European Society for Paediatric Research
Society for Pediatric Research
www.nature.com/pr

INSIGHTS

Check for updates

Family reflections: parents and caregivers of people with FASD: what research do we need?

Adrienne Ehlert Bashista[1] ✉

Pediatric Research (2022) 92:331–332; https://doi.org/10.1038/s41390-021-01926-4

My youngest son, Jamie, age 19, has a diagnosis of partial fetal alcohol syndrome, which is one of the six diagnoses recognized as FASD. He was diagnosed at age 9, although our family searched in earnest for answers about his behavioral and developmental differences from the time we adopted him at 15 months. Before his diagnosis at an FASD clinic, we took him to 26 different medical and behavioral health professionals for evaluation, all of whom were presented with information about his birth mother's alcoholism, his behavioral and developmental profile as evidenced by comprehensive neuropsychological reports, and his struggles in school and in our family. None of these professionals considered a diagnosis on the FASD spectrum to be relevant. While they acknowledged our difficulties, all of them dismissed my questions about the disorder except for number 27. She, a psychiatric PA who we saw for medication management, took me seriously only when I was in her office crying out of frustration, worry, and stress.

I've come to realize that the majority of the professionals to whom we took our son knew little about the disorder, which is likely why they were quick to dismiss it. They didn't know that 2–5% of the population has an FASD,[1] a prevalence greater than any other intellectual disability, nor did they know that children from foster and adoption backgrounds have a prevalence of more than ten times greater than the general population.[2] They didn't know the neurobehavioral profile of FASD, which my son clearly fit as demonstrated by comprehensive neuropsychological testing, nor did they recognize that he had facial features associated with FASDs—facial features that approximately 90% of those with FASDs do not have, by the way[3]—but which he did.

These professionals, like us, were interpreting his behavioral differences as purposeful and psychologically motivated. They, like us, didn't consider that his behavioral differences were examples of "can't" do it, vs. "won't."

So while eventually we came to understand that he met the criteria for FASD quite clearly, we weren't taking him to people who had the expertise we needed. We saw pediatricians, family practice physicians, child psychologists, child psychiatrists, family therapists, occupational therapists, a whole team of developmental pediatricians and PhDs in child development, learning specialists, school psychologists, neuropsychologists, special educators, and others—all of whom a struggling parent would think would know something about FASD, but who didn't. Before he was adopted we even had his paperwork reviewed by an international adoption specialist—paperwork that clearly stated his birth mother was an alcoholic and he was removed from the home because of this, as well as indications of global developmental delay—but we were told there was no sign of FAS based on the evidence provided.

Since his behavioral differences ticked the boxes of many other diagnoses—ADHD, ODD, intermittent explosive disorder, mood disorder—these were what was suggested as the root of his, and our, problems. But none of these really fit him. They simply described some of what we were seeing. Worse, the "treatments" for these disorders fit even less. Typical medications had odd side effects and he either responded to tiny doses too strongly, or needed huge doses to see any impact at all. Behavioral therapies, which largely relied on positive and negative consequences, made things worse, and systems of support were mostly nonexistent or, when they did exist, focused on fitting our square peg kid into a round hole.

[1]Training Director, Families Affected by FASD, Florence, MA, USA. ✉email: info@pedres.org

Received: 10 December 2021 Accepted: 10 December 2021
Published online: 12 January 2022

As a small child he didn't receive services through Early Intervention because we made too much money, yet our health insurance wouldn't pay for the recommended OT and Speech. He did not qualify for special education as a 3-year-old because of a single percentile point outside the cutoff. In early elementary school, his work refusal, disinhibition, dysregulation, difficulty interacting with his peers, and inability to read, write, or do math were interpreted as "poor choices" and he was denied special education services there as well. He spent a great deal of time being punished and sitting in the principal's office. We got a note home about his poor behavior every single day.

Now that my son is 19, we can attest that yes, he has an FASD, and yes, diagnosis matters. The most impactful intervention he—and we—have experienced has been gaining the understanding that FASD is a neurobehavioral and neurodevelopmental disorder and as such, the best way to help is to provide accommodations for his difficulties and modify the environment to meet his needs as much as possible. This approach is beginning to have crucial research behind it[4,5] and even if that evidence didn't exist, through trial and error we've learned this is the only way forward for our family.

It was this shift in our paradigm of understanding his behavioral symptoms—from a fixing-it mode to an accepting-it mode—that has made all the difference in the end. Accepting that he has permanent brain differences with behavioral symptoms is the key to knowing what to do to help him. The "fix" is to understand, accommodate, and provide an environment in which he can thrive.

Our understanding of his disability started with diagnosis, but the diagnosis didn't come easy. Even for a child like my son, who met three of the four main criteria for diagnosis of full FAS (facial feature differences, central nervous system impairments, and proof of maternal alcohol use), the diagnosis was delayed many years beyond what it should have been and where researchers have shown there is a critical diagnostic window for more favorable outcomes.[6]

I would love to think that our family's experience is unusual, but in fact it's the norm. In 9 years of teaching people about FASDs I've met thousands of people whose stories echo ours, and the statistics around FASD diagnosis back this up. As mentioned earlier, current prevalence rates are that 2–5% of the children born in North America have an FASD, but only 0.1% with an FASD achieve a proper diagnosis.

That means 99.9% of individuals with an FASD are either misdiagnosed or missing a diagnosis altogether. 99.9%!

Why so few people with an FASD are undiagnosed or misdiagnosed is a complicated issue, but it seems obvious that one of the biggest factors is that most physicians and other clinicians as well as individuals who work with people with FASDs and their families know very little about FASDs, and it's even more rare for clinicians to be trained to diagnose.[7]

FASD is a true invisible disability unless you know how to see it. The good news, however, is that we actually do know how to see it. The neurobehavioral profile is well defined[3] (among others), and models for diagnosis are readily available. The American Academy of Pediatrics, specifically the Medical Home model as described in the October 2018 issue of Pediatrics[8] as well as the Centers for Disease Control, the American College of Obstetricians and Gynecologists all have guidelines for diagnosis.

Although there are many issues that researchers could focus on when it comes to FASD, I feel the most important one is any research that results in a greater diagnostic capacity. With that in mind here are some questions I'd like to see answered by researchers:

- How can we improve diagnostic capacity, particularly when it comes to first-line clinicians? Pediatricians, family practice doctors, and nurse practitioners can all be trained to diagnose, or at least refer. If considering the guidelines in the DSM-5, psychologists, neuropsychologists, and clinical social workers can also be trained to diagnose, or at least refer. How can we get this to happen?
- What is preventing pediatricians and other clinicians who interact with children and families from understanding FASD? From diagnosing it? How do we break down those barriers? In communities with higher diagnostic rates, what are those clinicians and the medical community doing that can be replicated?
- How do we improve education for "everyone involved" in the circle of care for individuals with an FASD? Between 1 in 50 and 1 in 20 people have an FASD. This seems significant enough to warrant attention.

FASD is a lifelong disability, but we know from the research that poor outcomes aren't inevitable if we create educated support systems and provide needed accommodations and environmental change.[9] This all starts with the diagnosis.

(In writing this piece I queried my online support group for those of us in the FASD community (parents, professionals, and adults with FASDs) other areas they thought were important to research, and they had many suggestions. For a full list of other areas families feel research is necessary, please see the post on the FAFASD website, "FASD topics for Researchers," fafasd.net.)

REFERENCES

1. May, P. A. et al. Prevalence of fetal alcohol spectrum disorders in 4 US communities. *JAMA* **319**, 474–482 (2018).
2. Popova, S., Lange, S., Shield, K., Burd, L. & Rehm, J. Prevalence of fetal alcohol spectrum disorder among special subpopulations: a systematic review and meta-analysis. *Addiction* **114**, 1150–1172 (2019). PMID: 30831001; PMCID: PMC6593791.
3. Wozniak, J. R., Riley, E. P. & Charness, M. E. Clinical presentation, diagnosis, and management of fetal alcohol spectrum disorder. *Lancet Neurol.* **18**, 760–770 (2019). PMID: 31160204; PMCID: PMC6995665.
4. Olson, H. C., Oti, R., Gelo, J. & Beck, S. "Family matters:" fetal alcohol spectrum disorders and the family. *Dev. Disabil. Res Rev.* **15**, 235–249 (2009). PMID: 19731388.
5. Petrenko, C. L. M., Pandolfino, M. E. & Roddenbery, R. The association between parental attributions of misbehavior and parenting practices in caregivers raising children with prenatal alcohol exposure: a mixed-methods study. *Res Dev. Disabil.* **59**, 255–267 (2016). PMID: 27662038; PMCID: PMC5159297.
6. Connor, P. D. & Streissguth, A. P. Effects of prenatal exposure to alcohol across the life span. *Alcohol Health Res. World* **20**, 170–174 (1996). PMID: 31798126; PMCID: PMC6876509.
7. Smith, V. C., Matthias, P., Senturias, Y. N., Turchi, R. M. & Williams, J. F. Fetal alcohol research caring for patients with prenatal alcohol exposure: a needs assessment. *J. Popul. Ther. Clin. Pharmacol.* **24**, e25–e39 (2017). 10.22374/1710-6222.24.1.4. PMID: 28186713.
8. Turchi, R. M. & Smith, V. C., Committee on Substance Use and Prevention; Council on Children with Disabilities. The role of integrated care in a medical home for patients with a fetal alcohol spectrum disorder. *Pediatrics* **142**, e20182333 (2018). PMID: 30201625.
9. Petrenko, C. L., Tahir, N., Mahoney, E. C. & Chin, N. P. Prevention of secondary conditions in fetal alcohol spectrum disorders: identification of systems-level barriers. *Matern. Child Health J.* **18**, 1496–1505 (2014). PMID: 24178158; PMCID: PMC4007413.

CONFLICT OF INTEREST

The author declares no competing interests.

ADDITIONAL INFORMATION

Correspondence and requests for materials should be addressed to Adrienne Ehlert Bashista.