



"FASD has sat in the dark for far too long. If nobody points big lights at the problem, others will never know."

By Emily Speybroeck and Ruth du Plessis

(Knispel, 2024)

Defining Fetal Alcohol Spectrum Disorders (FASD)

Get familiar with FASD by taking a look at our factsheet: ["The Overrepresentation of Children with Fetal Alcohol Spectrum Disorders in the Child Welfare System"](#).

Prevalence Statistics

Studies have documented about 2-5% of the United States population has FASD. That is as many as 1 in 20 children. As many as 80-90% of people go undiagnosed or misdiagnosed (Promoting Resilience Podcast, 2023). Experts estimate that the rate of FASD is 17 to 19 times higher in the child welfare system than in the general population (Translating Science to Practice Factsheet).

Value of a Diagnosis

A diagnosis adds value to people's lives through more understanding and support from their care team (Promoting Resilience Podcast, 2023). Without adequate understanding and support, people with FASD are at higher risk for academic challenges, mental health conditions, housing and independent living issues, and trouble with the law. FASD has a considerable public health impact representing substantial societal and economic costs (Rockhold et al., 2024). Research shows that people with FASD who receive appropriate developmental disabilities services have better outcomes (Knispel, 2024).

Importance of Awareness

Despite the great need for support and care for those with FASD, most families cannot access FASD-informed services due to significant barriers like economic and location restraints, as well as pervasive stigma. In a podcast by TRANSFORM, Dr. Petrenko speaks with host, Dr. Cerulli, about the need to advocate for those with FASD: "We could make lives better for people if we had broad, population-wide awareness, and that there were representations of people with FASD that offered hope and show what is possible when folks get what they need" (Promoting Resilience Podcast, 2023).

Christie Petrenko's Work

Under the leadership of Dr. Petrenko, the FASD Program at Mt. Hope Family Center is leading the way in increasing access to care for people with FASD and their families. The FASD Program integrates rigorous research, direct service provision for children and families, training and dissemination in the community, policy, and stigma reduction. In coordination with partners in the Division of Developmental & Behavioral Pediatrics, the FASD Team serves over 600 families each year. To learn more about Dr. Petrenko's work, listen to our podcast titled: ["Empowering People Living with Fetal Alcohol Spectrum Disorder."](#)

"Our jobs would be so much easier if we had a more knowledgeable workforce who were open to learning more about FASD."
(Promoting Resilience Podcast, 2023)

- Christie Petrenko

Empowering people living with fetal alcohol spectrum disorder. Promoting Resilience. (n.d.).

<https://thetransformcenter.libsyn.com/empowering-people-living-with-fetal-alcohol-spectrum-disorder>

News Center, & Knispel, S. (2024, November 4). Thriving while living with fetal alcohol spectrum disorders (FASD). News Center. <https://www.rochester.edu/newscenter/fetal-alcohol-syndrome-fasd-survivors-thriving-499312/>

Resources For Families and Professionals

Centers for Disease Control and Prevention. (n.d.). Fetal Alcohol Spectrum Disorders (fasds). Centers for Disease Control and Prevention. <https://www.cdc.gov/fasd/index.html>

Fasdunited.org. (n.d.). <https://fasdunited.org/fasd/> – National Organization on FASD, Family Navigator Program

Home. FASD Collaborative. (n.d.). <https://www.fasdcollaborative.com/> – Webinars, Special Interest Groups, and Support Groups

Language & stigma guide | FASD united. (n.d.). <https://fasdmap.org/wp-content/uploads/2024/12/FASD-United-Language-and-Stigma-Guide.pdf>

Olson, H.C., Pruner, M., Byington, N., Jirikowic, T. (2023) FASD-Informed care and the future of intervention. In: Abdul-Raham, O.A., Petrenko, C.L.M. (eds.) Fetal Alcohol Spectrum Disorders: A Multidisciplinary Perspective Springer, Cham. https://doi.org/10.1007/978-3-031-32386-7_13

Overarching Issues

Rockhold, M.N., Gimbel, B.A., Richardson, A.A., Kautz-Turnbull, C., Speybroeck, E.L., de Water, E., Myers, J., Hargrove, E., May, M., Abdi, S.S., & Petrenko, C.L.M. (2024, February 16). Racial and ethnic disparities in psychological care for Individuals with FASD: A Dis/Ability studies and critical race theory perspective toward improving prevention, assessment/diagnosis, and intervention. *Frontiers*. <https://doi.org/10.3389/fpubh.2024.1355802>

Roozen, S., Stutterheim, S.E., Bos, A.E.R. et al. Understanding the social stigma of Fetal Alcohol Spectrum Disorders: From theory to interventions. *Found Sci* 27, 753-771 (2022). <https://doi.org/10.1007/s10699-020-09676-y>

FASD Experiences and Outcomes

Mattson, S.N., Bernes, G.A., Doyle, L.R. Fetal alcohol spectrum disorders: A review of the neurobehavioral deficits associated with prenatal alcohol exposure. *Alcohol Clin Exp Res*. 2019 Jun;43(6):1046-1062. <https://doi.org/10.1111/acer.14040>

Rockhold MN, Handley ED, Petrenko CLM. Understanding the intersection of prenatal alcohol exposure and postnatal adversity: A systematic review from a developmental psychopathology lens. *Alcohol Clin Exp Res* (Hoboken). 2025;49(1):25-42. doi:10.1111/acer.15483

Streissguth AP, Bookstein FL, Barr HM, Sampson PD, O'Malley K, Young JK. Risk factors for adverse life outcomes in fetal alcohol syndrome and fetal alcohol effects. *J Dev Behav Pediatr*. 2004;25(4):228-238. doi:10.1097/00004703-200408000-00002

Specialized Settings

Brown, J., Jonason, A., Asp, E., McGinn, V., Carter, M. N., Spiller, V., & Jozan, A. Fetal alcohol spectrum disorder and confabulation in psycholegal settings: A beginner's guide for criminal justice, forensic mental health, and legal interviewers. *Behav Sci Law*. 2022; 40(1), 46–86. <https://doi.org/10.1002/bsl.2540>

Brown, N.N., Burd, L., Grant, T., Edwards, W., Adler, R., Streissguth, A. Prenatal alcohol exposure: An assessment strategy for the legal context. *Int J Law Psychiatry*. 2015 Sep-Dec;42-43:144-8. <https://doi.org/10.1016/j.ijlp.2015.08.019>

Kautz-Turnbull C, Speybroeck E, Rockhold M, Petrenko CLM. Teachers' needs for an FASD-informed resource: a qualitative interview needs assessment based on the ADAPT-ITT framework. *Psychol Sch*. 2024;61(3):1255-1279. doi:10.1002/pits.23110

Lange S, Shield K, Rehm J, Popova S. Prevalence of fetal alcohol spectrum disorders in child care settings: a meta-analysis. *Pediatrics*. 2013;132(4):e980-e995. doi:10.1542/peds.2013-0066