



HEADS UP: Fetal Alcohol Spectrum Disorders/Fetal Alcohol Syndrome

What is FASD/FAS?

Fetal alcohol spectrum disorders or FASDs are preventable birth defects or disorders caused by maternal alcohol use during pregnancy. This spectrum includes fetal alcohol syndrome (FAS), the cluster of physical, mental and behavioral disorders that represent the most severe effects of alcohol use during pregnancy.

The syndrome is diagnosed by using a combination of findings, which may include poor growth, central nervous system disorders, certain FAS-related facial features, and a history of maternal alcohol use during pregnancy. The syndrome is often more difficult to recognize in newborns than in older children. For children who suffer from this spectrum of disorders, the result may be lifelong learning and behavioral difficulties.

According to the Centers for Disease Control and Prevention (CDC), alcohol use during pregnancy is one of the top causes of preventable birth defects and developmental disabilities.

How often does FASD/FAS occur in New York ?

The actual occurrence of the disorders is unknown, but is estimated to affect between one and ten out of every 1,000 births. The Early Childhood Knowledge Learning Center (www.eclkc.org) reports the incidence of FAS at 1% of all children. This means that if you have 100 children in your program, there will be at least one child with FAS. In programs like Head Start, where the requirement is that 10% of the children have disabilities, it can be expected that the incidence will actually be higher.

New York State data is also available from the **Pregnancy Risk Assessment Monitoring System** or **PRAMS**. **PRAMS** collects information from a sample of women who have recently given birth. There are two separate PRAMS surveys, one for New York City and one for the rest of New York State. In 2006, the New York City PRAMS found that 10.5% of women reported drinking alcohol during pregnancy, higher than the rate of 7.6% for the rest of the state. 2007 data indicated that 9.6% of New York City women and 7.2% of women interviewed from the rest of New York State used alcohol during the last 3 months of pregnancy.

Actual use may be higher. Past studies have shown that drinking during pregnancy tends to be under-reported. Also, while most women reduce or stop drinking once they know they are pregnant, pre-pregnant levels of alcohol use may continue in the earliest stages of pregnancy until the woman realizes or is told she is pregnant. *It is important to keep in mind that there is no safe level of alcohol consumption for pregnant women.* Because alcohol easily passes through the placenta to damage fetal tissue, medical

professionals no longer suggest that pregnant women can safely drink a glass of red wine or any other alcoholic drink.

What can Head Start/Early Head Start do to prevent FASD/FAS?

Early Head Start is the perfect place to work with pregnant women to reduce, and preferably *eliminate*, use of alcohol during pregnancy. Head Start programs also enroll a number of young families who may experience a subsequent pregnancy. For them, program staff can help prevent the devastating effects of alcohol-related childhood disorders in their subsequent children.

There are three main focal points for prevention:

Primary Prevention – Preventing FASD/FAS by eliminating alcohol use during pregnancy. Women need to abstain from alcohol when planning for pregnancy, as well as during all pregnancies. For that reason, it is important that every pregnant woman be screened for alcohol use and that every pregnant woman and every woman considering pregnancy receive education about the FASD. Several important messages for women to hear are these:

- Alcohol consumed during pregnancy increases the risk of alcohol-related birth defects, including growth deficiencies, facial abnormalities, central nervous system impairment, behavioral disorders, and impaired intellectual development.
- Defects caused by alcohol consumption during pregnancy have been found in virtually all parts of the body, including the brain, the eyes, the ears, the face, the heart, the kidneys, and bones.
- No amount of alcohol consumption can be considered safe during pregnancy.
- Alcohol can damage a fetus at any stage of pregnancy.
- Damage can occur even before a woman knows that she is pregnant.
- The learning and behavioral problems resulting from prenatal exposure to alcohol are lifelong.
- Alcohol-related birth defects are completely preventable.

Discussing alcohol use with mothers whose children have learning problems may be difficult and uncomfortable. Many programs opt to take a blanket approach by providing information to all parents so that everyone gets the message that using alcohol when planning a pregnancy or pregnant is not a good idea. This ensures that no one parent or family feels singled out.

On the other hand, most staff, at some time during their relationship with the family, will ask questions that are designed to elicit whether alcohol use is a problem in the family. When this question is asked, the staff person can make the asking of the question a “teachable moment” by explaining why the question is asked and why alcohol consumption is particularly troublesome for women planning pregnancy or pregnant.

Secondary Prevention – Finding children with FASD/FAS early. If infants and children showing the effects of prenatal alcohol exposure are identified early, this will result in more effective assistance being given to the child and may help prevent secondary problems. Early and appropriate intervention services can enable the child’s brain to build new connections that bypass the damaged parts of the brain. This must begin early because as the brain ages it loses the ability to compensate in this way. Therefore, it is very important to find FASD children early.

The first discussions with the family should focus on the desire to better understand and help the child. It is important not to imply blame.

Most children with FASD show no visual signs of alcohol exposure, however, there may be behavioral signs. Staff should consider an evaluation for FASD if “red flag” behaviors are observed:

- The child has been excluded from another preschool or nursery school programs for behavioral issues.
- The child requires “hands on” or visual learning, rather than auditory.
- The child is easily fatigued and overwhelmed by external stimulation.
- The child has problems applying what has been learned.
- The child is a concrete thinker and does not understand, for example, similes, metaphors or jokes.
- The child has been diagnosed with a mental health disorder during the preschool-aged period, such as ADHD, oppositional defiance or bi-polar disorder.
- The child responds to immediate feedback rather than distant consequences such as point or reward systems.
- The child has received multiple diagnoses and has a history of failed interventions, which may include medication and treatment.

What should a program staff do if they suspect an enrolled child has signs of FASD? As child-serving organizations, Head Start and Early Head Start programs recognize the importance of the first years of a child’s life. In the first three years, particularly, children grow very quickly and have so much to learn. Clearly, getting help early can make a major difference! If program staff suspect that a child is not performing at the same level as his or her peers, the parents may have also noticed the delays. Parents can be advised to talk to their health care provider or to call (if the child is under age three) the local Early Intervention Program (EIP) or the local school district (for children over age three). The New York State Growing Up Healthy Hotline (1-800-522-5006) is open twenty-four hours-a-day and seven days-a-week and can help direct parents. Parents in New York City can call 1-800-577-2229.

Here are some other hints that can be given to parents:

- When calling their pediatrician or health care provider to schedule a visit, they should tell the receptionist that there are concerns about the child’s development. HS/EHS staff can talk with the parent about how to make a phone call to their provider to get the child checked and can practice with the parent what to say about their concerns.
- If the child is under age three, the parents may elect to call Early Intervention directly. The Early Intervention Program is located within their local Department of Health. They can request that EI screen the child at Head Start or at home.
- Once the child has turned three, he/she is eligible for care from the local school district. In that case, parents will be asked to request a formal evaluation to get started.

Reaching the diagnosis of FASD can be devastating for a family, especially for the mother. Staff should remain sensitive to the mother’s feelings and not contribute to the guilt she may carry. One reason often given for under-diagnosis of FASD is the stigma attached to this disability for the mother and for the child. It might be helpful to staff to remember that even if a mother stopped drinking as soon as she learned she was pregnant, damage may have occurred before that time. Initial conversations should occur one-on-one, so that the mother does not feel confronted or overwhelmed by a committee.

Reaching a diagnosis can often be very helpful to the family. It can reduce the frustration that occurs when the parents or caretakers don’t have a good understanding of the child’s behavior. The diagnosis can bring

them hope and understanding. They can then become more active partners in their child's education and development, which can increase the likelihood of positive outcomes. If there are siblings, these other children may benefit from the family's new understanding of the effect of alcohol.

Tertiary Prevention – Ensuring children with FASD/FAS have the needed services. The appropriate diagnosis of FASD marks the start of the process of developing appropriate, individually tailored interventions. Knowledge and understanding of FASD helps make sense of the challenges facing students with the disability. Once a diagnosis is reached, appropriate interventions can increase the child's chances of academic and social success. Children with FASD can learn, but they will require a different approach.

According to researcher Ann Streissguth, there are five factors that are universally protective for children with FASD:

- Living in a stable and nurturing home;
- Not having frequent changes of household;
- Not being a victim of violence;
- Receiving developmental disability services; and
- Having been diagnosed before age six.

These are all protective factors that Head Start/Early Head Start programs can help support.

There are several effective techniques that classroom staff can employ to improve the child's learning experience and reduce troublesome secondary behaviors. These interventions must be individualized, based on the severity and types of difficulties the child presents. Successful strategies can be carried over to the home setting, which can help reduce family stress.

What kinds of resources are available in NYS for Head Start/Early Head Start Programs?

A guide entitled "Take Another Look," can be found on the website maintained by the NYS Council on Children and Families. Written for school psychologists and counselors, it is also helpful for programs serving young children. The guide contains some useful classroom strategies. The address for the guide is: <http://www.ccf.state.ny.us/Initiatives/FASDRelate/FASDGuide.pdf>

That guide suggests the following resources:

FASD Toolbox for Teachers <http://www.dotolearn.com/disabilities/FASDtoolbox/index.htm>

Making a Difference – Working with students who have Fetal Alcohol Spectrum Disorders. 2006. Yukon Department of Education. http://www.education.gov.yk.ca/pdf/fasd_manual_2007.pdf

Reach to Teach: Educating Elementary and Middle-School Children with Fetal Alcohol Spectrum Disorders. <http://www.fasdcenter.samhsa.gov/publications/reachToTeach.cfm> (Ideas may need to be adapted for a younger age group.)

Fetal Alcohol Spectrum Disorders Center for Excellence. <http://www.fasdcenter.samhsa.gov/>

National Organization of Fetal Alcohol Syndrome. <http://www.nofas.org/>. NOFAS has developed a K-12 FASD Education and Prevention Curriculum: <http://www.nofas.org/about/K-12Curriculum.htm>

Fetal Alcohol Disorders Society. <http://www.faslink.org/>

The Centers for Disease Control and Prevention have Fact Sheets available in English and Spanish. http://www.cdc.gov/ncbddd/actearly/pdf/parents_pdfs/FASD_english_spanish.pdf. They also have information for pregnant women <http://www.cdc.gov/ncbddd/fas/default.htm>.

The Early Childhood Learning Knowledge Center:

<http://eclkc.ohs.acf.hhs.gov/hslc/ecdh/Health/Health%20and%20Wellness/Health%20and%20Wellness%20Families/Getting%20an%20Early%20Start%20on%20Fetal%20Alcohol%20Spectrum%20Disorders.htm>

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