



Why do we need a family-focused FASD organization?

I started FAFASD in 2013 with the help of Tina Andrews, another mom to a child with FASD and now, an officer on our Board of Directors, because I was angry. I was angry that my son’s journey to diagnosis took so long and was met with such resistance. I was angry that once he was diagnosed with an FASD doors of understanding, accommodation, and services didn’t magically open up for our family. I was angry that even though the past forty years we’ve seen tens of thousands of published studies about FASD, I had to educate every single professional my child encountered. I was especially angry that all the attention around FASD seemed to be about preventing it, and very little was focused on the millions of people living with it or on the caregivers who struggled every day.

I wanted there to be a national organization that put the focus on the families, many of whom were caring for children, young adults, and adults who had been misdiagnosed and misunderstood for years. I wanted professionals to understand what we needed to help our children, and I wanted the number one cause of developmental disabilities, impacting between 1 in 50 to 1 in 20 births, to be more well-known! I couldn’t believe at the time—and still don’t—that this disorder, more common than autism, isn’t widely recognized, accepted, and understood. It’s my hope that through FAFASD, a group of fellow angry, bewildered, but also motivated and mobilized parents can make a difference for people living with, caring for, and working with the millions of individuals with fetal alcohol spectrum disorders.

Adrienne Bashista
Co-Founder and Director, FAFASD

JOIN US!

Yes, we want to train the WORLD about best practices for helping people with FASDs, but our mission goes beyond that fantastic goal. With your help, we want to:

- **Create even more in-person and online trainings and keep them as affordable as possible;**
- **Present at education, law enforcement, mental health, juvenile justice, and other conferences about FASD;**
- **Create more resources in our RESOURCE LIBRARY that you can use to help your child’s support system “get” FASD;**
- **Develop Family and Individual centered CONFERENCES and RETREATS that go beyond research to focus on what people really need to succeed! And**
- **Be THE VOICE of FAMILIES impacted by FASD. Create meaningful change through education, awareness, and presence when it comes to FASD.**

We need your help! Please consider donating to FAFASD. For more information about becoming a member please go to our website: fafasd.org



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SPECIAL POINTS OF INTEREST

- **JOIN US!** Become a member at fafasd.org
- **UPCOMING** Spring webinars, including a **FREE** introductory session!



FOCUS ON RESEARCH:

Recent study says changing parenting focus a positive for families impacted by FASD.

In “The association between parental attributions of misbehavior and parenting practices in caregivers raising children with prenatal alcohol exposure: A mixed-methods study,” published in the September, 2016 issue of *Research in Developmental Disabilities*, Christie Petrenko, Mary E. Pandolfino, and Rachael Roddenbery of the Mount Hope Family Center at the University of Rochester, investigate whether parenting practices and beliefs and understanding about the causes of unwanted behaviors impacts parent confidence in managing those behaviors. Families of 31 children between the ages of 4 and 8 with a diagnosed FASD were studied to consider that parenting strategies, including knowledge (or not) about FASD, influence parenting confidence and feelings of frustration.

“Parents who attributed the cause of unwanted behaviors to their child’s brain and developmental differences caused by FASD ...were more confident in their ability to manage...”

UPCOMING TRAININGS

FASD and the Brain-Based Approach

FREE 2-hour WEBINAR:

Introduction to the Brain-Based Approach
March 13, 7-9 pm, EST

Please check our website and Facebook page for more trainings, posted as scheduled, including:

5-week, 12 hour spring webinar, starts March 28

5-week summer webinar

In person trainings in:

Massachusetts,

North Carolina,

Texas, and the DC area.

The authors of the study concluded:

Parents who attributed the cause of unwanted behaviors to their child’s brain and developmental differences caused by FASD and who used antecedent strategies to prevent unwanted behavior were more confident in their ability to manage behaviors. Antecedent strategies are those which recognize triggering events or environments and which attempt to change these environmental triggers before unwanted behaviors occur.

Parents who attributed the cause of unwanted behaviors to their child’s “willful disobedience” and who relied on a consequence-based behavioral management strategy felt more ineffective at managing their children’s behaviors and felt more frustration as parents.

They also included these key points:

“Caregivers who had greater knowledge about FASD were more likely to view their children’s misbehavior as relating to their neurodevelopmental disabilities and use antecedent strategies to prevent misbehavior.” (p. 265)

Children who were punished more severely tended to be those with the most unwanted behaviors as well as those without characteristic facial features associated with FASDs. “...people are more likely to recognize children with physical manifestations of PAE [prenatal alcohol exposure] as having a developmental disability than children who appear typical. When children are viewed as having a developmental disability, people are less likely to interpret their misbehavior as willful disobedience and use harsh punishments.” (p. 265)



Spotlight on THE KELLER FAMILY

We have two young daughters living with FASD. “A” is 5 ½ and “J” is 4.

“A” struggles with cognitive impairments, executive functioning, sensory integration and anxiety. She is technically potty trained, but still struggles to stay dry. She attends Kindergarten at a Montessori and this seems to be working well for her as there are visual tools for learning. She is a slower learner than others, but because kindergarten is a lot of repeat until mastered it isn’t noticed. She doesn’t engage much with other students, but she does her work and listens to the teachers. We had a few struggles at the beginning of the year because the teachers assumed “A” knew common sense things like putting her bag of wet clothes in her backpack to take home, instead of leaving them in the shared locker. Once we explained she needed more instruction, it got better. Her teachers have also been trained in OT techniques to help regulate her throughout the day. She currently has a 504 as she doesn’t qualify for an IEP because her impairments aren’t affecting her academic progress. We have a lot more behavioral issues at home. The second she’s in the car from school she’s usually throwing things and yelling at me. We have to be careful to limit the activities on the weekend because after a week of school her brain struggles to keep her together. We have made some changes at home that have helped. Her room has very little in it, but it does have a swing and a spinning egg chair from Ikea. We also have a climbing wall, crash pad and calming room in our basement. All of these are tools that we use to help her de-escalate. We have also worked to only ask her something once and ignore her automatic “no, I hate you” response. If I count to myself, by the time I get to 20 she’s usually complying with my request.

“J” has different struggles. She was recently diagnosed with selective mutism and now takes medication to treat it. It has made a huge difference. “J” is also very impulsive and struggles with safety rules. We have also seen a recent upswing in subtle oppositional behavior. “J” participates in gymnastics and does very well due to her small size, strength and need for physical input. We are hoping that this will be a lifelong activity that helps her.

Both girls are doing well considering their challenges. We have changed the environment and expectations to better meet their needs. This means less stress for everyone. We are currently planning a trip to Disney World for the whole family, a decision we made after much thought as vacations are never quite as nice as we hope. I’m hopeful with some extra planning and some adjustments that we can all have a nice time.

FASD SUPERSTARS! Our loved ones are...

- ...curious
- ...athletic
- ...great with kids
- ...tenacious
- ...hard workers
- ...loving
- ...compassionate
- ...creative
- ...fun
- ...hilarious
- ...musical
- ...sportsmanlike
- ...great at origami
- ...good friends
- ...energetic
- ...outdoorspeople
- ...artistic
- ...agile
- ...great at fixing things
- ...helpful around the house
- ...musical
- ...living in the moment
- ...mountainclimbers
- ...acrobatic
- ...helpful
- ...kind
- ...amazing swimmers
- ...great drummers
- ...amazing actors
- ...good at Lego
- ...kind to other children
- ...caring for animals



HELP WANTED!

Do you have a story to tell?

Is something working for YOU or your family member with an FASD?

Do you run a support group?

Have an upcoming event to promote?

CONTACT US! We'd love to help you get the word out. The newsletter email is newsletter@fafasd.org

Our focus, of course, is on families and individuals WITH FASDs. We support prevention efforts but events, groups, and activities that are prevention-focused will not be included.

We will be publishing this newsletter every other month:

Feb, April, June, August, October, December.

You can always post to our Facebook page and we will repost for you if you have something more timely to let folks know about.

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FASD: Why get it diagnosed?

~by the parents of the online support group: **Shifting the Paradigm. Printable pdf @ <http://fafasd.org/fasd-why-get-it-diagnosed/>**

For many parents, professionals and individuals who already have a confirmed FASD diagnosis, this is a confusing question. Why wouldn't you want a correct medical diagnosis of an FASD? For most of us, proper and accurate diagnosis has opened doors to understanding – in our families, in ourselves, and for professionals and the support systems around us. For many of us, a diagnosis of FASD is driving care, serving as a vehicle for awareness, and gives crucial comfort and relief: there's a reason for these behaviors, and it has to do with the brain. It helps us shift our understanding (and everyone else's) from this person WON'T behave as others do to this person CAN'T behave as others do because their brain does not work the same.

Nevertheless, this question is often asked by parents and family members who suspect an FASD but who haven't yet gotten a diagnosis, particularly in areas where there is little diagnostic capacity, support for individuals or families impacted by the disorder, or any real understanding of FASD. Professionals who know little about FASD often discourage diagnosis, saying that 'there's nothing you can do' about it, or the WHY of behaviors doesn't matter when considering what to do about them. But parents, family members, caregivers, professionals, and individuals themselves who have been impacted by FASD know that diagnosis is crucial, and in fact, the question of WHAT to do about behaviors has everything to do with the WHY.

We asked our online parent forum, *Shifting the Paradigm* (on Facebook), reasons to diagnose, and here's what parents said:

1. Because the information you get at a diagnosis is very valuable. Diagnosis involves neuropsychological testing, adaptive functioning, speech, and occupational therapy evaluations. All of this helps you understand the person with FASD.
2. Understanding leads to appropriate accommodations and environmental change. Once we understand the behaviors associated with FASD as the result of brain damage acquired in utero, we can see these behaviors as symptoms of a permanent physical disability, vs. a 'choice' or evidence that the child is 'bad.' It shifts our understanding of the meaning of behaviors: from the person IS a problem, to the person HAS a problem. As our understanding changes, so does our response as caregivers, parents, professionals, and support personnel.

(cont. page 5)

FASD: Why get it diagnosed (cont. from p. 4)

3. Even though there may not be many people around you who understand what FASD is, there is actually a huge body of information and research out there and having the diagnosis will lead professionals, support personnel, and all other people around you or your child to greater understanding.
4. Because if you use medications, they usually work differently in individuals with FASDs, and this provides a reason why.
5. Diagnostic rates are incredibly low and the majority of people with FASDs are either undiagnosed or diagnosed incorrectly. In order to drive increased diagnostic capacity and create accurate diagnostic rates, we need to seek out diagnosis whenever possible.
6. Having a proper diagnosis allows you to network with other families who have similar diagnoses. There is great power in community.

“If we bury our heads in the sand, people with FASDs might think they are bad or something is wrong with them.”

7. It gives you a diagnostic trail that can be used to acquire services and monies (e.g., ID/DD services or SSI) .
8. A diagnosis of one of the FASDs is increasingly being recognized as a mitigating factor in the criminal justice system. Of course, prevention of criminal acts by appropriate supervision and support is everyone’s goal, but if there is justice involvement a diagnosis on the spectrum can help everyone involved understand the situation differently, and may result in more appropriate sentencing.
9. If we bury our heads in the sand, people with FASDs might just think they are bad or something is wrong with them. Many individuals who have received a diagnoses report feeling better knowing it is not their fault.
10. Labels happen to those who are different, and by getting an accurate diagnosis we take control of that label. Labeling a person with FASD comes with a wealth of information explaining the “whys” of behavioral differences. Instead of uninformed people around him choosing labels like “stupid, willful, defiant, delinquent, incorrigible, trouble maker, bad, lazy “–people can see individuals with FASD as who they really are: sweet, eager to please, creative, bright, and disabled due to prenatal alcohol exposure.



Families Affected by Fetal Alcohol Spectrum Disorder (F.A.F.A.S.D) seeks to spread information, awareness, and hope for caregivers of people with FASD.

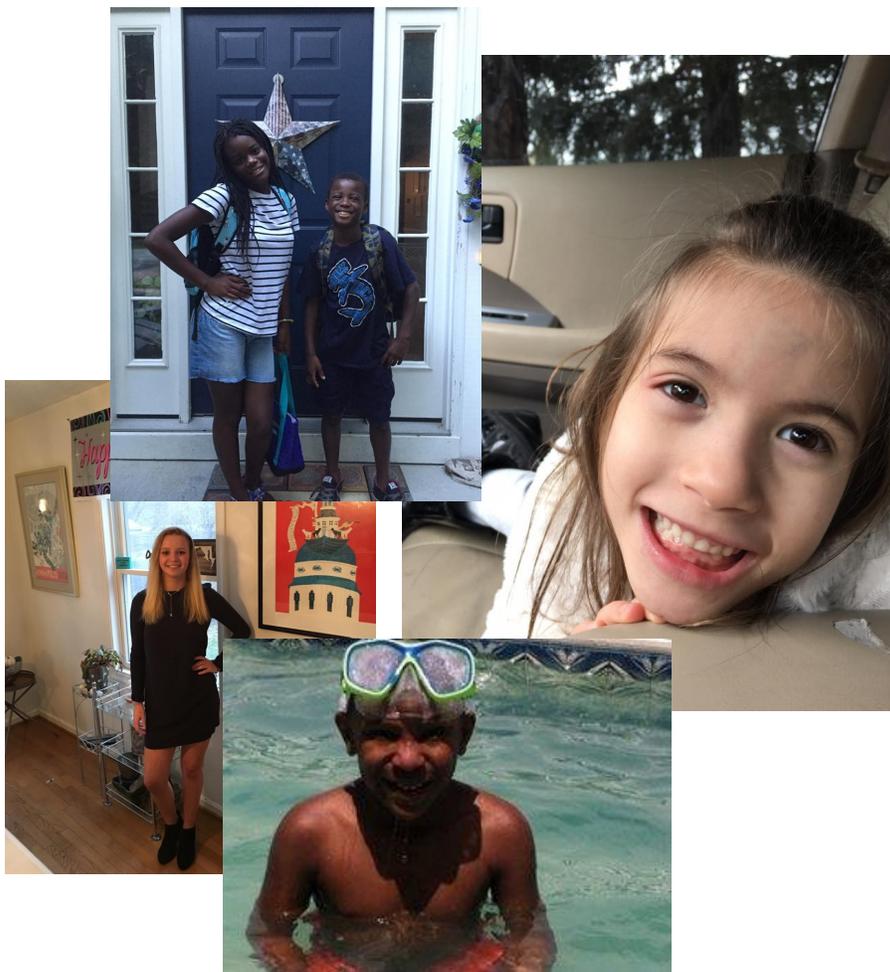
FAFASD is a 501c3 non-profit organization.

Your donations are tax deductible

FAFASD.ORG

On Facebook:

facebook.com/fasdfamilies/



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