

The Overrepresentation of Children with Fetal Alcohol Spectrum Disorders in the Child Welfare System

What is Fetal Alcohol Spectrum Disorder (FASD)?

- FASD encompasses the diverse patterns of neurodevelopment and physical differences associated with prenatal alcohol exposure (PAE).²
- Diagnoses of fetal alcohol syndrome (FAS) partial FAS (pFAS), and alcohol-related neurodevelopment disorders (ARND) all fall under the FASD umbrella.



What is Prenatal Alcohol Exposure (PAE)?

- To constitute PAE, there must be confirmed alcohol exposure reported by: the biological mother, a family member of the biological mother, a social service agency, or medical record.
- Research shows no amount of alcohol exposure during pregnancy can be considered as safe. Furthermore, there is no safe trimester for the fetus to be exposed to alcohol, and all types of alcohol have the same effects.²

Why does understanding FASD and PAE matter?



- There is great variability of the effects of PAE among individuals, as they may present physical and/or neurodevelopmental differences.
- PAE has been linked to growth deficiencies and facial dysmorphia including a smooth area between the nose and upper lip, thin upper lip, and short opening between the two eyelids.² These physical effects are most likely to occur when there is heavy drinking early in pregnancy, often before a person knows they are pregnant.
- The brain is developing throughout pregnancy. PAE can impact the brain at any time during the pregnancy. Individuals do not have to present with physical features to be diagnosed with FASD.
- Affected neurodevelopmental areas can include:²
 - Cognition: More difficulty with abstract concepts, reasoning skills, understanding time-sensitive tasks, and presenting behavior that is not consistent compared to chronological age.
 - Executive function: Difficulties with planning ahead, cognitive flexibility, multiple-step instructions, generalizing information from one situation to another, and understanding consequences.
 - Social: Struggle with cooperation, initiating conversations, making friends, responding appropriately to conflicts and self-regulation.
 - Language: Difficulties with language learning, fluency, and comprehension.
 - Learning and memory: short-and long-term memory difficulties. Have more difficulty with learning academic skills, especially math.

FASD In The Child Welfare System

- In the general US population, conservative estimates say 1.1-5% of school-aged children have FASD.⁵ In the child welfare system, experts estimate that the rate of FASD is 17 to 19 times higher than in the general population.⁴
- FASD United (formerly National Organization on Fetal Alcohol Syndrome [NOFAS], 2012) highlights some key points from the foster care system:
 - It is estimated that about 80% of children with FASD in the US are raised in out-of-home care.
 - Children with FASD have a more difficult time in the foster care system because it is hard for them to adjust to a new environment.
 - Children prenatally exposed to alcohol are more likely to stay in foster care longer because of behavioral and social problems.
 - The foster care system has the potential to help children with FASD by providing training to staff and foster families to recognize the symptoms and seek diagnoses.

How Can We Help?

- **Help reduce stigma of FASD.** Because the effects of PAE are not well known and physical features may not be present, there is public stigma and stereotyping of individuals with FASD.⁷
- **Reframe expectations and interpretation of behaviors.** Difficulties with learning, memory, behavior regulation, and information processing are often mistaken as being stubborn, non-compliant, unorganized, lazy, or unmotivated.⁶
- **Be strengths-based.** FASD research has been largely deficit focused. This has contributed to stigma to some degree and left a gap in our understanding of the strengths and capabilities of people with FASD.
 - People with FASD have many strengths, being described as loving, affectionate, helpful, generous, funny, happy, curious, and eager, and have talents in athleticism, creativity, and intelligence.³

For more information, please visit:

http://www.sas.rochester.edu/psy/people/faculty/petrenko_christie/index.html

1. FASD United (2012). FASD: what the foster care system should know [Fact sheet]. <http://www.nofas.org/wp-content/uploads/2012/05/fostercare.pdf>
2. Hoyme, H.E., Kalberg W.O., Elliott A.J., Blankenship, J., Buckley, D., Marais, A. S., ... & May, P. A. (2016). Updated clinical guidelines for diagnosing fetal alcohol spectrum disorders. *Pediatrics*, 138(2):e20154256.
3. Kautz-Turnbull, C., Adams, T., & Petrenko, C. L. (in press). The strengths and positive influences of children with Fetal Alcohol Spectrum Disorders. Manuscript submitted for publication.
4. Lange, S., Shield, K., Rehm, J., & Popova, S. (2013). Prevalence of fetal alcohol spectrum disorders in child care settings: a meta-analysis. *Pediatrics*, 132(4), e980-e995.
5. May, P. A., Chambers, C. D., Kalberg, W. O., Zellner, J., Feldman, H., Buckley, D., ... & Hoyme, H. E. (2018). Prevalence of fetal alcohol spectrum disorders in 4 US communities. *JAMA*, 319(5), 474-482.
6. Olson, H.C., Oti, R., Gelo, J., & Beck, S. (2009). "Family matters:" Fetal alcohol spectrum disorders and the family. *Developmental Disabilities Research Reviews*, 15(3), 235-24.
7. Roozen, S., Stutterheim, S.E., Bos, A.E.R., Kok, G., Curfs, L.M.G. (2020) Understanding the social stigma of fetal alcohol spectrum disorders: From theory to interventions. *Foundations of Science*, 1-19.