

News You Can Use
July 2006

Getting an Early Start on Fetal Alcohol Spectrum Disorders

Nearly forty years ago, doctors in France reported that infants and children who had high levels of alcohol exposure during pregnancy had a pattern of birth defects and developmental disabilities. Several years later, doctors in the United States (US) observed this same finding and used the term fetal alcohol syndrome (FAS) to describe the symptoms of abnormal facial features, growth deficiency and brain damage. Once thought to be rare, alcohol exposure during pregnancy is now commonly known to cause birth defects, mental retardation and developmental delay worldwide. The current term used to describe the full range of these problems is fetal alcohol spectrum disorders (FASD) and many children who participate in Early Head Start (EHS) and Head Start (HS) programs have some form of this disorder.

This article will cover the following topics on FASD:

- ✓ What is FASD
- ✓ Prevalence of FASD and Complexities in Early Identification
- ✓ How Alcohol Exposure During Pregnancy Causes FASD
- ✓ Screening and Diagnosis for FASD
- ✓ Early Intervention for Infants and Young Children with FASD
- ✓ Prevention and Management of FASD

What is FASD?

FASD is not a diagnosis but refers to a spectrum of impairments resulting from alcohol exposure to the fetus during pregnancy. FAS is the complete manifestation and most the severe form of the disorder causing growth impairment in height and weight (usually below the 10th percentile), distinctive facial features (see embedded figure) and central nervous system dysfunction (1-3). Some people have only some of the symptoms of FAS and would be given a diagnosis of partial FAS (1-3).

Alcohol related neurodevelopmental disorders (ARND) are thought to be the most common outcomes from prenatal alcohol exposure. Common findings in ARND are changes in the structure of the brain, increased risk of mental retardation, attention deficit-hyperactivity disorder, learning disabilities, depression, sleep disorders and difficulty in peer relationships. This category of FASD typically does not have the abnormal facial features and growth impairments found in FAS. ARND is complex to diagnose, especially in infants and young children. The necessary essential features to make a diagnosis of ARND need further refinement since the conditions most commonly associated with ARND can have multiple causes. However, ARND is a very important category of FASD since most of the impairment and resultant disability from FASD results from damage in the central nervous system. These impairments change over the life of the person and increased age brings increasing risk of substance abuse, mental disorders and school failure.

Prevalence of FASD and Complexities in Early Identification

Although the syndrome is completely preventable, unfortunately each year in the US about 39,000 infants are born with FASD. FASD is more common than Down Syndrome or Spina Bifida and is found in more than 1% of all children in the US. The disorder will affect about one child in a program serving one hundred children. In programs like EHS and HS where at least 10% of the total enrollment opportunities are made available to children with disabilities, FASD will be more common. FASD infants require early identification, specialized intervention programs and some form of ongoing long-term management.

Many EHS programs provide services to expectant families and therefore need to understand the challenges and risks for unborn children of alcoholic mothers. The most effective way to prevent FASD is by educating early childhood educators and staff, expectant parents, and treatment of substance abuse prior to pregnancy. Early recognition of alcoholism in pregnant mothers and their subsequent entry into a substance abuse treatment program is also important. However, early recognition of alcoholism and alcohol use during pregnancy is difficult to identify unless the pregnant

mother is self-referred, an identified member of a high-risk population for alcohol abuse and use or has already given birth to a child with FASD. Aside from being a member of one of these three groups, a pregnant woman with alcohol abuse problems is not that easy to identify at face value. Many pregnant women are able to function daily without “visible” signs of an alcohol addiction problem. Furthermore, some of these women do not receive prenatal care early enough in their pregnancies, and when they do, health care providers often do not ask the “right” questions. Some questions providers might consider are the following:

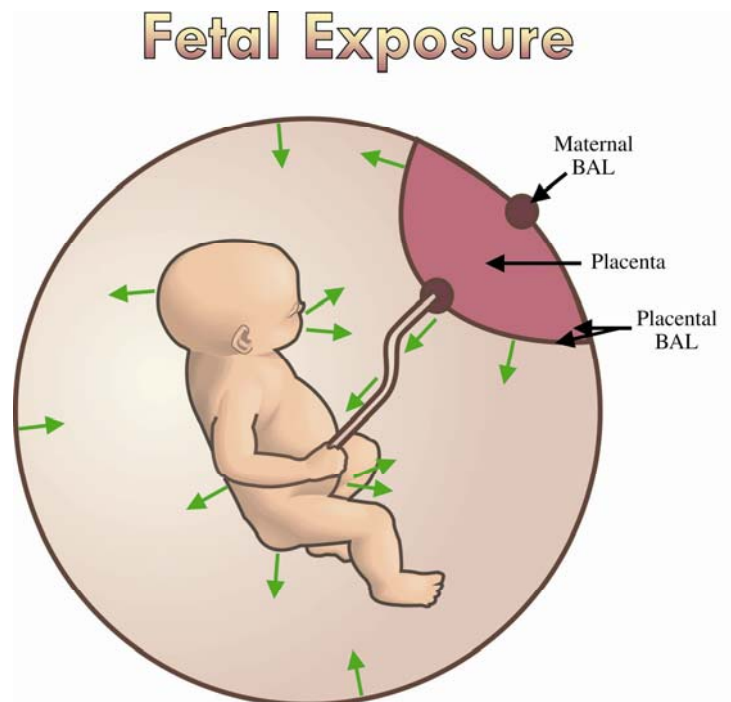
- When was your last drink?
- Do the expectant parents have current substance abuse problems?
- Do the expectant parents have depression?
- Do the expectant parents need extra support parenting a child predicted to have complex health and development problems after birth?

The barriers mentioned above create understandable difficulties in providing early identification and intervention for these women. However, once identified, pregnant women at risk for alcoholism need the support to enter and complete treatment and maintain a life of sobriety.

How Alcohol Exposure During Pregnancy Causes FASD

Once thought to be harmless if used during pregnancy, alcohol was at times even used to prevent complications of pregnancy. Recent research has demonstrated that alcohol exposure during pregnancy is still very common. In fact, approximately 40% of all current pregnancies are alcohol-exposed although in most cases the amount is very small and occurs before women know they are pregnant. Alcohol use in these pregnancies is usually limited to one or two times with very few drinks each time. However, in about 6 to 10% of pregnancies, alcohol use continues for most or all of the pregnancy and the amount of use can be quite high. A pregnant woman, for example, could expose herself and her unborn child to several days of most weeks of drinking, or binge drinking with four or more drinks per occasion. Since no known level of alcohol use in pregnancy has been proven to be safe, the United States Surgeon General recommends that all alcohol use during pregnancy be avoided (4). The most severe form of alcohol abuse and an addictive disorder, alcoholism is one of the most common public health problems in the US. The figure below shows how alcohol can cross the placenta and surround the fetus.

In the figure, we can see that after drinking, the mother’s blood alcohol levels (BAL) rise rapidly and the alcohol easily crosses the placenta (red semi-circle) to the fetus. Alcohol crosses through the placenta to the fetus each time the mother drinks. The green arrows show how alcohol enters the fetus and amniotic fluid. The levels of alcohol in the fetus are similar to those in the mother. However, while it takes about one hour for a woman’s body to eliminate a drink of alcohol, it takes nearly twice as long for alcohol to be removed from the fetus and the amniotic fluid. Fetal alcohol exposure increases the risk for miscarriage, stillbirth and infant death. Prenatal alcohol exposure also causes birth defects and brain damage in the fetus. (With permission from Am Fam Phy 2006)



Screening and Diagnosis for FASD

Screening for early identification of FASD has several important benefits in EHS and HS programs, including early intervention and improved educational and functional outcomes for infants, toddlers and young children. Early screening increases the number of young children identified and this allows them early access into intervention programs. Early intervention increases the amount of time these very young children can be served in the critical developmental periods of life. An additional and often unappreciated benefit for many infants and toddlers is that early treatment decreases the duration of some aspects of FASD, which may, in turn, decrease the severity and frequency of associated problems. For example, speech and language delays (commonly seen in children with FASD) are often associated with the development of difficulties relating to peers and are strongly associated with reading problems at school age. Early intervention for an infant or toddler in this case could result in positive changes in behavior, decreased temper tantrums and less difficulty with reading in later development.

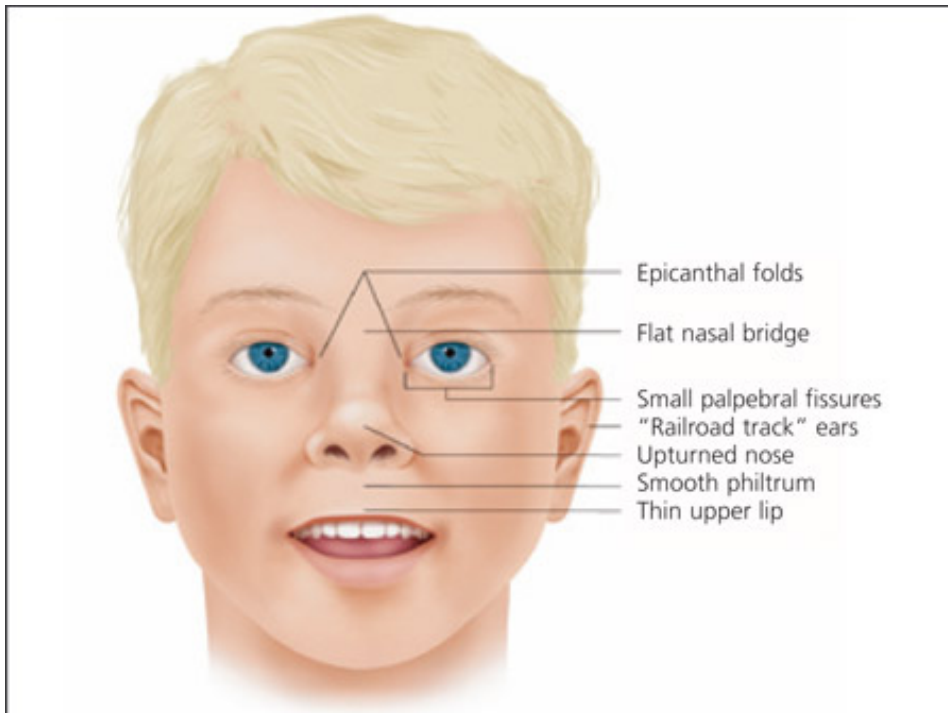
Selective or indicated screening and program or population-based screening are two common strategies used in screening for FASD. Only trained health care providers and specialists are qualified to screen and diagnose young children with FASD.

- **Selective or Indicated Screening.** All infants, toddlers and young children whose mothers have current alcohol use disorders or a recent history of alcohol use would be screened. These very young children would be at increased risk for FASD. This strategy identifies three groups of children typically screened.
 - 1) Children whose mothers have received substance abuse treatment or who have legal problems suggestive of alcohol abuse. Although some mothers use alcohol with other substances including methamphetamine, crack and intravenous drugs, all infants and toddlers of substance abusing mothers should be screened regardless of type of substance abuse.
 - 2) Children who are in foster care or relative care because of a maternal history of substance abuse and children whose mothers are in jail or prison due to a drug-related charge would be screened. Although others are caring for these very young children, they are likely to be at risk for having FASD due to maternal substance use and abuse.
 - 3) Infants, toddlers and young children with siblings who have FASD should be screened. Young children in this population are very likely to have FASD since there is up to a 75% rate of this disorder co-occurring in siblings who have brothers or sisters with FASD.
- **Program or Population-Based Screening:** A second type of screening program is a systematic program-based screening for FASD. Using this method, all children who enter a program would be screened by a trained health care specialist and either ruled-out for FASD or referred for further screening, diagnosis and early intervention. This is much more effective for identification of infants, toddlers and young children who are at increased risk for FASD.

Referrals

Despite the fact that screening is an important aspect in identifying children who need to be referred for further testing and diagnosis, some EHS or HS programs may be challenged to locate referral sources after the screening is completed. Programs needing to identify referral sources can work through their Health Services Advisory committee to identify local health care providers, developmental disabilities clinics at hospitals, universities, children's hospitals, Part C programs and other Early Intervention programs. State Health departments may also be able to provide information on programs with which EHS or HS can collaborate. Some pediatric clinics have developmental pediatricians who may also be useful referral sources.

The diagnosis of FASD is not complicated and pediatricians and specialty care providers can readily identify many children with the disorder (3). Children are often first identified because of their unique facial features. The figure below is an example of the facial features of FASD. For more involved cases, pediatricians can coordinate the additional testing needed for a diagnosis. This may include speech and language evaluations, physical or occupational therapy, hearing testing or psychological testing. EHS and HS programs that do not have access to diagnostic services may want to encourage the development of a diagnostic program in their area. This can often be accomplished by working with local pediatric providers or by collaborating with an FASD specialty clinic. Since FASD is a common problem, this may be a very worthwhile effort for EHS and HS programs to consider in order to improve care for diagnosed infants, toddlers and young children.



The figure to the left demonstrates the facial features of FAS. These are always present in FAS and are accompanied by growth impairment both in height and weight. In other FASD the range of signs of the disorder are quite variable and many affected children do not have the facial features seen in FAS. These children may have a partial FASD or an ARND where growth impairment and facial features of FAS are not present. (With permission from Am Fam Phy 2006)

Early Intervention for Infants and Young Children

Although research has demonstrated that early diagnosis and intervention with infants, toddlers and young children with FASD may improve long term outcomes, the diagnosis is associated with specific risks across the life span. Pediatric specialists and other qualified professionals often have the following concerns and questions when assessing very young children with this disorder:

- Is this infant at high risk for abuse and neglect?
- Does the child have birth defects (heart defects are especially common)?
- Is this child in foster care or at high risk for out of home placement?
- Does the child have increased susceptibility to infectious illness?
- Is the child at risk for inadequate health care and follow-up of known health problems?

FASD is a serious and long-term problem and many young children with this disorder require annual evaluations. At each evaluation, parents, caregivers, teachers and health care providers should be provided with information on the management of age-appropriate behavior and development of specific issues they will encounter with their infant or toddler. This information sharing among team members will help prevent some of the problems and minimize the severity of many others. In order

to effectively manage FASD, parents, caregivers and teachers are encouraged to ask questions, anticipate developmental events, share information and learn the signs for early identification in young children.

The following three examples could be problems with infants and toddlers who do not have FASD but are often more pronounced in young children diagnosed with the disorder.

1) **Sleep problems.** Few problems are more difficult for parents than infants who have sleep disturbance. Infants and toddlers impacted by FASD often have difficulty maintaining a regular sleep schedule. Lack of sleep disrupts parents' ability to care for infants and increases irritability, frustration and feelings of helplessness, all raising the risk for child abuse. Parents can be supported in establishing sleep schedules for infants and toddlers and managing frequent nighttime awakening for very young children. An important step in getting infants and toddlers to sleep through the night is setting a regular four or five step bedtime routine (It's almost bedtime, time to brush your teeth, get your PJs on, let's do our bedtime story – you pick the book and time to go sleep). It's important to get ready for sleep with quiet activities. For some families, success in starting a sleep routine (napping) may begin with success at EHS/HS. The use of a consistent schedule, having a nap routine and responding with consistency to infants or young children who have difficulty sleeping will often be the first steps toward self-regulation. Early Head Start staff and parents can work together in partnership to help FASD infants become more regulated in their sleep patterns.

2) **Regulation of Emotions.** Caregivers expect to see a wide range of emotions in healthy functioning infants and toddlers. Several useful strategies can help parents manage these behaviors. The first is for parents to be sure they have control over their own emotions. Infants and toddlers with FASD frequently have episodes of extreme emotional outbursts for which typical calming strategies are not quickly effective. For caregivers, the inability to help calm or soothe an infant or toddler can be distressing and often frustrating. Strategies for infants and toddlers with FASD such as holding, rocking or playing soft music may help soothe these children after a period of time. Bouncing, loud noise, or becoming upset are not helpful parenting strategies.

Temper tantrums are common in older toddlers and preschoolers with FASD. Teachers can ask a few simple questions to help them determine how to respond to a young child having a temper tantrum. For example, do temper tantrums often follow some event or do they seem to be occurring at random? Can the young child be taught how to respond to the event or similar events? Parents are encouraged to sit quietly nearby without responding while the temper tantrum is occurring, as many young children will not continue if they do not have an audience. Temper tantrums are also strongly associated with speech and language delays as young children with FASD often become easily frustrated by their own inability to communicate clearly. Early identification and entry into speech and language therapy can be very helpful in managing temper tantrums in young children with FASD.

3) **Social Skill Deficiencies.** In young children with FASD, social skills are often impaired. In older toddlers and preschoolers, these deficiencies are often seen as challenging behaviors and include aggression, poor turn taking, difficulty with cooperative play and problems in age-appropriate social interaction. A common response is to give the young child a consequence for displaying challenging behavior with the goal of modifying the behavior. Sometimes adults assume that the young child has the necessary social skills to function in settings with other peers and siblings and that they are “choosing” not to use these skills. However, many young children with FASD have difficulty understanding how to respond to peers and adult caregivers in social situations that, for them, are confusing.

It is more helpful to teach the young child appropriate responses to each social situation by anticipating problems before they occur. Parents, teachers and caregivers can use these “teachable moments” to elicit the desired response and encourage the young child to use the new skills in home and classroom settings. This approach—often called anticipatory guidance—utilizes positive rewards, skill rehearsal and catching the young child “being good.” Focusing on the desired behaviors in young children with FASD encourages them to continue working on their learned skills. This also encourages parents, caregivers and teachers to “expect” these young children to display the desired behaviors more frequently. For the adults in the young child’s life, the goal is to help them understand these behavioral issues as skill deficiencies rather than simply willful misbehavior.

Prevention and Management of FASD

FASD is a familial (often several affected children in the same family) and generational problem. Parents affected by this disorder may require specialized attention to help them learn how to manage their own children appropriately. The diagnosis of FASD is central to the development of intervention and educational plans for young children and their families as it is a highly recurrent disorder in this population. Diagnosing young children with FASD provides the opportunity for preventing subsequent cases by identifying parents in need of substance abuse treatment. Early diagnosis is an essential prevention component of FASD for future children born into these families.

FASD is an important problem in programs serving young children that can be managed by early identification and development of individualized intervention plans and goals. These goals can be realized by understanding that this disorder requires parent, caregiver and teacher education and training to build capacity in supporting young children with the disorder. The lives of very young children born with FASD do not have to begin and end with the disorder. Getting an EARLY START is the key to effective prevention and improved intervention for young children with FASD and their families.

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RESOURCES YOU CAN USE

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Centers for Disease Control and Prevention, <http://www.cdc.gov>

Fetal Alcohol Syndrome Family Resource Institute, <http://www.fetalalcoholsyndrome.org/index.html>

National Organization of Fetal Alcohol Syndrome, <http://nofas.org>

United States Department of Health and Human Services. Substance Abuse and Mental Services Administration, FASD Center for Excellence, <http://www.fasdcenter.samhsa.gov/>