Fetal Alcohol Spectrum Disorders (FASD)

Fetal Alcohol Spectrum Disorders (FASD) is an umbrella term describing the range of effects that can occur in an individual prenatally exposed to alcohol. These effects may include physical, mental, behavioral, and/or learning disabilities with lifelong implications. Often, a person with FASD has a combination of these conditions. These conditions can affect each person in different ways and can range from mild to severe (FASD United, 2022).

Up to 1 in 20 US school children may have FASDs.
(May, P.A., et al, JAMA, 2018)

Fetal alcohol spectrum disorders or FASD is a descriptive term and not a diagnostic term. FASD is a spectrum disorder, meaning difficulties occur on a continuum and can vary in severity. Fetal Alcohol Syndrome (FAS) represents the severe end of the FASD spectrum. The term spectrum disorder indicates that there is a variety, or a continuum of effects caused by prenatal alcohol exposure.

Fetal alcohol spectrum disorders are permanent conditions, with lifelong implications. There is no cure for FASD, but research shows that early intervention services can improve a child's development and outcomes. The needs of an individual with FASD are likely to change over time. No one treatment is right for every child. Good treatment plans include close monitoring, follow-ups, and changes as needed along the way. With the right supports, skills can be acquired, and strategies learned, to manage the impact of symptoms (CDC, 2021).

Protective factors can help reduce the effects of FASD and help people with these conditions reach their full potential (Streissguth, A.P., et al. 2004).
These include:

- Diagnosis before 6 years of age
- Loving, nurturing, and stable home environment
- Absence of violence
- Involvement in special education and social services

Key Facts

FASD may affect at least one child in every classroom. In a recent research study in the United States, the most conservative prevalence estimate of FASD was found to be as many as 1 in 20 first-grade students.

Protective factors can help individuals reach their full potential. Early diagnosis, before age 6, along with early intervention services help reduce the effects of FASD.

FASDs last a lifetime. There is no cure for FASD, but research shows that early intervention treatment services can improve a child's development.

There is no safe amount of alcohol to consume during pregnancy. A developing embryo cannot process any amount of alcohol since the liver is not fully formed. The alcohol is absorbed at the same rate, resulting in the same blood alcohol content as the mother.

(Source: www.fasdunited.org)

FASD is caused by prenatal exposure to alcohol. According to the surgeon general, there is NO safe amount or type of alcohol to consume during pregnancy or when planning to become pregnant. It makes no difference if the alcohol is wine, beer, or liquor. To prevent FASD, a woman should not drink alcohol while she is pregnant, or when planning to become pregnant. This is because a woman can get pregnant and not know for several weeks. Almost half of all pregnancies in the United States are unplanned (CDC, 2021).

Characteristics often seen . . .

Newborns or Infants

- Difficulty Sleeping - Unpredictable Sleep/Wake Cycle
- Electroencephalogram (EEG) Abnormalities
- Small in size or Failure to Thrive
- Feeding Difficulties including Weak Sucking Reflex
- Heart Defects, Kidney Problems, or Skeletal Anomalies
- Increased Sensitivity to Light and Sound - Easily Overstimulated
- Poor Fine and/or Gross Motor Control
- Seizures, Tremors, or Jitteriness
- Susceptibility to Infections

Preschool Aged Children

- Emotional Over-Reaction and Tantrums
- Hyperactivity
- Lack of Impulse Control
- Cognitive Impairment
- Poor eye-hand and physical coordination
- Poor Judgment (often seen as difficulty recognizing danger including not fearing strangers; children of this age may seem overly friendly)
- Speech & Language Delays (may include poor articulation, slow vocabulary or grammar development, or perseverative speech)

Elementary School Aged Children

- Attention Deficits or Hyperactivity
- Language Difficulties (delayed development or difficulties with expressive, receptive, and social pragmatic language)
- Learning Disabilities or Cognitive Disabilities
- Memory Difficulties
- Poor Impulse Control (often seen as lying, stealing or defiant acts)
- Small in size
- Social Difficulties (may include overly friendly, immaturity, easily influenced)

Adolescents and Young Adults

- Difficulties with Memory and Abstract Reasoning
- Difficulty Anticipating Consequences (which may lead to poor decision making)
- Confabulation is a type of memory error in which gaps in a person's memory are unconsciously filled with fabricated, misinterpreted, or distorted information
- Low Academic Achievement
- Low Self-Esteem
- Poor Executive Function (e.g., judgment, planning, organization)
- Unevenness in skills and functioning levels across environments, content, or over time (e.g., responds appropriately on one day but not the next)

. . . with FASD

Special Consideration – Confabulation:

Confabulation is a type of memory error in which gaps in a person's memory are unconsciously filled with fabricated, misinterpreted, or distorted information. Many people wrongly assume that if people with FASD "know" right from wrong then they can and should be able to "do" the right thing in situations that require it. However, "knowing" and "doing" require different sets of skills and subskills. "Doing is more complex and typically performed under more demanding circumstances that "knowing" and therefore will be more significantly impacted in people with FASD (*They Know Better!* www.jumpstartpsychology.com).

Here are some facts about confabulation:

- A person with FASD has **NO AWARENESS** that they aren't telling the truth.
- The confabulation is not a lie. The imaginations are real memories.
- A person with FASD may subconsciously create a story to fill in answers they can't think of.
- **KNOWING** better is a completely different brain process that **DOING** better.

If confabulation goes unrecognized, the implications can be very detrimental.

What can be done?

Most students with Fetal Alcohol Spectrum Disorders (FASD) are unidentified, go misdiagnosed, or have several diagnoses designated over the years. Although there may be similarities, many students may be misidentified as having Autism Spectrum Disorder (ASD) or Attention Deficit Hyperactivity Disorder (ADHD) or a myriad of other conditions.

Each student with FASD is different and has different needs. Therefore, to provide a Free Appropriate Public Education (FAPE), educators should identify needs through **neuroeducational evaluation** and match the programming, supports and services to meet those needs. Whether the appropriate supports are provided via the general education classroom or across different center-based classrooms (e.g., Autism, significant support needs programs). For more information on neuroeducational evaluation and a free user-friendly framework for educators, visit: http://www.cde.state.co.us/cdesped/sd-tbi_buildingblocks

Due to the nature of the brain damage incurred from prenatal exposure to alcohol, students may experience significant difficulties which are not reflected on formal assessments. When considering special education services, it is imperative to identify specific student needs and determine whether a student meets the criteria for specially designed instruction within a category. Since there isn't a specific special education category for FASD, the school team may consider the category that best addresses the needs of the student and ensure details are provided in the body of the Individualized Education Program (IEP). Educators must be supportive and non-judgmental and partner with the student and parent to address needs.

Since FASD is a health condition and acknowledged as a health condition by the U.S. Department of Education (comments to IDEA Regulations, 71 Fed. Reg. 46550, August 14, 2006), CDE recommends the consideration of the special education category of Other Health Impairment (OHI).

Planning for Success

Educators play a critical role in ensuring children with FASD reach their maximum potential.

> "Change the environment, not the child" – *Let's Talk FASD-Parent Driven Strategies in Caring for Children with FASD*

✓ Partner: Educators and parents must work together and learn from each other to develop consistent support for students with FASD.
- Maintain a positive, non-judgmental approach
- Discuss physical, behavioral, social, and learning strengths as well as concerns.
- Encourage and be a conduit for early intervention services which can help children from birth to 3 years of age (36 months) learn important skills. Services include therapy to help the child talk, walk, and interact with others.

✓ Shift attitudes and improve understanding: FASD is a health condition with cognitive and behavioral symptoms. Children with FASD may test well on standardized tests and may have IQ scores in the average range. This and uneven manifestation of skills may lead parents and educators to believe the student could do better if only he or she tried harder. Recognizing that a child is trying hard, but is nevertheless struggling, goes a long way toward facilitating learning. Think "this child can't" do what is being asked versus "this child won't", is crucial. For more information on Can't vs Won't Behavior, please visit: Understanding the Brain – Online Learning Series for **free training opportunities** at: www.cde.state.co.us/cdesped/fasd_pd

Individuals with FASD can benefit from:
- Consistent routines
- Limited stimulation and explicit teaching of strategies for emotional regulation
- Concrete language and examples
- Realistic expectations
- Assistance with transitions
- Supportive environments and supervision.

Successful strategies for educating children with FASD include:
- Using concrete, hands-on learning methods
- Establishing structured routines
- Keeping instructions short and simple
- Providing consistent and specific directions
- Repeating tasks again and again
- Allowing extra time
- Offering active supervision and timely feedback on learning & behavior.

> "Eliminate the word "don't" from your vocabulary, simply state what you would like the child to do" – from a parent of a child with FASD

What should I do if I suspect my child has a FASD?

- ✓ Tell your child's doctor of your concerns. Share with their doctor any issues about your child's development or behavior, and any information you have about possible prenatal alcohol exposure.
- ✓ Ask for a referral to a specialist such as a developmental pediatrician, child psychologist, or clinical geneticist, or contact Illuminate Colorado (www.illuminatecolorado.org/fasd) or FASD United (www.fasdunited.org) for a referral.
- ✓ If your child is younger than 3 years old, you can contact your state's early intervention program to find out if your child is eligible for a free evaluation and services. If your child is 4 years old or older, contact your local public school to request that they be evaluated for special education services.
- ✓ Explore and share the following resources with educators and service providers
  - Brain Injury in Children and Youth: A Manual for Educators - www.cde.state.co.us/cdesped/tbi_manual_braininjury
  - CDE Guidance for Determining Eligibility for Special Education Students with Other Health Impairment - www.cde.state.co.us/cdesped/guidance_determiningeligibility_sped_students_ohi

Additional information and training opportunities to address the needs of students with FASD & Neuroeducational Evaluation are available at the Colorado Department of Education. Go to: www.cde.state.co.us/cdesped/FASD.asp or contact the Brain Injury/FASD Specialist, Heather Hotchkiss (hotchkiss_h@cde.state.co.us) in the Exceptional Student Services Unit.

Resources

- CDE FASD Webpage – www.cde.state.co.us/cdesped/fasd
- Brain Injury in Children and Youth: A Manual for Educators – www.cde.state.co.us/cdesped/tbi_manual_braininjury
- CDE Guidance for Determining Eligibility for Special Education Students with Other Health Impairment – www.cde.state.co.us/cdesped/guidance_determiningeligibility_sped_students_ohi
- CDC Centers for Disease Control and Prevention – www.cdc.gov/ncbddd/fasd/
- FASD United – fasdunited.org (formerly National Organization on Fetal Alcohol Syndrome)
- Illuminate Colorado – www.illuminatecolorado.org/fasd

References

- Centers for Disease Control and Prevention – www.cdc.gov/ncbddd/fasd
- Prevalence rates of FASD – May, P.A., et al, JAMA, 2018 https://pubmed.ncbi.nlm.nih.gov/29411031
- Jumpstart Psychology - Dr. Vanessa Spiller – www.jumpstartpsychology.com
- Fetal Alcohol Exposure - National Institute on Alcohol Abuse and Alcoholism – www.niaaa.nih.gov/publications/brochures-and-fact-sheets/fetal-alcohol-exposure
- Streissguth, A.P., Bookstein, F.L., Barr, H.M., Sampson, P.D., O'Malley, K., & Young, J.K. (2004). Risk factors for adverse life outcomes in fetal alcohol syndrome and fetal alcohol effects. Developmental and Behavioral Pediatrics, 5(4), 228-238.
- Streissguth A. (1997). Fetal Alcohol Syndrome: A Guide for Families and Communities. Baltimore, MD, Paul H. Brooks Publishing

This CDE guidance document is meant for clarification, is not legally binding, and is not to be confused with legal advice. This guidance reflects CDE's recommendations, but Administrative Units (AUs) may have developed their own policies or procedures that differ from those described herein. Be sure to refer to your local AU's policies and procedures through the Director of Special Education. If you are seeking legal advice, please contact your legal counsel.

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