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Fact Sheet

FETAL ALCOHOL SPECTRUM DISORDERS

Information Compiled by Tanni Anthony

Editor's Note: During my time in another state, I worked with many children who had a diagnosis of Fetal Alcohol Syndrome or Fetal Alcohol Effect. As a result of statewide attention to this diagnosis, I received specific training, at that time, on the unique educational needs of these learners. I gathered ophthalmological information specific to the high incidence of visual problems (refractive error, strabismus, and ptosis) and visual impairment (often ONH) specific to this disorder as a lot of the literature, at that time, did not detail these concerns. I was surprised when I moved to Colorado so many years ago that there was not state-level training on FAS/FAE. The purpose of this article is to increase awareness of Fetal Alcohol Spectrum Disorders, so that we can better understand the mental health and learning challenges, and provide appropriate accommodations and learning strategies. Not every child with the physical and/or behavioral indictors listed in this article will be a child who has a fetal alcohol spectrum disorder. It is a diagnosis that must be made by the appropriate professionals. One may ask why we need to have this diagnosis. My experience has been that such a diagnosis be treated with care to avoid any judgment of a family and/or as a label that may create a stigma for the child. When we understand the physiology of the diagnosis and its implications, it can lead to an understanding of why a child may struggle in certain areas and what strategies may be helpful to address sensory concerns, unique memory challenges, and other associated problems. Information taken primarily from: <u>http://www.nofas.org/about/</u> and http://fascenter.samhsa.gov

What is FASD? Fetal Alcohol Spectrum Disorders (FASD) is a descriptive term and not a diagnostic term. The term "FASD" indicates that there are a variety of effects of prenatal alcohol exposure. FASD is not a diagnosis. Although the various fetal alcohol spectrum disorders are permanent conditions, specific symptoms may be treatable or manageable. Thus, the definition notes possible lifelong implications, depending on the specific nature of the

disorder and the individual affected. Nationally, Fetal Alcohol Spectrum Disorders (FASD) affects 1 in 100 live births or as many as 40,000 infants each year.

What are Fetal Alcohol Spectrum Disorders? FASD is an umbrella term describing the range of effects that can occur in an individual whose mother drank alcohol during pregnancy. These effects may include physical, behavioral, mental, and/or learning disabilities with possible lifelong implications. FASD refers to several conditions.

The most well-known diagnosis is **fetal alcohol syndrome (FAS)**. Signs of FAS include distinct facial features (smooth philtrum [groove between nose and upper lip], thin upper lip, small eye openings), growth deficiencies, and central nervous system (CNS) defects. The Institute of Medicine has identified three other diagnoses:

- Partial FAS: facial anomalies and other symptoms without all the signs of FAS
- **Alcohol-Related Neurodevelopmental Disorder (ARND):** CNS defects and behavior problems or cognitive deficits (e.g., speech delays, hyperactivity)
- Alcohol-Related Birth Defects (ARBD): damage to organs, bones, or muscles

Another term that has been used over the last 30 years is Fetal Alcohol Effects (FAE).

How can I recognize FASD? Only trained professionals can make a diagnosis. Teachers or relatives may identify a problem, but they cannot diagnose an FASD. Signs that may indicate the need for assessment include:

- Sleeping, breathing, or feeding problems
- Small head or facial or dental anomalies
- Heart defects or other organ dysfunction
- Deformities of joints, limbs, and fingers
- Slow physical growth before or after birth
- Vision problems (ptosis, syndrome of optic nerve hypoplasia, refractive error, strabismus)
- Hearing problems
- Intellectual disability or delayed development
- Behavior problems

Why is Diagnosis Important? Because most people with FASD have no visible signs of alcohol exposure, their problems may be wrongly blamed on poor parenting or on other disorders. Early diagnosis and intervention contribute to positive long-term outcomes.

Accurate diagnosis can:

- Help the person receive appropriate services.
- Aid communication among clinicians, caregivers, educators, and families
- Provide better self-awareness and understanding by family members.

What are Characteristics of Individuals with FASD? The following was adapted from the FASD Center for Excellence. The original information is on their website at http://fascenter.samhsa.gov

Overall difficulties for persons with an FASD

- Taking in information / Storing information / Recalling information when necessary *
- Using information appropriately in a specific situation

(Editor's Note: One concern may be a lack of understanding that the child is not willfully misbehaving in a task where there has been prior success, as the child may literally have recall problems that result in inconsistent task mastery).

Common Difficulties for Persons with an FASD

- **Sensory Integration Issues:** The child may be overly sensitive to sensory input (e.g., upset by bright lights or loud noises, annoyed by tags in shirts or seams in socks, bothered by certain textures of food, and/or have problems sensing where their body is in space (clumsy).
- Memory Problems (e.g., multiplication recall, time sequencing).
- Information Processing Problems: The child may: not complete tasks or chores and appear to be oppositional, have trouble determining what to do in a given situation, not ask questions because he or she wants to fit in, say the understand when they do not, have verbal expressive skills that often exceed their level of understanding, misinterpret others' words, actions, or body movements, have trouble following multiple directions.
- Self-Esteem and Personal Issues: The child may: function unevenly in school, work, and development, experience multiple loses, be seen as lazy, uncooperative, and unmotivated, and/or have hygiene problems.
- *Multiple Issues:* The child may: not be able to entertain him/herself, have trouble changing task, and/or not accurately pick up social cues

Educational Implications: Not all students with on the Fetal Alcohol Syndrome Spectrum will have vision and/or hearing loss issues. If they do, however, it will be important to have teachers specializing in sensory disability(ies) involved in the child's assessments and programming. The document noted in the reference section of this article will provide general educational strategies.

Resources

- National Organization on Fetal Alcohol Syndrome: The National Organization on Fetal Alcohol Syndrome (NOFAS) is a resource to the Fetal Alcohol Spectrum Disorders (FASD) community. Founded in 1990, NOFAS is an international non-profit organization committed solely to FASD primary prevention, advocacy and support. Their website is: <u>http://www.nofas.org/</u>

- Web Resources for Teaching Children with FAS or FASD:

http://www.nofas.org/educator/links.aspx

- Fetal Alcohol Spectrum Disorder: Education Strategies This manual can be downloaded from http://www.usd.edu/medical-school/center-for-disabilities/upload/fasdeducationalstrategies.pdf

For more information about the Colorado Services for Children and Youth with Combined Vision and Hearing Loss Project contact:

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Fact Sheets from the Colorado Services to Children and Youth with Combined Vision and Hearing Loss Project are to be used by both families and professionals serving individuals with vision and hearing loss. The information applies to children, birth through 21 years of age. The purpose of the Fact Sheet is to give general information on a specific topic. More specific information for an individual student can be provided through personalized technical assistance available from the project. For more information call (303) 866-6681 or (303) 866-6605. Updated: 3/11