



Families Affected by Fetal Alcohol Spectrum Disorder
FAFASD.ORG

Dear SAMSHA Advisory Council,

My 13 year old son, Jamie, has pFAS, a fetal alcohol spectrum disorder. We took him to 27 experts and clinicians before he was diagnosed, and each therapist, doctor, or other “expert” who we took him to dismissed the information I provided about his alcohol exposure in utero. This led to massive frustration for us as the treatments these experts provided were ineffective, leading us to misunderstand his behavioral differences. It wasn’t until he was diagnosed with and FASD and we understood his brain differences that we were able to parent him effectively.

Jamie, and the millions of other people living in this country with FASDs, deserve professionals who understand FASD, who can diagnose it, who can help families, and support them effectively. By defunding the FASD Center for Excellence, the only federally funded organization that supports people suffering from FASDs, the powers that be are removing what very little support people and families impacted by FASD have had.

It is vital to families, children, and individuals living with FASDs, that the Center be maintained and refunded by SAMHSA and the US Congress. SAMHSA’s FASD Center for Excellence focuses on preventing FASDs among women of childbearing age and improving the quality of life for individuals and families affected by these disorders. It is the only federal agency that focuses on treatment for affected individuals and families.

Experts estimate that FASDs, a group of conditions that can result from prenatal alcohol exposure, affect 2-5% of the US population or 24-48 per 1,000 births.¹ This is more than the rate of Autism, Down Syndrome, Cerebral Palsy, and Spina Bifida *combined*.² Vulnerable populations are even more affected, as a recent study indicated 28.5% of foster and adoptive children may be living with FASDs.³ Children and adults who live with FASDs face a range of cognitive, physical, and neurobehavioral issues that last a lifetime. Ineffective treatment and support results in an overwhelming number of people with FASDs unnecessarily suffering from additional mental health disorders, school failure, employment failure, institutionalization, and trouble with the law.⁴

Ironically, the defunding of the Center comes at a time when mental health experts are acknowledging the need for identification and treatment of people with FASDs and prenatal alcohol exposure. The most recent addition of the leading manual used by mental health experts, the Diagnostic and Statistical Manual of Mental Disorders, 5th edition (DSM 5), identifies *Neurobehavioral Disorder Associated with Prenatal Alcohol Exposure (ND-PAE)* as one of only eight conditions for further study. The inclusion of this disorder represents a consensus in the mental health community that prenatal alcohol exposure significantly impacts the mental health of people in today’s society and that further attention by the mental health community needs to be given to this disorder.

In the proposed 2017 budget, the only SAMHSA program with FASD in its mission is one that targets low income women for prevention efforts.⁶ Focusing only on prevention efforts ignores the millions of children and adults living with fetal alcohol spectrum disorders. Until the often quoted goal of making FASDs “100% preventable” is achieved, the people and families impacted by FASDs need federal support for education, assistance, and advocacy.

Children, families, and individuals living with FASDs need federal support for appropriate and effective treatment. The FASD Center for Excellence must remain open and funded as a vital part of SAMHSA’s mission.

Sincerely,

Adrienne Bashista
Training Director and Founder

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¹May, P. A., Baete, A., Russo, J., Elliott, A. J., Blankenship, J., Kalberg, W. O., Buckley, D., Brooks, M., Hasken, J., Abdul-Rahman, O., Adam, M. P., Robinson, L. K., Manning, M., Hoyme, E. (2014). Prevalence and characteristics of Fetal Alcohol Spectrum Disorders. *Pediatrics*, 134(5), 854-866.

²Minnesota Organization on Fetal Alcohol Syndrome. (2015) Fetal Alcohol Spectrum Disorders Prevalence. Available at <http://www.mofas.org/wp-content/uploads/2015/09/FASD-Prevalence2015.pdf>

³Chasnoff, I. J., Wells, A. M., & King, L. (2015). Misdiagnosis and missed diagnoses in foster and adoptive children with prenatal alcohol exposure. *Pediatrics*, 135(2), 264-270.

⁴Streissguth, A. P. & O'Malley, K. (2000). Neuropsychiatric implications and long-term consequences of Fetal Alcohol Spectrum Disorders. *Seminars in Clinical Neuropsychiatry*, 5, 177-190.

⁵SAMHSA. (2017). Justification of Estimates for Appropriations Committees. Available at: <http://www.samhsa.gov/sites/default/files/samhsa-fy-2017-congressional-justification.pdf>

⁶SAMHSA. Services Grant Program for Residential Treatment for Pregnant and Postpartum Women. Available at: <http://www.samhsa.gov/grants/grant-announcements/ti-14-005>