to FAS/PFAS

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The above information is from the FAS Diagnostic & Prevention Network at the University of Washington Seattle Washington. <https://depts.washington.edu/fasdpn/index.htm>

### **The Idea Of The “Hidden Disability”**

What is important to remember is that these disorders are not considered a “milder” form of Fetal Alcohol Syndrome. FASD refers to the whole spectrum of alcohol exposure related effects, but there is one that seems to be constant -- impact on brain development. A child may have no physical facial characteristics of alcohol exposure, but may be profoundly impacted because of the damage done to his brain during fetal development. It is the hidden nature of the disability of FASD that is often the most difficult for children. Without the facial or physical features associated with the full Fetal Alcohol Syndrome, children are often perceived to not have a disability. Their actions, which may make more sense in the context of their disability, are perceived to be behavior problems. We often label these children defiant, non-compliant, delinquent, or even stupid. *We think they **should** do better than they can.*

Children with FASD have many abilities. They may function very well in many areas of their lives, such as social or academic activities or athletics. But children with FASD have varying degrees of brain dysfunction and that brain dysfunction may show up in many different ways. They may look good, or speak well. But their disability lies with the way their brain works and how the child understands the world. Prenatal exposure to alcohol can damage parts of the brain, though this does not necessarily mean that a child will be born mentally retarded. Children with FAS have IQs that range from 30 to 105. Children with other alcohol effects may exhibit an even higher range of IQ scores.

Fetal Alcohol Syndrome is more likely to be accurately diagnosed the other forms of FASD because it involves physical abnormalities that can be measured and defined. FASD may go unnoticed because children often have fairly good verbal skills. The difficulties resulting from alcohol exposure may not be severe enough to be easily noticed or even identified. Because affected individuals may “look good” and “sound good”, we often have unrealistic expectations or attribute difficulties to being stubborn or defiant. This is why an accurate and early diagnosis is so important for children with alcohol effects. An FASD should not be seen as a milder form of FAS. Some of the behavioral and central nervous system damage can be as severe as or worse than a child with FAS.

# Common Misconceptions About Fetal Alcohol Spectrum Disorders (FASD)

*This list has been adapted and modified from the original listing by Ann P. Streissguth, Ph.D., University of Washington - Seattle*

## **MISCONCEPTION #1: FASD means mental retardation.**

**IN FACT:** -Some people with FASD are mentally retarded, others have normal intelligence.  
-People experiencing an FASD have a brain based disability. They have specific areas of strengths and weaknesses. It's similar to people who have sustained brain injury from an auto accident.

## **MISCONCEPTION #2: The behavior problems associated with FASD are all the result of poor parenting or a bad environment.**

**IN FACT:** -Having a brain based disability can lead to behavior problems because people with a brain based disability don't process information the same ways that other people do. So they don't always behave like others expect them to.  
-Children with a brain based disability are difficult to raise in the best environments. Parents need help, not criticism.

## **MISCONCEPTION #3: Children will outgrow it when they grow up.**

**IN FACT:** -FASD lasts a lifetime. The type of problems will change with each age.  
-It takes a longer period of sheltered living for children with an FASD to grow up.

## **MISCONCEPTION #4: To admit children have a brain based disability is to give up on them.**

**IN FACT:** -Have we given up on children with other birth defects?

## **MISCONCEPTION #5: Diagnosing children with FASD will brand them for life.**

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

## **MISCONCEPTION #6: We now know how to solve the problem of FASD.**

**IN FACT:** -Research is desperately needed. The magnitude of the problem necessitates more research.

## **MISCONCEPTION #7: Mothers of these children had an easy choice not to drink during pregnancy. Through callous indifference, these mothers permanently damaged their children.**

**IN FACT:** -Birth mothers need help with their alcoholism and with birth control.  
-Pregnancy is an excellent time for alcohol abusing mothers to stop drinking but most people need help in order to stop.



# FETAL ALCOHOL SPECTRUM DISORDER

## Part One: An Introduction For Foster Parents



### Unit Two: Effects of Prenatal Alcohol Exposure

Children prenatally exposed to alcohol may be very different from each other. The extent to which children are affected by prenatal exposure to alcohol depends on the following factors: *the level of drinking, mother's tolerance to alcohol, the fetus's resistance to alcohol and when the drinking occurs during fetal development.* That being said, there tends to be common clusters of behaviors and effects associated with prenatal exposure to alcohol. In this chapter, we will list these out.

#### Physical Effects Of Alcohol Exposure

The most immediate physical effect that we associate with prenatal alcohol exposure is the facial dysmorphology discussed in the previous section. This is usually associated with children with the full Fetal Alcohol Syndrome. The development of major organs seems particularly sensitive to alcohol exposure during the first three months of pregnancy. Alcohol affected children, especially those with full Fetal Alcohol Syndrome, may have malformations of the ears and eyes and cleft lip and palate. Skeletal abnormalities and aberrant development of internal organs are common; one third of these children have heart defects. Liver, skeletal system, and genital urinary systems may also be affected. Children may have dental problems because of over crowded and misaligned teeth. Children with FAS are often smaller, shorter and weigh quite a bit less than their peers, sometimes to the point of appearing emaciated, even when receiving adequate nourishment.

Children<sup>5</sup> may also be excessively limber or excessively stiff. They might be overly or under sensitive to stimuli. This might include *tactile defensiveness*, which means that a child is very sensitive to touch. A light touch may drive him crazy, such as a brush of fingers on the skin, bumping against kids in a school hallway or a clothing tag that irritates. Yet he may actually calm down with stronger sensations such as jumping, being wrapped up tight, head banging or body slamming.

For some children, this over sensitivity extends to other senses such as taste and sight. Children may dislike specific textures or tastes, or be overly sensitive to hot and cold. Some children are hypersensitive to light or are overly stimulated by looking into the eyes of another person.

#### POSSIBLE PHYSICAL EFFECTS

Characteristic facial dysmorphology associated with alcohol exposure

Malformations of eyes, teeth, ears and mouth

Organ malformation (heart, liver, kidney)

Excessively limber or stiff

Overly or under sensitive to touch, noise, light, and taste

Eating or Sleeping Problems

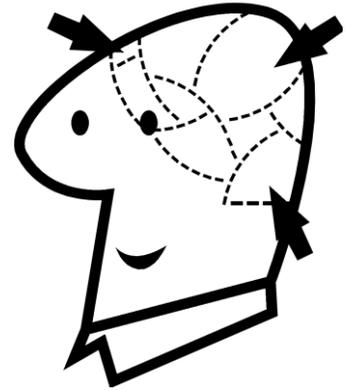
Sensory Integration Problems

<sup>5</sup> This section adapted from the handout "Characteristics of a Child with Alcohol Effects" written by Sally Caldwell, trainer from Fairbanks, Alaska.

Still other children are hypersensitive to sound. Loud noises may be very stimulating to them, or distract them. Children may hear quiet noises and be distracted. In the everyday environment of a classroom, the noise may be overwhelming, even though it sounds “normal” to us. Often these children benefit by using one kind of noise (such as headphones to listen to music or the white noise of a blank television) to block out another noise. Other children may be under-sensitive to stimulation, including pain. One young man who was prenatally alcohol exposed incurred serious heart damage, because even though he was having a heart attack at the age of 19, he did not feel the level of pain to indicate that something was wrong.

## Effects On The Brain From Alcohol Exposure

Alcohol is considered a *neurodevelopmental teratogen*, which means that it can damage the brain and change behavior. In early pregnancy, alcohol can interfere with the migration and organization of brain cells. As pregnancy develops, alcohol continues to impact whatever part of the brain is developing at the time. Alcohol may effect different parts of the brain, but leave others undamaged, giving children uneven abilities, such as a gift for music, yet difficulty in reading comprehension. Sometimes this damage can actually be seen in an MRI or PET Scan. Sometimes that damage cannot be seen with our tools, but still makes the brain work in very quirky ways.



Individuals with Fetal Alcohol Spectrum Disorders 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 control executive functions. Executive functions refer to impulse control, planning, perception of time, memory and verbal regulations. A child’s problems are often seen as “behavior” problems and are treated as such. Yet if his actions are related to damage to how his brain works, it may be more accurately a matter of the child not doing something, not because he “won’t” but because he “can’t”. This change in mindset is necessary for all foster and adoptive parents who are caring for a child with FASD who want to be successful in working with these children.

Children with alcohol effects may appear to behave in unexpected ways. Because pre-natal exposure to alcohol affects parts of the brain, it is helpful to look at the cause of unwanted behavior as a misfiring of how the brain processes information. This is referred to as an *information processing deficit*.<sup>6</sup> The brain has difficulty in some area of taking in information, processing it and resulting in a corresponding behavior. There is trouble or obstruction in the way that we take in information (such as sight, sound, noises, emotions) and translate it accurately in our heads and responds appropriately.

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<sup>6</sup> For an excellent review and discussion of this, please refer to the chapter “Information Processing” in Fantastic Antone Succeeds, University of Alaska press..

## EXAMPLES:

- *Five year old Jessie verbally repeats your direction to pick up her toys now so you can leave for the store. She immediately turns around, picks up a truck and starts to play. She seems surprised when you become angry.*
- *Your foster son Jamie struggles to learn a list of spelling words. You are confident that by the end of the evening he can spell almost all the words in the list correctly. The next day, he comes home with nine out of ten words marked wrong on his quiz.*
- *Sammy is warned not to hit his classmate in the classroom or his fourth grade class. He obeys and stops hitting. But out in the hallway, he punches the boy again and ends up in the principal's office.*

### ***Effects Related To Impact On Brain Development***

- Difficulty with abstractions, (math, money , time)
- Trouble with cause and effect reasoning
- Ability to repeat instructions, but inability to put them into action ("talk the talk but don't walk the walk")
- Impulsiveness, distractibility
- Inconsistent performance ("on" and "off") days
- Cognitive processing deficits (may think more slowly)
- Slow auditory pace (may only understand every third word of normally paced conversation)
- Judgment problems
- Developmental lags (may act younger than chronological age)
- Memory Problems

At first glance, these examples might show children who are willful, lazy, forgetful or defiant. But for children with difficulty processing information, these examples may also show Jamie who has a chronic memory problem, or Jessie who has trouble translating words into appropriate action, or Sammy who cannot generalize rules to different situations. Punishment will not make these kids learn. If we can look differently at the child's behavior, we can act differently. If we can understand how a child's brain is working, we can construct an environment around him so that our foster child can succeed. Instead of using traditional parenting patterns or reward, punishment and behavior management, we may spend more time setting up routines, visual clues, and prompting. This is what Diane Malbin, M.S.W. means by "trying differently not harder."

## Developmental Effects

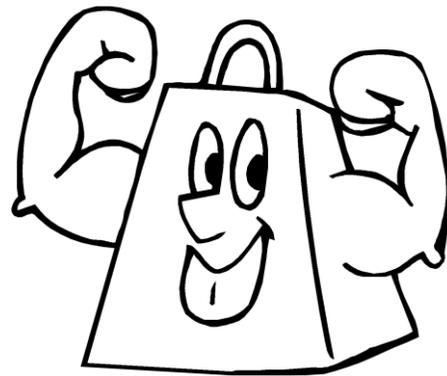
The effects and the challenges faces by the child with FASD and his family will change as the child grows and develops. Following is a chart adapted from the book **Fetal Alcohol Syndrome** by Ann Streissguth (1998) that details by development age some of the effects of FASD.

AGE	Effects
<b>Newborn</b>	Jitteriness, arching back, seizures, tremors, weak suck, unpredictable sleep-wake cycles, stiff muscle tone, weak muscle tone, failure to thrive, highly sensitive to stimulus, microcephaly (small head)
<b>Infancy</b>	Delayed development in several areas; head banging, body rocking, poor fine or gross motor control, neurological dysfunction
<b>Preschool</b>	Hyperactivity, poor eye-hand coordination, poor balance, poor tandem gait, central auditory dysfunction, delayed or perseverative language, mental retardation. Thin, below expected weight level. Delays in development are more obvious
<b>Early School Age</b>	Attentional impairments, learning disabilities, arithmetic disabilities, specific cognitive disabilities, deficits in higher order receptive and expressive language, poor impulse control. Difficulty with peers
<b>Later school age and Adolescence</b>	Sexual development begins, though emotional development may be delayed. Memory impairments, difficulties with judgment, difficulties with abstract reasoning, poor adaptive function. Puts on more weight, but often time is shorter than expected height. Facial features become not so prominent. May be prone to depression or social isolation.

### *Children With FASD Have Gifts And Talents, Too!*

Many people with FASD have strengths that mask their cognitive challenges. Some of these strengths include:

- Highly verbal
- Bright in some areas
- Artistic, musical, mechanical
- Athletic
- Friendly, outgoing, affectionate
- Determined, persistent
- Willing, helpful , loyal
- Generous
- Imaginative
- Strong sense of humor
- Good with younger children



## **Preventing Secondary Disabilities In Alcohol Exposed Children**

Often the difficulties in these children's lives occur because of the *secondary disabilities* they develop. *Primary disabilities* refer to the direct effects of alcohol exposure, including central nervous system impact or physical effects. *Secondary disabilities* refer to the problems that result from interaction in the world as they grow older. Secondary disabilities include mental health problems, dropping out of school, trouble with the law, inappropriate sexual behavior and alcohol and drug problems. Several "universal protective factors" seem to decrease the risk of secondary disabilities.

1. *Living in a stable and nurturing home for over 72% of a child's life.* A permanent plan for young children in foster care needs to be pursued swiftly.
2. *Receiving a diagnosis of FAS before age six.* When a child's disability and alcohol effects are diagnosed early in life, he has a chance to receive appropriate services and support.
3. *Never having experience violence against self.* Foster care can be a protective factor for children from violent and abusive homes.
4. *Staying in each living situation for an average of more than 2.8 years.*

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From *Understanding the Occurrence of Secondary Disabilities in Clients with FAS and FAE*, Ann Streissguth, et al 1996

The earlier the diagnosis is made of a child's alcohol effects, the sooner services and adjusted parenting can be used and the better the chance the child has to learn to manage his condition. If children go unidentified, a pattern of frustration and failure begins. This can lead to deterioration of a child. This includes delayed development, early school failure, inappropriate discipline (such as behavior modification programs), social isolation and sexual acting out. This pattern can be prevented in most cases if early diagnosis and intervention happens.



# **FETAL ALCOHOL SPECTRUM DISORDER**

## *Part One: An Introduction For Foster Parents*



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### **Unit 3: Diagnosing FASD**

Some families hesitate to pursue a diagnosis of disorders related to prenatal alcohol exposure because they feel it will brand a child as different, or put a label on him for the rest of his life. Others family would like help, but don't find resources in their own community. A diagnosis does not always mean that services will be available or always tell you as a parent how to work with a child. But a diagnosis tells you what is the problem, helps you figure out how to treat the problem, and relieves the person of having to meet unrealistic expectations. It can assist an individual later in adulthood, especially in qualifying for supportive services or if involved with the justice system. When we know what we are dealing with, we can more effectively advocate for what the child needs. A diagnosis may also help a child be eligible for certain educational and medical services.

Fetal Alcohol Syndrome is a medical diagnosis usually made by a physician specifically trained in the assessment of birth defects. In Alaska, the FASD Diagnostic teams also use other professionals to complete a more thorough assessment. Getting a thorough assessment and possible diagnosis of fetal alcohol syndrome or possible alcohol effects is an important step to securing services for a child. Teachers, social workers, and foster parents cannot diagnose Fetal Alcohol Syndrome though they are often the first step in identifying children with known maternal drinking histories or suspected problems.

#### ***For a diagnosis of full Fetal Alcohol Syndrome, the following must be present***

1. *Prenatal or postnatal growth deficiency* (either weight, length, or both below the 10th percentile when corrected for gestational age)
2. *Central nervous system (CNS) disorders*, including neurological abnormality, developmental delay, intellectual impairment, and structural abnormalities
3. A distinctive pattern of *facial anomalies*, including short palpebral fissures (eye openings); a thin upper lip; an elongated, flattened midface; and an indistinct philtrum (the zone between the nose and the mouth)
4. Confirmed *Maternal alcohol use* during pregnancy

If a child is alcohol affected but doesn't have all the characteristics of the full syndrome, he may still receive a diagnosis of other FASDs. Other diagnosis may include *FAS with confirmed maternal alcohol exposure*, *FAS without confirmed maternal alcohol exposure*, *partial FAS with confirmed maternal alcohol exposure*, *alcohol-related birth defect (ARBD)*, and *alcohol-related neurodevelopmental disorder (ARND)*.

## Using The FASD Diagnostic Community Team Approach

Many of Alaska’s FASD Diagnostic Teams have received their training a clinic model from the University of Washington Fetal Alcohol Syndrome Diagnostic and Prevention Network. The Diagnostic Clinic Approach conducts a clinic involving assessing a child in different areas of the four areas of diagnoses. The goal is not only to determine if a child has been affected by prenatal alcohol exposure, but also to gauge how that child is impacted, in order to get a more accurate diagnosis. Depending on the availability of professionals in the community, the diagnostic team may include a physician or nurse practitioner, a psychologist, a physical or occupational therapist, a social worker, a speech specialist and a parent navigator. The team approach is a more thorough assessment of a child’s needs than having a single physician a positive or negative diagnosis. The teams use a four-digit code in their assessment that rates each of the diagnostic categories on a scale of 1 to 4. This allows a more specific and accurate diagnosis of the severity of the effects of prenatal exposure upon a particular child.



There is also a built-in component through the Parent Navigator to support families during and after the diagnosis. Each FASD Multidisciplinary Community Team has at least one Parent Navigator (PN) to work with families going through a diagnosis. The role of the PN is to provide emotional support to families before, during and after the evaluations and diagnosis. They provide connection between the evaluating clinic and the family and provide information that will assist the family in obtaining appropriate services for their child.

The team approach used in the diagnostic clinic means that the bulk of the testing of a child is done in one place, usually on a given day. The team approach means that the child is not sent from one practitioner to another with independent and often conflicting opinions and recommendations over a period of months. The team assists in the education of the parent or caregiver about how the assessment pieces fit together and how a child is truly functioning. The caregiver or parent should be an active member in the process.

4-Digit Diagnostic Code Grid								
One Example of FAS								
		3 4 4 4						
significant	significant	definite	4	X	X	X	4	high risk
moderate	moderate	probable	3	X			3	some risk
mild	mild	possible	2				2	unknown
none	none	unlikely	1				1	no risk
<b>Growth Deficiency</b>	<b>FAS Facial Features</b>	<b>Brain Dysfunction</b>		<small>Growth</small>	<small>Face</small>	<small>Brain</small>	<small>Alcohol</small>	<b>Gestational Alcohol</b>

GRAPHIC: Example of the 4-Digit Code Diagnostic Code

**TEST**