

Fetal Alcohol Spectrum Disorders: Advocating for At Risk Infants and Toddlers

Safe Babies Court Teams Project

Presentation Overview



- Providing an Overview of the Safe Babies Court Teams Project
- Causes of FASD
- Defining Fetal Alcohol Spectrum Disorders (FASD)
- Signs and Symptoms
- The Prevalence of FASD
- Advocating for Affected Children: Useful Strategies
- FASD In Adults
- Questions

The Safe Babies Court Team Project



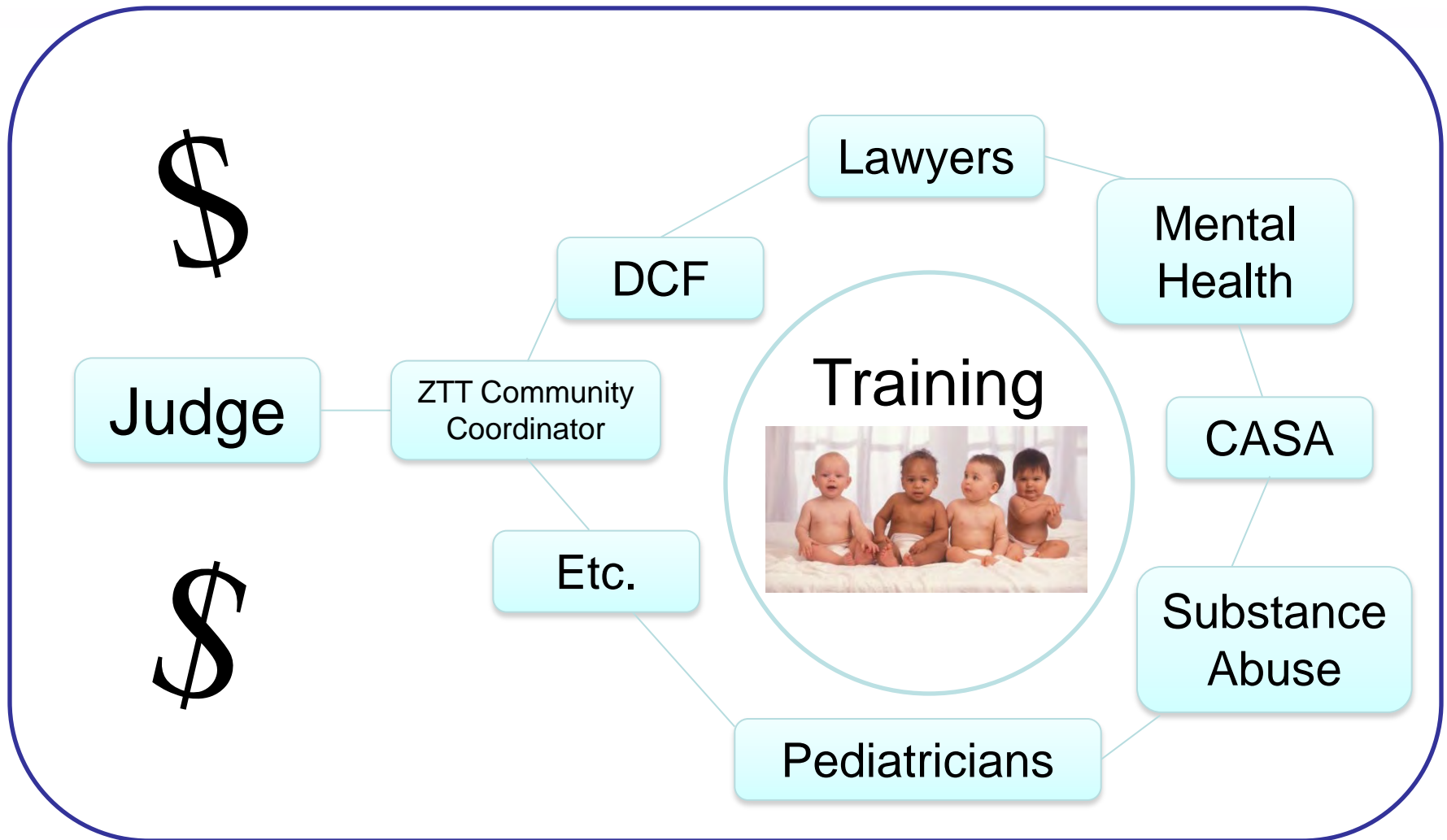
The Safe Babies Court Teams Project Goals

1. To increase awareness among all those who work with maltreated infants and toddlers about the negative impact of abuse and neglect on very young children.
2. Change local systems to improve outcomes and prevent future court involvement in the lives of very young children.



Photo credit: Lifestock Photos

The Safe Babies Court Teams: An Overview



The Safe Babies Courts Teams: Core Components

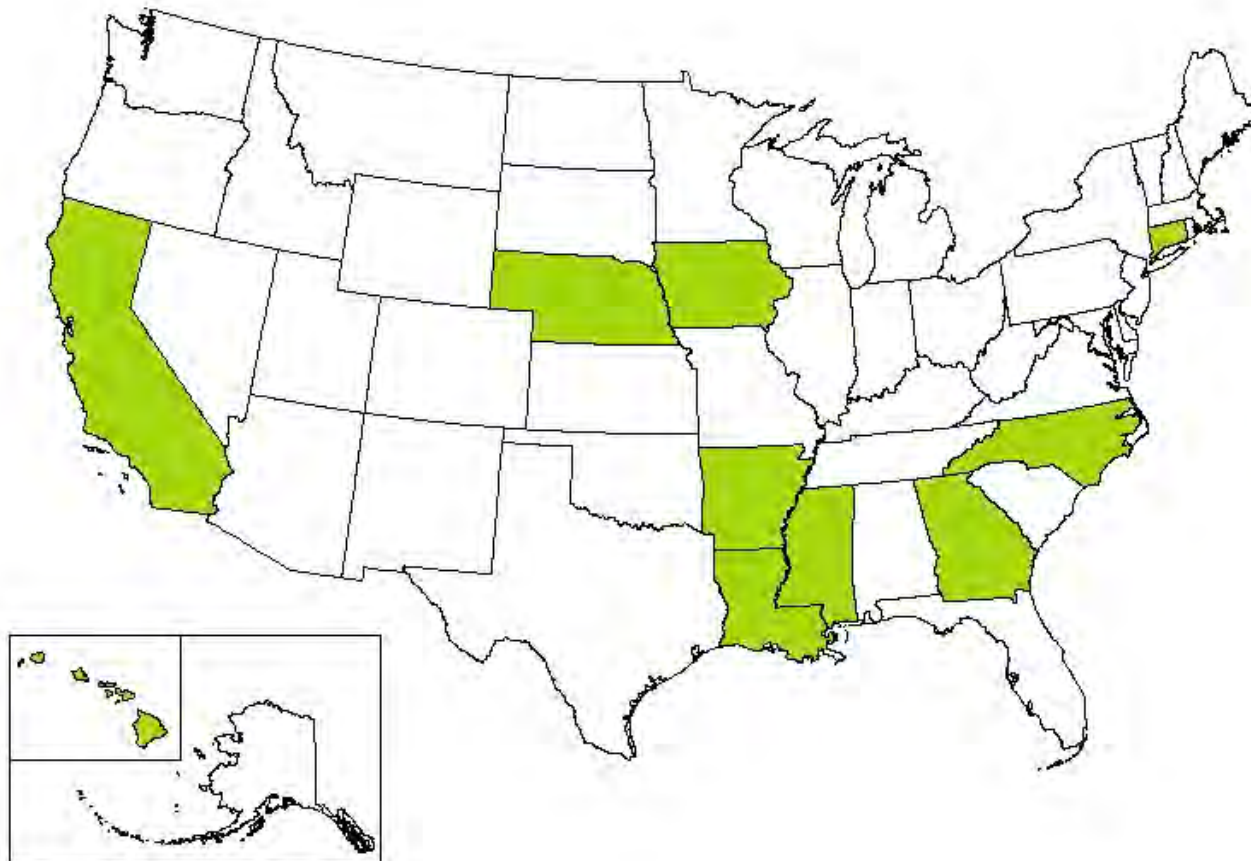


The Safe Babies Court Teams Project has 10 Core Components including:

- Increased Parent Child Contact
- Monthly Case Reviews
- Concurrent Planning
- Appropriate Services

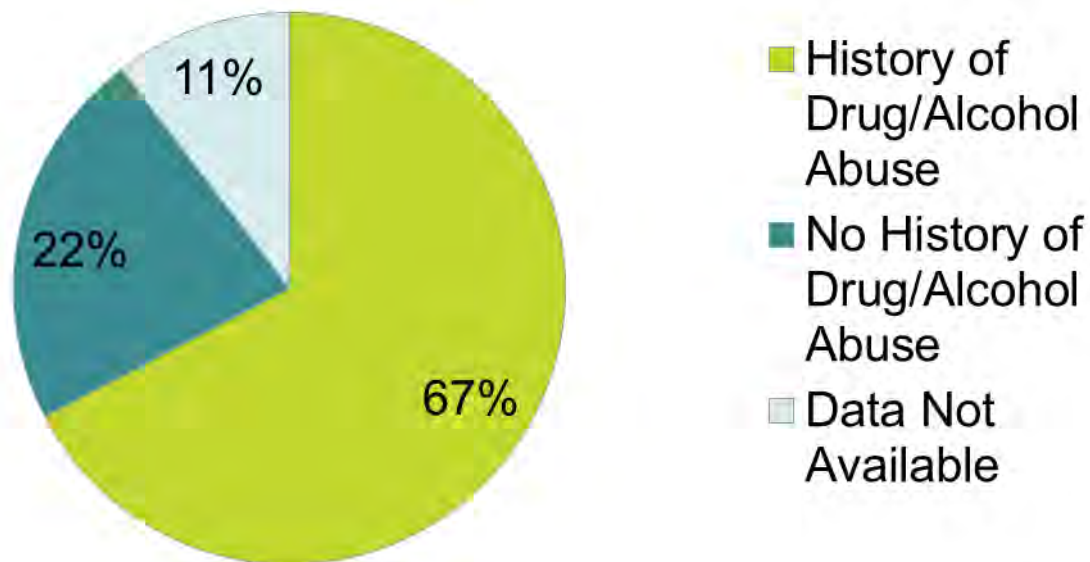


Court Team Locations



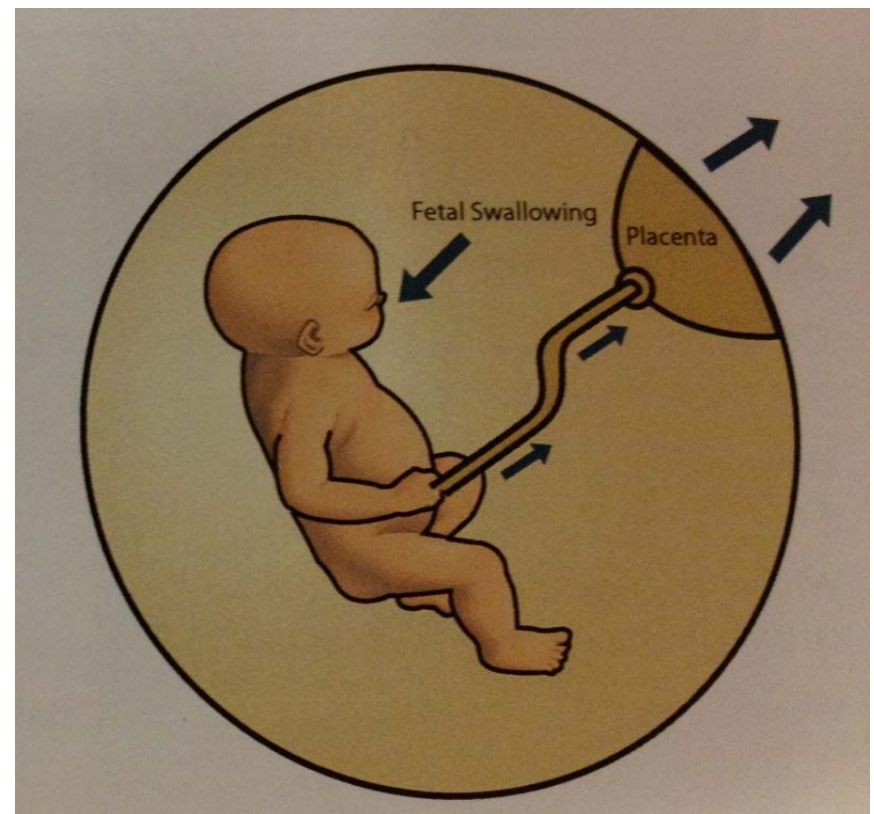
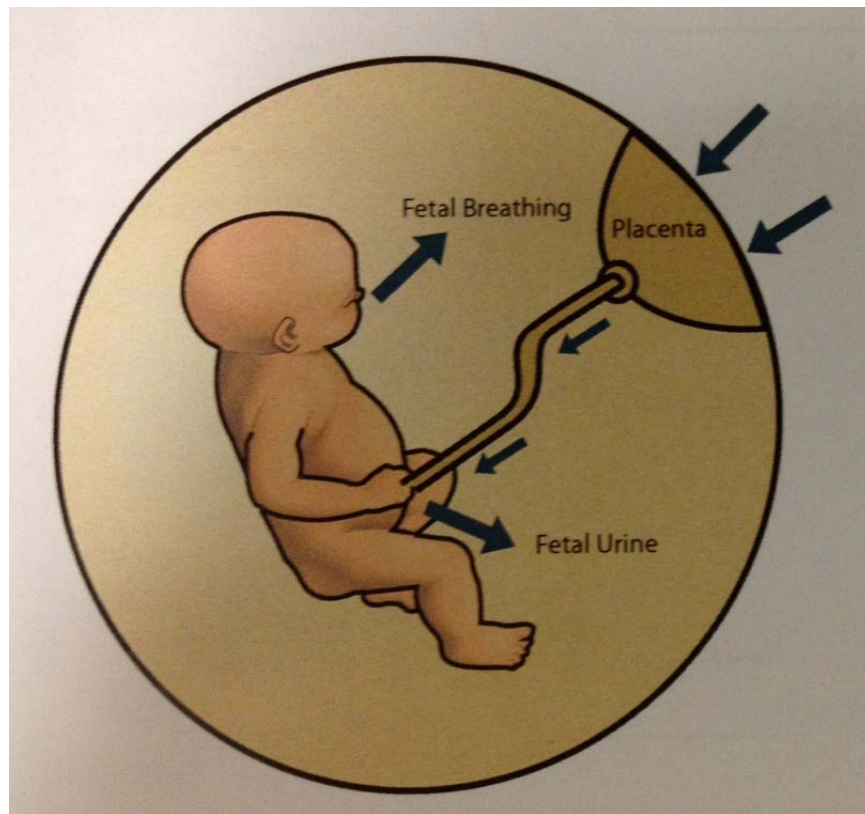
Parents in the Safe Babies Court Teams

History of Drug and Alcohol Abuse in Court Teams Parents



The Effect of Alcohol on a Fetus

The Effect of Alcohol on The Fetus

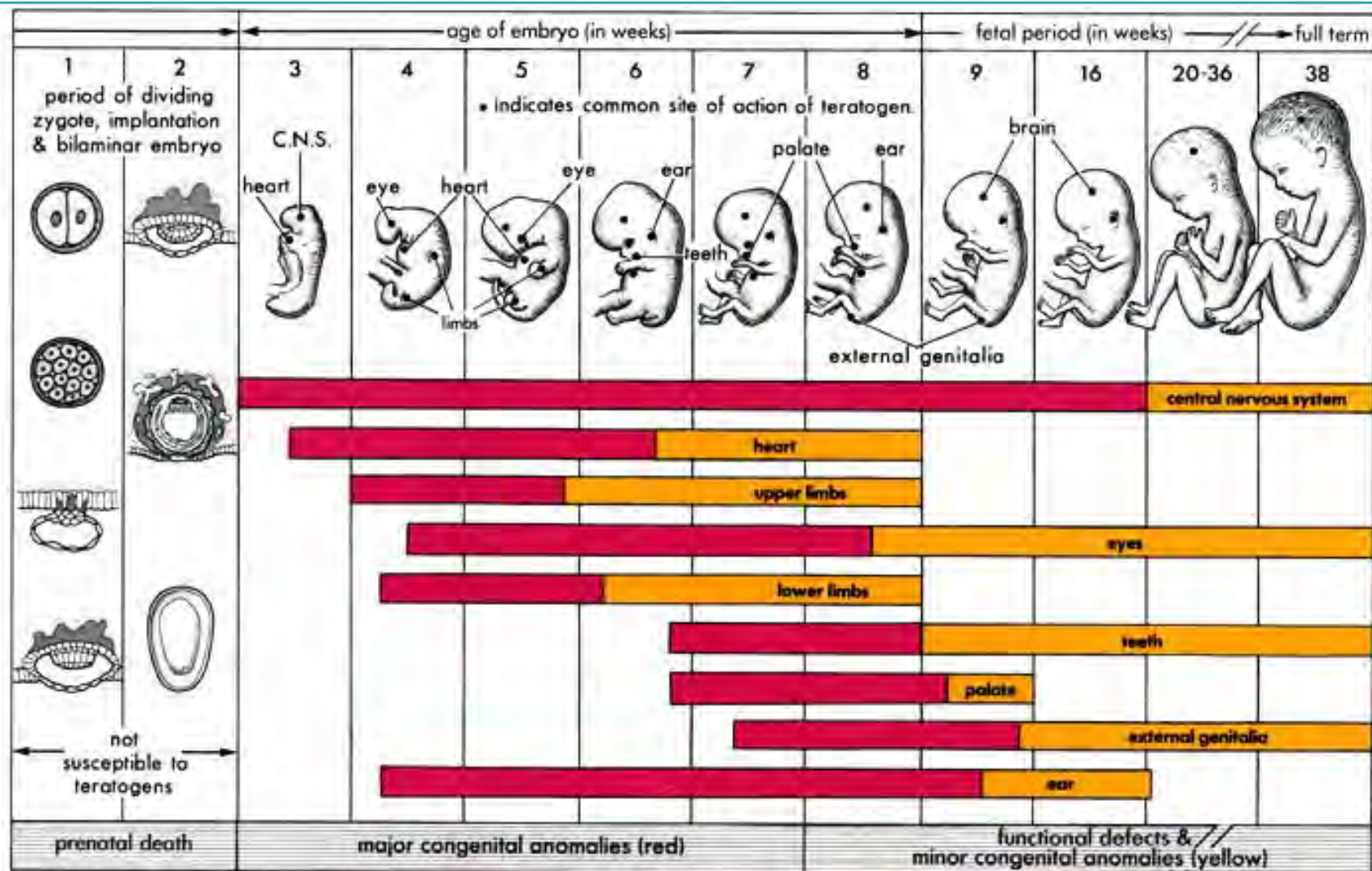


Credit: Dr. Larry Burd

Alcohol

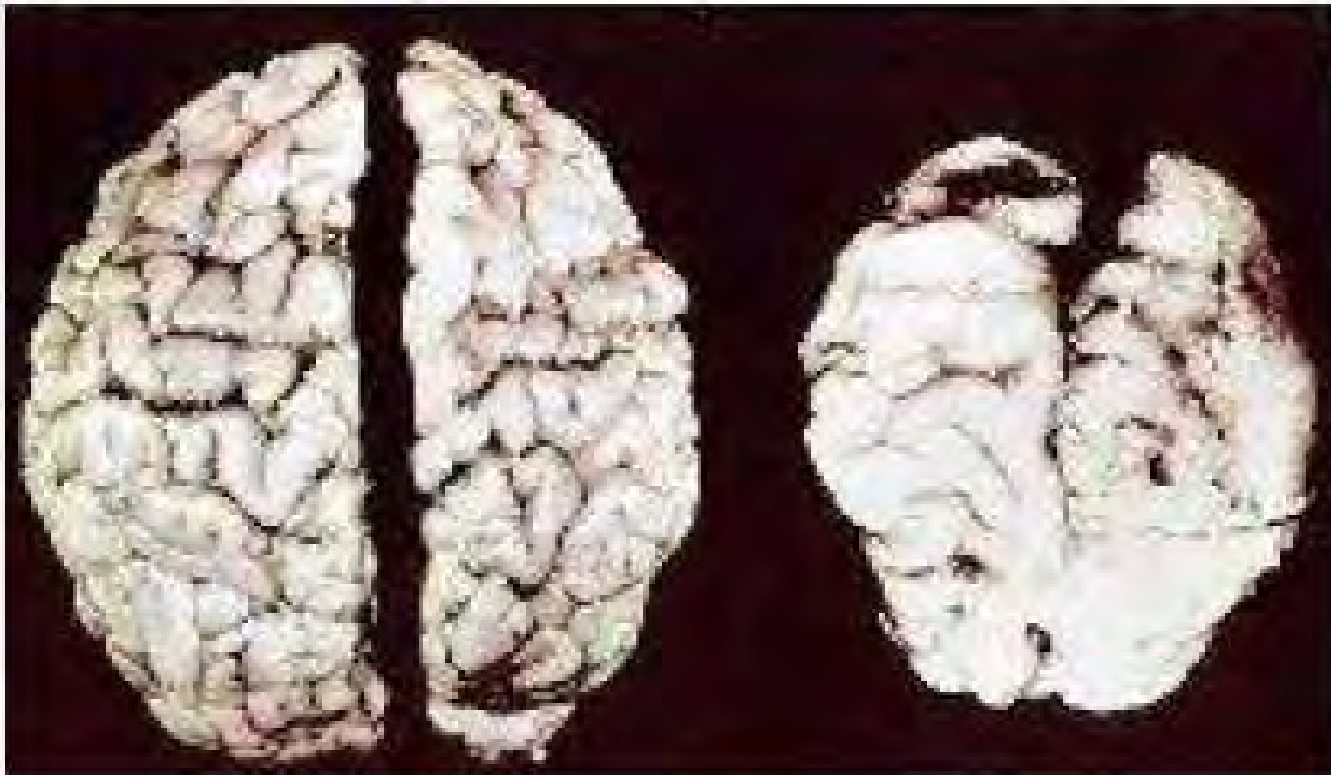


Effects of Alcohol Throughout Pregnancy



Reference: FASlink Fetal Alcohol Disorders Society. *Effects of alcohol as a teratogen on the baby*. Retrieved from: <http://www.faslink.org/Graphics/teratogens.jpg>

The Effect of Alcohol on the Brain



Normal Brain

Severe FAS-Affected Brain

Harwood, Am. J. Med, Genet. 2002

Defining FASD

Fetal Alcohol Spectrum Disorders is an umbrella term that covers:

- Fetal Alcohol Syndrome (FAS)
- Alcohol Related Birth Defects (ARBD)
- Alcohol Related Neurodevelopmental Disorder (ARND)

Defining FASD: Looking Deeper

- **Fetal Alcohol Syndrome** – Fetal Alcohol Syndrome is a clinical diagnosis for those exposed to alcohol prenatally showing growth retardation, facial features that are characteristic of FASD, and central nervous system problems.
- **Alcohol Related Neurodevelopmental Disorder** – individuals with a confirmed maternal alcohol use, neurodevelopmental abnormalities, and unexpected slow development.
- **Alcohol Related Birth Defects** – individuals with confirmed maternal alcohol use and one or more congenital defects which includes the heart, bone, kidney, vision or hearing abnormalities.

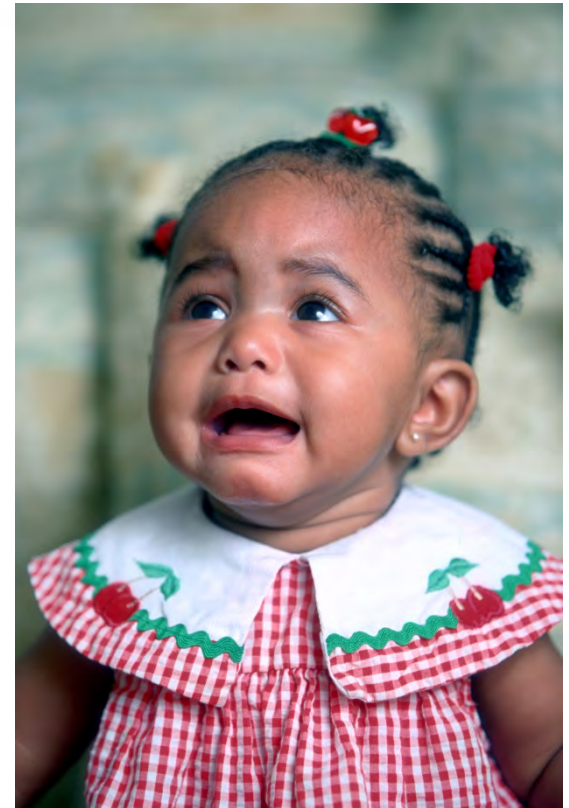
The Symptoms of FASD

Signs and Symptoms: Ages 0-3

- Prematurity
- Low birth weight
- Sleep disturbances
- Difficulty feeding
- Failure to thrive
- Poor muscle tone
- Excessive Crying
- Irritability
- Sensitivity to sound and light
- Distractibility/hyperactivity
- Difficulty following directions
- Delays in walking, talking and toilet training

Signs and Symptoms: Preschool

- Hyperactivity
- Distractibility
- Temper tantrums
- Toilet training delays
- Difficulty following instructions
- Trouble organizing own play
- Poor motor coordination
- Lack of physical boundaries
- Verbal ability higher than thinking ability



Signs and Symptoms – Elementary Years

- Impulsive
- Increasing difficulty with school
- Socially isolated
- Difficult behavior
- Slow growth

Signs and Symptoms – Adolescent Years

- No personal boundaries
- Poor reasoning and judgment
 - High risk behavior
- Poor social skills
 - Likely a follower
 - Sometimes isolated or depressed
- Poor memory, does not learn from mistakes
- Vulnerable

Signs and Symptoms - Adulthood

- Short in stature
- Difficulty managing money
- Unpredictable
- Unable to read environment
 - Difficulty understanding laws
 - Difficulty understanding social situation
 - Difficulty judging right from wrong

Secondary Disabilities

- Mental illness
- Disrupted school experiences
- Alcohol and substance abuse
- Dependent living
- Problems with employment
- Involvement in the criminal or juvenile justice system
- Confinement (jail, mental health)

Fetal Alcohol Spectrum Disorders Video



Zero to Three: Safe Babies Court Teams

Available now on DVD.

To order, go to:

<http://www.zerotothree.org/maltreatment/safe-babies-court-team/safe-babies-products.html>

Advocating for Affected Persons



Advocating for FASD Affected Children

Needs:

- Early identification
- Appropriate early intervention
- A stable, loving caregiver
- A routine

Solutions:

- Provide in-person developmental screenings
- Ensure quick referrals to early intervention services
- Document prenatal alcohol use
- Create concurrent plans
- Ensure routine case plans

Advocating for FASD Affected Adults

Adults with FASD may have difficulty:

- Telling time
- Remembering multiple instructions
- With reading comprehension
- With large groups
- With cause-an-effect

Advocating for FASD Affected Adults

Recognizing these needs, the Court Teams aim to:

- Identify the adult's capabilities
- Create an achievable case plan
 - Write down the case plan in simple language
 - Create routine case plans
 - Utilize praise
- Educate
- Create support systems.

- Create an FASD Task Force.
- Conduct a Community Resource/Needs Assessment.
- Train Pediatricians on FASD Screens.
- Refer all children for an FASD Screen.
- Train providers on working with FASD children.
- Create all adult case plans as if FASD existed.

Questions?



References



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For far too long the courts in Mississippi just applied a Band-Aid to the problems presented by abused and neglected babies. We didn't have the knowledge or tools to put together an effective approach. Now our small community has really come together to ensure babies are getting what they need to develop medically, socially, and cognitively.

~Judge Michael McPhail, Forrest County Youth Court, Hattiesburg, MS

Safe Babies, Strong Families, and Healthy Communities

Every seven minutes a baby or toddler in America is removed from his parents' care because of alleged abuse or neglect. At a time when these children are first exploring the world, when their lives as learners are just beginning, they are learning that the world is a dangerous and frightening place. Their brains are assaulted by stress hormones that can diminish their IQs and social interactions. Their need to find safe, trusting relationships overrides their curiosity. Their future and the future of their communities are compromised. These young children, a disproportionate percentage of whom are children of color, are often overlooked in the range of approaches designed to improve the early learning environments for poor children. Despite this grim forecast, research confirms that the early years present an unparalleled window of opportunity to effectively intervene with very young victims of maltreatment. Research-informed decision-making combined with developmentally appropriate services can change the odds for these babies and toddlers. Yet, the child welfare system is not guided by what science says babies need. As a result, what unfolds is a developmental disaster for babies.

ZERO TO THREE has instituted a groundbreaking program in ten diverse sites. *Safe Babies, Strong Families, and Healthy Communities* is operating in Hattiesburg, MS; New Orleans, LA; Des Moines, IA; Honolulu, HI; Cherokee, NC; San Francisco, CA; Omaha, NE; Douglasville, GA; New Haven, CT; and Little Rock, AR. The principle strategy of the Safe Babies program is the Safe Babies Court Team, which combines judicial muscle with child development expertise and community partnerships so that babies and toddlers are given the life-changing help they need. By working together, multidisciplinary teams are developing and implementing comprehensive research-based approaches to meet the needs of these young children. In each site the Safe Babies project will:

- Establish and support a team representative of all the decision-makers, services and resources which can support abused and neglected babies in the community
- Help individual team members apply evidence-based whole-child decision-making to improve healthy developmental outcomes one baby at a time
- Utilize the whole team to create systemic changes that build community capacity to improve outcomes for all babies and toddlers in the child welfare system

Safe Babies is an opportunity to invest in an initiative that is transforming the way communities approach the needs of marginalized babies and toddlers to lay a healthy foundation for their educational and social success. The strength of *Safe Babies, Strong Families, and Healthy Communities* lies in the expertise and networks present at the local level supported by the knowledge and guidance of ZERO TO THREE.

The court team model has revolutionized the way we do business in this courthouse. And I can't imagine ever doing it any other way. It is so valuable in helping me make the best decisions I possibly can and to know that the work that we're doing is backed up by the science of what's best for children. It's very comforting for someone who puts her name on the line and decides where a child will spend the night because that can be a life and death decision.

~Judge Constance Cohen, Associate Juvenile Judge Iowa Courts, District 5

The Elephant in the Cradle

Fetal Alcohol Spectrum Disorders

KATRINE HERRICK

LUCY HUDSON

ZERO TO THREE

Washington, DC

LARRY BURD

University of North Dakota School of Medicine

Grand Forks

Although legal, alcohol is a substance of abuse for many individuals. Alcohol can permanently damage children born to mothers who drink when they are pregnant. The amount of damage varies, depending on when and how much the mother drinks during her pregnancy, but every drop is potentially damaging (Helfer et al., 2009). Think of it as IQ points slipping away.

The effects of alcohol and fetal alcohol syndrome (FAS) are becoming increasingly known, but many more people are affected by fetal alcohol spectrum disorders (FASD) than those who have the characteristic facial features of FAS. In fact, most people with an FASD do not have the FAS facial characteristics and are hence living with a real but invisible disorder (Kelly, 2005).

The severe implications of FASD make early diagnosis critical. The best outcomes are for people diagnosed before age 6 (Kelly, 2005). If FASD is not diagnosed (or if it is incorrectly diagnosed as one of many other conditions with similar symptoms), the child is at risk to develop secondary disabilities. These additional problems are potentially preventable and are often due to inappropriate treatment resulting from a misunderstanding of the link between the child's brain damage and behavior (Malbin, 1999; Streissguth, 1997).

The goals of this article are:

1. To provide an overview of FASD;

2. To increase knowledge about FASD and hence to increase the visibility of the disorders;
3. To educate more people on the harm of drinking during pregnancy to reduce the number of prenatally exposed births in the future.

Why Care About FASD?

DESPITE ITS INVISIBILITY, FASD is a large problem that affects society every day. In the United States, approximately 40% of all pregnancies have some alcohol exposure before birth, and 3–5% of pregnancies are heavily exposed to alcohol before birth (Burd, 2006; Centers for Disease Control and Prevention, 2004). Approximately 1% of all U.S. newborns are diagnosed with a birth defect or developmental disability related to prenatal alcohol exposure (Burd & Christensen, 2009; Sampson et al., 1997). That may seem like a small percentage, but the number of new cases of FASD each year exceeds the number of cases of muscular dystrophy, spina bifida, and Down syndrome



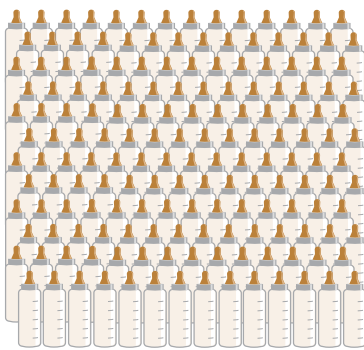
combined (National Organization on Fetal Alcohol Syndrome, n.d.-a). FASD also affects more children than autism (Autism Society of America, 2010).

The lack of an accurate understanding of FASD often leaves parents searching to try to understand why their child learns and behaves in ways that create such conflict with society. They spend years seeking treatment

Abstract

Alcohol can tremendously inhibit the lives of children exposed prenatally, yet many pregnant women still fail to recognize the seriousness of prenatal alcohol exposure and the alcohol-related disabilities captured under the umbrella term fetal alcohol spectrum disorders. Prenatal alcohol exposure can cause extensive damage that alters the formation of the brain and vital organs, causing lifelong damage. The consequences of prenatal alcohol exposure are often grave, inhibiting both physical and intellectual development, societal acceptance, and adult success. This article describes the negative effects alcohol can have on the developing fetus and the coping strategies professionals can use when working with affected children and parents.

Table 1. Drinking During Pregnancy

Drinks Per Day	Cumulative Fetal Exposure (Drinks per day x 270)	Fetal Exposure to Absolute Alcohol in Ounces	Full Baby Bottles
1	270	135	15 
2	540	270	33 
10	2700	1350	168 

Source: University of North Dakota Fetal Alcohol Syndrome Center. Reprinted with permission.

● **Alcohol-related birth defects:** This term is used to describe individuals with confirmed maternal alcohol use and one or more congenital defects that include heart, bone, kidney, vision, or hearing abnormalities. This category is rarely used as a diagnosis.

Because the mother's drinking history is a key for diagnosis on the FASD spectrum, many children are not accurately diagnosed. Most professionals working with parents are reluctant to question women about alcohol consumption during pregnancy. When they ask at all, they ask in a way that elicits misinformation. "Did you drink during pregnancy?" is easily misinterpreted to mean only hard liquor. Wine, beer, and hard lemonade are just a few of the alcoholic beverages that are overlooked when pregnant women and mothers reply to this question.

Causes of FASD

DESPITE THE FACT that 40% of pregnancies are exposed to alcohol prenatally, 1% of children are diagnosed with an alcohol-related disorder (Burd & Christensen, 2009; National Organization on Fetal Alcohol Syndrome, n.d.-b; Sampson et al., 1997). What makes some children more susceptible to FASD than others? It is still unclear what in a genetic makeup makes some children resistant to FASD and why some genes increase risk from the harm of alcohol. One factor that has been shown to contribute is birth order. Younger children in the birth order are more likely to be affected by FASD than older children. The younger sibling of a child with an FASD is at an increased risk for an alcohol-related disorder and should be screened (Abel, 1998). In addition, even if a mother drinks the same amount of alcohol through three pregnancies, it is possible that the youngest child might be the only one with an FASD. Mother's age also contributes. The older the mother is, the higher the risk is that her child will have an FASD if exposed to alcohol prenatally (Abel, 1998). This is not to imply that young women are not at risk to have a baby with an FASD, but rather that older women have increased risk.

Although genes play a role, alcohol consumption during pregnancy is the essential cause of FASD. Despite this fact, there are a number of myths about drinking during pregnancy. Many people believe that some alcohol is okay (e.g., the medicinal glass of wine before dinner) while "hard" liquor is harmful to the developing fetus. In fact, all kinds of alcohol are equally to blame for FASD. There is no level of drinking during pregnancy that is known to be safe. Obstetricians who counsel their patients to enjoy a glass of wine each evening are putting the fetus at risk. More

FETAL ALCOHOL SPECTRUM DISORDERS (FASD) IN THE UNITED STATES

Every year:

- Exposed pregnancies: 1,560,000
- Pregnancies with frequent heavy drinking: 137,000
- New cases of FASD: 40,000

Every day:

- Birth of a child with FASD: 109 (4 per hour)
- Cost of health care and related services: \$55.4 million
- Lost productivity: \$2.3 million (Burd, 2006; Lupton, Burd, & Harwood, 2004)

with other abused substances such as marijuana, cocaine, heroin, and tobacco (FASLink Fetal Alcohol Disorders Society, 2010; Gray et al., 2009). Children in foster care are at an even greater risk for FASD. Whereas 40% of children are prenatally exposed to alcohol in the general population, nearly 70% of children in the foster care system were prenatally exposed (National Organization on Fetal Alcohol Syndrome, n.d.-b).

What Is FASD?

FASD HAS CLEAR implications for society, yet many people are still unaware of what FASD is or what its effects are. FASD is an umbrella term that covers a range of disorders caused by prenatal alcohol exposure. These disorders include the following:

- **FAS:** This is often considered the most serious in the FASD spectrum because, in addition to central nervous system damage, stunted growth and facial abnormalities are present.
- **Alcohol-related neurodevelopmental disorder:** This disorder describes individuals with confirmed maternal alcohol use, neurodevelopment abnormalities, and behavioral or cognitive abnormalities that compromise their development. This category was previously referred to as fetal alcohol effects.

for problems experienced but not correctly identified. Not only is the process frustrating for the parents and child, but the economic cost of this process is staggering; the facts are summarized in the box Fetal Alcohol Spectrum Disorders in the United States.

The publicity and concern over the use of crack cocaine and other drugs during pregnancy eclipse professional and popular concern about the use of alcohol during pregnancy. However, it is alcohol that causes the most serious neurobehavioral effects in the fetus and long-term deficits when compared

importantly, patients who bring up the subject of drinking with their obstetrician are raising a red flag that alcohol may be playing an unhealthy role in their lives.

Every week of development is crucial to a baby's development; hence, any amount of alcohol can affect the baby's development at any time during the pregnancy. Alcohol can damage different body systems related to the fetal development that is happening during each week of pregnancy. The brain is developing throughout the entire gestational period. As a result, alcohol can have a very large impact on brain development and babies' ability to think, communicate, learn, and understand the world around them.

FASD in Infants and Toddlers

THE SIGNS AND symptoms of FASD change with age (see box Diagnosing Fetal Alcohol Spectrum Disorders). It is important to remember that the signs and symptoms listed here are the general ones for very young children (although some of these symptoms can be seen later in life as well). Because FASD is unique to each person, affected children may display only some of these symptoms. In addition, these symptoms are experienced in varying degrees ranging from mild to severe. The box Signs and Symptoms of Fetal Alcohol Spectrum Disorders lists those that are most frequently seen for the birth to 3 years age group.

Just as the signs and symptoms differ from person to person, successful strategies differ as well. It might take time to find the strategies that work best for the FASD-affected person. A good place to start is with the following strategies that many have found useful when working with the birth to 3 years age group:

- **Reduce noise and keep lights low.** This will reduce distractions and help the child sleep better.
- **Introduce stimuli one at a time.** FASD-affected children react better to one change at a time. Instead of introducing a child to a group of people, introduce the child to one person at a time. FASD-affected children can also be overstimulated by a large selection of toys. Reducing toy selection may improve behavioral outcomes.
- **Use calming techniques.** When an infant gets upset, a warm bath or shower, music, and rocking might help. Swaddling is the most highly recommended calming technique for infants.
- **Develop and follow routines.** Routines help with all aspects of managing the child's symptoms, but they especially help to reduce temper tantrums and to aid in sleeping.



PHOTO: UNIVERSITY OF NORTH DAKOTA FETAL ALCOHOL SYNDROME CENTER

A drink a day during pregnancy

DIAGNOSING FETAL ALCOHOL SPECTRUM DISORDERS

If you think someone has Fetal Alcohol Spectrum Disorders (FASD), it is important to start the diagnostic process. It is also important to remember that getting a diagnosis can be difficult. Here are some tips for getting a diagnosis:

1. An honest appraisal of the mother's drinking during pregnancy is important. Many diagnosticians will not make a diagnosis without this information.
 2. Early diagnosis is critical: If you suspect FASD, do not delay in getting a diagnosis.
 3. It may take several tries to get a diagnosis. Persist if you believe the child is affected.
 4. Contact the National Organization on Fetal Alcohol Syndrome to get advice on where to get a diagnosis and where people who live in your area have found support.
- **Simplify.** Because FASD-affected children are easily distracted, white or plain colors lessen distractions. Special attention should be paid to minimizing the use of overstimulating colors (e.g., bright red, lime green, or yellow) and decoration (e.g., multiple themes or clutter) in the bedroom.

SIGNS AND SYMPTOMS OF FETAL ALCOHOL SPECTRUM DISORDERS

Signs and symptoms of Fetal Alcohol Spectrum Disorders (FASD) in children from birth to 3 years old include the following:

- a. Prematurity
- b. Low birth weight
- c. Sleep disturbances (up frequently at night)
- d. Difficulty feeding—infants with FASD often have a hard time sucking
- e. Failure to thrive
- f. Low muscle tone
- g. Excessive crying
- h. Irritability
- i. Extreme sensitivity to sound and light
- j. Easily distracted or hyperactivity
- k. Difficulty following directions
- l. Delays in walking, talking, and toilet training
- m. Hearing problems potentiated by frequent ear infections
- n. Heart problems
- o. Tremors
- p. Vision problems

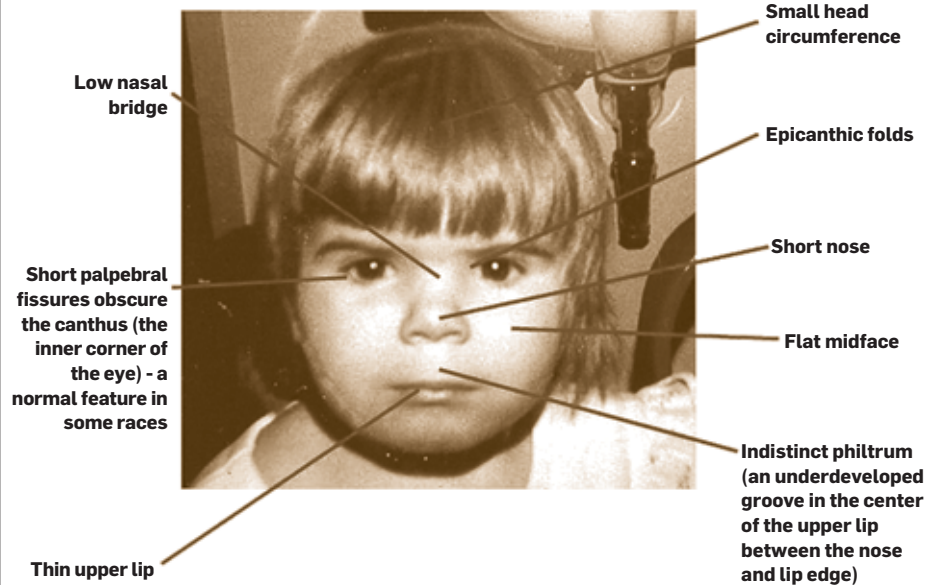
- **Use simple words when giving directions.** Speak slowly, and repeat what you have said. Directions should be given one step at a time rather than all at once. Picture cues can also be helpful (e.g., a picture posted over the toy box showing the child putting toys in the toy box).
- **Provide calming activities.** As children reach the toddler age, they are likely to become hyperactive. It is important to provide calming activities that do not overstimulate. Some suggestions might be coloring, singing, working with play dough, or finger painting.
- **Provide a safe place.** When children are overwhelmed or overstimulated, they need a spot that is uncluttered and offers relaxation. A corner space, in a muted color, with a soft comfortable mat, a blanket, and one special stuffed animal might provide the ambience to help an overstimulated child calm down. The caregiver will have to work with the child to teach him to utilize this spot when he is overstimulated. It is important that this spot be viewed as the child's special safe spot and not a disciplinary (e.g., time-out) location (Streissguth, 1997).

FASD in Older Children

AS CHILDREN GROW, the impairments they live with often become more noticeable and may include deficits in the following:

- **Abstract reasoning.** The ability to analyze information and form theories to explain problems is very difficult for people with FASD, making it difficult for them to understand and participate successfully in the world around them.
- **Cause and effect.** FASD-affected people have difficulty learning from their mistakes. They have difficulty understanding that their behavior has consequences. This is why many FASD adults get in trouble with the law enforcement system.
- **Generalization.** Those affected by FASD have trouble applying information gained in one situation to another. For example, if Tommy borrows Pedro's bike without asking and is told not to borrow Pedro's bike without asking, Tommy might think it is okay to borrow Margaret's bike instead.
- **Right and wrong.** Children and adults affected by FASD have difficulty understanding why some actions are acceptable and other actions are not. And because they are readily influenced by other people, they are easily led into delinquent behavior.
- **Interpreting people's behavioral cues.**

Figure 1. Fetal Alcohol Syndrome



Source: University of North Dakota Fetal Alcohol Syndrome Center. Reprinted with permission.

Although FASD-affected children and teens have an intense desire to please authority figures, they are not able to gauge facial and conversational cues that assist most people in understanding what other people are saying.

- **Time.** FASD-affected people have difficulty with time in two ways: telling time and understanding the passage of time. In children, this means that they don't understand warnings like "You have to clean up in 10 minutes."
- **Memory.** Though FASD-affected persons have difficulty with memory in general, short-term memory poses the greatest difficulty. As a result of this impairment, any instructions require regular and frequent repetition.
- **Behavior.** Many of the cognitive impairments translate into behavior more consistent with a much younger age than the person's chronological age. FASD-affected children are more comfortable interacting with children much younger than they are. A 10-year-old child will behave more like a 5-year-old and be happier engaged in activities appropriate for a 5-year-old.

It is critical that professionals working with children consider the possibility that these signs are potential symptoms of FASD; children who exhibit these difficulties should be tested as early as possible.

FASD in Parents

IN ADULTS, BEHAVIORAL vulnerabilities continue. More problems surface as the added expectations of adulthood are not

met. For example, the difficulties with math during the school years are the precursor to adult difficulties in telling time, managing money, and planning ahead for appointments such as court appearances or meetings with social services. Without services, adults with FASD continue to be unpredictable, volatile, and impulsive. Their inability to read the environment is demonstrated in difficulty understanding laws, evaluating social situations, and judging right from wrong. These symptoms often result in mental health problems, substance abuse, and difficulty finding or keeping employment. It is important to realize that these impairments vary from day to day and that doing well on one day does not mean that the person can do well every day; this variability often makes professionals think that problem days are a result of rebellion or a lack of commitment to services or to their children's well-being.

When FASD-affected adults become parents, they need varying levels of assistance depending on the severity of their alcohol-related disability. Adults who have been identified as FASD-affected and who have great supports can become successful parents. Unfortunately, many affected people are never correctly diagnosed, resulting in secondary disabilities that make parenting even more difficult. Some FASD-affected parents, identified by the child welfare system in relation to a child abuse or neglect allegation, still do not receive the diagnosis that would permit effective case planning. At that point, their disability is likely to be severe enough to require significant assistance, often for long periods of time. FASD impairments make typical case plan activities (e.g., parenting classes

or a job search) inappropriate for affected parents.

Parenting education programs often do not meet the needs of FASD-affected parents. One-to-one, hands-on instruction may be needed to help these parents meet their children's needs. Substance abuse treatment programs, which also rely on group interaction to accomplish their therapeutic goals, are less effective for FASD-affected parents because they cannot retain information unless it is presented simply and repeated often. They cannot focus well in group settings and can be disruptive to the group as well as to their own learning. In identifying possible employment, success will require a structured work environment with an understanding supervisor. Routine at work often helps. Transitions should be talked about ahead of time and practiced, and then should be implemented only if the parent is successful during practice.

It is crucial that professionals understand the problems parents face so that they can provide services that will allow adults to become successful parents and members of society. Eighty percent of adults with FASD have memory problems and executive functioning problems. And 75% also have residual attention deficit/hyperactivity disorder (Burd, Cotsonas-Hassler, Martsolf, & Kerbeshian, 2003). In addition to these problems, the average FASD-affected adult reads at a fifth-grade level, comprehends at almost a fourth-grade level, and can speak at a fifth-grade level (L. Burd, personal communication, 2010; see box Summary Characteristics). Additional symptoms of FASD in adulthood include the following:

- **No personal boundaries and impulsivity.** This can lead to promiscuous sexual encounters and increased risk of teen pregnancy.
- **Poor reasoning and judgment.** This contributes to high-risk behavior.
- **Inability to correctly interpret social cues.** Because FASD-affected adults do not process voice tone or unspoken forms of communication (e.g., body language or facial expressions), they convey a vulnerability that makes them easy targets for bullies.
- **Poor social skills.** Poor social skills increase risk of depression, isolation, and substance abuse.
- **Bad choices of friends.** These choices lead many into delinquent behavior and increase the risk of criminal acts.
- **Inability to learn from mistakes.** This inability leads FASD-affected adults to repeat bad decisions in new settings and with new people.

FASD-Adapted Treatment

THE FOLLOWING SUGGESTIONS can help parents with FASD be more successful in parenting intervention programs:

- Go slow (treatment or services may take much longer).
- Make it concrete (picture guide or lists are helpful).
- Reduce group size: Small groups lead to better participation and more attentiveness.
- Remember that anxiety increases impairment.
- Work on one problem at a time.
- Recognize and appreciate impairments.
- Develop a long-term plan that includes ongoing support services.
- Keep directions short.
- Anticipate needs and create opportunities for success.

Many interventions targeting maltreating parents (e.g., parenting education or substance abuse treatment) use a group setting. FASD-affected adults do not do well in these settings. They need very small groups in which people are prepared to listen patiently and discuss issues calmly. The FASD-affected person needs help to focus on what is being said so that she can, as much as possible, understand the situation.

Professionals working with FASD-affected parents need to orchestrate meetings with attorneys, child welfare agency staff, service providers, and parents so the parent can remain attentive. When people walk into the room and within 5 minutes have passed judgment on the parent, the meeting has failed. If the other individuals are not able to restrain expressions of frustration because the parent was late to the meeting, the parent will grow anxious and then become unable to pay attention to the content of the meeting.

In addition to programmatic supports, FASD-affected parents will need someone to advocate for them over the long term. This advocacy should include help with money management. Assistance with day-to-day tasks is critical. Lists provide a concrete form of repetition that helps FASD-affected parents accomplish what they must do to care for themselves and their children.

Avoiding Secondary Disabilities

PROGRAMS THAT ADDRESS the adults' specific needs combined with good support not only increase their chance at success in life but reduce secondary disabilities. Secondary disabilities occur when FASD-affected people, frustrated by being misdiagnosed repeatedly and receiving interventions that don't improve their lives, turn to negative coping

SUMMARY CHARACTERISTICS OF ADULTS WITH FETAL ALCOHOL SPECTRUM DISORDERS

A longitudinal study of adults with Fetal Alcohol Spectrum Disorders (FASD) conducted by the North Dakota Fetal Alcohol Syndrome Center found the following characteristics

- Reading: grade 5
- Oral comprehension: grade 5
- Reading comprehension: grade 4.5
- Percentage of adults with memory deficits: 80%
- Percentage of adults with attention deficit: 75%
- Percentage of adults with executive function impairments: 80%

The North Dakota Fetal Alcohol Syndrome Center serves the entire state of North Dakota. The center has been in operation for 18 years. The Fetal Alcohol Syndrome Clinic sees 150 new patients each year from across North Dakota and surrounding states. Burd, Fast, Conry, & Williams, in press; www.online-clinic.com

strategies. Temper tantrums, alcohol and substance abuse, quitting or being fired from jobs, inappropriate sexual behavior, and involvement in the criminal or juvenile justice system are all examples of secondary disabilities that can likely be prevented or decreased with an accurate diagnosis and treatment.

When FASD-affected children or adults continue to behave in ways that they have been repeatedly counseled against, those around them express stern disapproval of this apparent willfulness. However, what on the surface appears to be disobedience is in fact an inability to learn acceptable behavior. One simple change in approach to FASD-affected children and adults can make all the difference in the way professionals and parents approach them: When it appears that they are refusing to obey, it is often far more accurate to say they are not able to understand what is being asked of them. It's not that they won't behave, it's that they cannot. It is those who work and live with FASD-affected people who must change their interactions to accommodate the cognitive disabilities characteristic of FASD. Successful management of the multiple disorders in FASD is possible. It requires the following:

- **Long-term planning.** With the difficulties of each day, it is hard to think

about planning in advance. Despite the difficulty, a long-term strategy focused on risk reduction will help the child avoid predictable dangers like school failure, teen pregnancy, and alcohol and drug use. Parents should work with their child early and often to prepare her for the teen and adult years that lie ahead.

- **Teaching the person to ask for help.** It is important to start working with the child to get him to recognize when he needs help and to learn to ask for help. The ability to ask for help will be very useful, especially when feeling overstimulated in school, or later on in life, such as at a workplace. It is equally important for professional staff to be able to recognize when the person with FASD is confused or does not understand.
- **Setting the child up for success.** If a toddler can only do two-piece puzzles, failing to put together a six-piece puzzle will lead to frustration. Give her two-piece puzzles until she struggles less. Then give her a three-piece puzzle. Being able to achieve success and be praised for success is much more helpful than failing.
- **Using praise.** Just as it is important to set the child up for success, it is important to focus on his positive behaviors and to praise them. It is critical to recognize the child's achievements and to praise him for the specific achievement he made (e.g., "good job building that tower" instead of "good job").

These strategies will go a long way toward reducing secondary disabilities and the havoc they reap in the lives of undiagnosed FASD-affected people.

Caring for the Caregiver

WORKING WITH SOMEONE affected by FASD is a difficult and taxing full-time job. It requires patience and persistence, devoted attention, and, despite a lot of effort, it can often feel as though there is no progress. Because a caregiver is so important in the life of a person with FASD, it is crucial to make sure the caregiver is cared for as well. Physical and mental breaks should occur regularly. Caregivers for FASD-affected persons recommend the approaches listed below:

- **Respite care.** A skilled caregiver comes into the home and works with the FASD-affected child for an hour or two while the parents go out or spend time in another part of the house.
- **Supportive friends and family.** A support system of caring people who are educated on FASD can remind the parents that they are handling things well

and that it is worthwhile.

- **Support groups.** Some communities have support groups for birth, foster, and adoptive parents who are caring for a child affected by FASD. If the adults are high-functioning and not themselves FASD-affected, they can benefit from spending time with people experiencing similar frustrations and a similar day-to-day routine. The burden is lessened when it is shared with others who appreciate the struggle, and hopes are raised by those who have learned ways to cope well. If the adult is FASD-affected, support groups are not helpful. The time would be more productively spent providing direct services to them.
- **Health maintenance.** It might seem easy for the caregiver to forgo a routine doctor's visit when the caregiver already has many doctor's visits to attend for the child. It is very important that the caregiver does not push her own health aside for the child. This includes not just physical health but mental health as well.

Each caregiver is different and may use different methods to maintain his own physical and mental health. Regardless of the method, service providers, friends, families, and communities should encourage and support the caregiver because he is crucial to the success of an FASD-affected person.

Conclusion

FASD PERMANENTLY AFFECTS the brain and the affected person's ability to function. Every fetus is at risk for FASD if the mother drinks during pregnancy. Because of the troubling circumstances that bring families to the child welfare system, children in foster care are at a vastly increased risk for these disorders. Professionals who work with children who are the victims of abuse or neglect must be vigilant in identifying the signs and symptoms of FASD and appropriately diagnose those who appear to be affected. Accurate diagnosis can lead to appropriate interventions. Appropriate interventions will reduce the risk of child maltreatment in FASD-affected families. ♣

KATRINE HERRICK, BS, is the database coordinator of the Court Teams for Maltreated Infants and Toddlers Project at ZERO TO THREE. She conducted research on FASD and its relationship to the work of the Court Teams Project prior to joining the staff in October 2010. She is responsible for ensuring consistent, thorough, and accurate data on the children served by the Court Teams and for contributing to data analysis that permits the Court Teams Project to make course corrections as needed.

LUCY HUDSON, MS, is the director of the Court Teams for Maltreated Infants and Toddlers Project at ZERO TO THREE. She has more than 30 years of experience in project management, program implementation, and policy development in public and private sector child welfare, child care, mental health, and youth-serving organizations. She has been instrumental in the planning and development of the Court Teams Project and is responsible for the daily operation and oversight of all project activities, project staff, and fiscal matters.

LARRY BURD, PhD, is a professor in the Department of Pediatrics at the University of North Dakota School of Medicine. He is the co-principal investigator for the Four-State Fetal Alcohol Syndrome Consortium and the Prenatal Alcohol and SIDS and Stillbirth (PASS) Network funded by the Substance Abuse and Mental Health Services Administration, which examines maternal and environmental risk factors for stillbirth, infant mortality including sudden infant death syndrome (SIDS), and FASD. Dr. Burd has been with the Pediatric Therapy Program for 25 years and has evaluated more than 13,000 children. He is also the director of the North Dakota Fetal Alcohol Syndrome Center and the FAS Clinic.

Learn More

CENTERS FOR DISEASE CONTROL AND PREVENTION

www.cdc.gov/ncbddd/fasd/

Contains facts, data and statistics, research, free materials, and a list of treatments.

FAS DIAGNOSTIC & PREVENTION NETWORK

<http://depts.washington.edu/fasdpn/>

Hosts trainings for clinicians and multi-disciplinary workers interested in learning how to screen and plan treatment and primary preventions.

THE FASD CENTER FOR EXCELLENCE

www.fasdcenter.samhsa.gov/

Contains information, publications, state systems, training, and more. Includes an online course that anyone can take to gain more information on FASD.

FAS COMMUNITY RESOURCE CENTER

www.come-over.to/FASCRG/

Contains several parent resources, as well as information on symptoms specific to age birth to 3 years.

NATIONAL ORGANIZATION ON FETAL ALCOHOL SYNDROME

www.nofas.org

Has fact sheets for all members of the community as well as a state-by-state resource guide.

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Judicial Bench Card			
Fetal	Alcohol	Spectrum	Disorders

Adverse outcomes from alcohol use during pregnancy

In the United States about 50% of pregnancies have some alcohol exposure. In most cases women find out they are pregnant and quit drinking. However, around 12% of women drink during pregnancy and 4-5% drink throughout pregnancy. Most of these women also smoke and many have other problematic life circumstances (other substance abuse, smoking, poor diet, late or no prenatal care).

The United States has about 40,000 new cases of fetal alcohol spectrum disorders (FASD) each year. For most affected people the primary problem from prenatal alcohol exposure is brain damage/dysfunction. For most people this will result in lifelong impairments which will change in response to age and development.

Fetal Alcohol Spectrum Disorders Comprised of four diagnostic categories

Fetal Alcohol Syndrome (FAS)

- Growth Impairments (height and weight < 3d)
- Abnormal Facial Features (2+)
- Brain Damage/Dysfunction
- Thought to result from prenatal alcohol exposure

Alcohol Related Birth Defects (ARBD)

- Birth defects thought to be due to prenatal alcohol exposure.
- Not commonly diagnosed
- Prevalence is as yet unknown

Partial Fetal Alcohol Syndrome (pFAS)

- Missing one or two key findings
- Prenatal Alcohol Exposure

Alcohol Related Neurodevelopmental Disorder (ARND)

- The primary features are brain damage /dysfunction (developmental delays, mental illness or cognitive impairments) thought to result from prenatal alcohol exposure.
- Most common FASD
- Often undiagnosed
- Changes across the lifespan

Judicial officers often see people with prenatal alcohol exposure and FASD should be a frequent consideration.

Mortality

People with FASD have increased mortality rates. Mortality risk is also increased for siblings (even if they do not have a diagnosis of FASD). Mortality rates are also increased for mothers of cases and siblings.

Miscarriage, stillbirth, sudden infant death syndrome (SIDS), birth defects, infectious illness other causes.

Prevalence

1% live births
Highly recurrent in families
Some families FASD is generational
Most affected people are undiagnosed

Cost of Care

US lifetime cost is \$2.5 million per person
Service systems most impacted are health care, foster care, education/special education, developmental disabilities, mental health systems, corrections systems and substance abuse systems.
Annual cost in US \$3.4 billion.

Outcomes

Manifestation of FASD changes over lifespan.
A two year old is at low risk for a substance abuse disorder, but adolescents are at very high risk.
Low rates of independent living
In Canada a juvenile with FASD is 14 times more likely to be in Corrections System than unaffected peer.

Every day in the United States we have 120 new cases. FASD has an exceptional recurrence rate and younger siblings tend to be the most severely affected. Diagnosis matters and appropriate services improve outcomes.

Actions from the Bench

Systems-Level Actions

- Make prenatal alcohol exposure (PAE) screening* a regular component of child welfare cases.
- Assess the community's diagnostic capacity.
- Assess interventions and treatment facilities for facilities that have appropriate training on, and services for, FASD.
- Train systems of care personnel on FASD and work to expand the community's capacity to screen, diagnose and provide interventions for affected persons.

Case-Level Actions

- Screen all children for PAE.
- Refer children with PAE for FASD assessments.
- If positive, refer child for developmentally appropriate and proactive treatment. Follow up on service utilization in subsequent hearings.
- If positive, screen siblings and parents.
- Pick placements carefully. Placements should be safe, stable and loving homes with caregivers willing to adopt if reunification fails.
- Tailor affected parent's case plans to meet their developmental needs.

*To learn more about prenatal alcohol exposure (PAE), please see the PAE Judicial Bench Card.