



My Road Trip with a Child Who has FASD

Parenting a child who has FASD is a trip that few parents dream about taking. There is no road map to follow as no two children with FASD are exactly alike. What might work for one child may not work for another, and just when you think the trip is moving along smoothly, a bump in the road occurs or a side trip happens.

My road trip with my daughter started out relatively smoothly. She was adopted at the age of two years old and met all of her developmental milestones within the normal timeframes and often ahead of schedule. My favorite and vivid memory of her was at the age of 2 ½ when I picked her up early from daycare because she had a fever. She held her arms up to me and said, "Mommy, you came for me." That was the first time she called me "mommy."

She was not diagnosed with FASD until she was 16 years old. She did not look like the "typical" FASD child with distorted facial features. We spent 14 years journeying through almost every agency in the State, utilizing individual counseling, family counseling, intensive in-home therapy, Family Court, Juvenile Drug Court, detention home, Home Maluhia, Department of Health, Catholic Charities, Palama Settlement, YMCA, Family Treatment Center, and therapeutic foster home placement. From my daughter's 13th birthday, we were frequent visitors to the Family Court and almost on a first-name basis with the Honolulu Police Department.

Until the diagnosis of FASD was put on the table, I thought I was going crazy. On a daily basis, I did not know what my daughter's demeanor would be when I got home. The money would be missing from my wallet and she denied taking any money and so I started to believe that I forgot to go to the bank or spent the money without remembering. Missing valuables became so frequent that I would sleep with my purse under my pillow and my bedroom door locked. I could not believe or even want to comprehend that my own child would steal from me.

Her behaviors were so unpredictable and dangerous. She started her violent behaviors, such as hitting and throwing things when she was 10 years old. She started to run away from home when she was 11 years old. She started drinking alcohol when she was 12 years old. She started having sexual relationships when she was 13 years old. She started to engage in hard drugs when she was 14 years old. Conversations with her were riddled with swear words and name-calling. It was not uncommon for a simple discussion to end in a violent episode with shoes, brooms or dishes being thrown at me. She stole and crashed two of my cars, one when she was 13 years old and the other when she was 16 years old. Through it all, I kept the vision of the little toddler who called me "mommy" for the first time, always thinking that the little toddler is still within my daughter.

But that is the rub of having a child with FASD: she was my child, but I was not her mother, or at least not the mother that she needed or wanted. She suffered the trauma of being removed from her birth mother and being placed in foster care. She did not develop the ability to decipher boundaries and respect. She was and still is unable to understand the level of trust that is required in any relationship, most importantly the relationship between parent and child.

The journey with a child with FASD made me question everything that I was. I tried to be, not a perfect mother, but a good mother. So why is she like this? Why can't she follow the rules? Why does she lie about things that are not important? Why does she do the opposite of what I had taught her? Why? What is wrong with me?

And then I understood. It was not me. It was not her. It was FASD. She cannot help herself, and all the therapy or medication in the world cannot make her not have FASD. Her journey with FASD is a lifelong journey for her, so I had to let her go as an adult and travel her own path. I do not know where she lives, what she does, if she is eating, who she is with or if she is safe. I do not maintain contact with her. Was this the right thing to do? I do not know, but then who is to say which parenting decision is correct.

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There is always that "mom guilt" that I should have done more; that I should have spent more time with her; and that I should have understood earlier. That is the journey that I have to travel. Would I do this journey again? No question I would. People ask why. My answer is always, she is my child, who happens to have FASD. You cannot stop being a parent because it gets tough or because your child has a diagnosis. To me, the most important part of the parenting journey is to know when to let go.

> Anonymous Mom September 2019

I wish we would have received and FASD diagnosis earlier in my son's life (not diagnosed until 18) as I would have done many things differently. I would have understood him with more compassion and been better able to educate all his teachers about FASD along the way. My son attended 10 different schools always trying to set him up for success and figure out more about his struggles. It would have also enabled me to better explain his behaviors to my family and friends. He has always been socially charming however he struggled big time to keep up with his peers. As he got older this disparity only increased. It was hard to know that he really didn't have true friends and was so vulnerable to being exploited. I was also focused on the importance of his obtaining a high school diploma however learning a trade or skill would have served him much more than a traditional high school course load which he could not keep up with.



STEM Akayla. Akayla's teachers admitted they had no idea what they were doing when it came to her and I appreciated that and we worked together with her.

Thanks for coming to Akayla's (5th grade) graduation as no one came to her birthday party.

Grandmother September 2019



Right now we are dealing with my 14-year-old having to do community service because she basically got ALL F'S and 2 D'S for the WHOLE SCHOOL YEAR!!

It appeared to me that no one but me and Vanna seemed to know how to deal with her. It got to the point that no one seemed to know how to deal with her. It got to the point that she went to school when she felt like going to school and no one seemed to care. Now she has to repeat 9th grade. I understand why but when we were having all these meetings (IEP)and when I was all but begging for help why wasn't someone catching it earlier. I don't understand.

> Grandmother September 2019

We are constantly reminded of how different our children are...we worry about what the future might hold for them.

How will their FASD develop as they grow older?

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Who will look after them when we're gone?

Bio & Adoptive Parents

September 2019

My son is 48 years old with FASD who was not diagnosed until he was 34. He had an evaluation in elementary school and placed in special education classes for inability to focus. He had a second evaluation by a psychologist as a child and a third as a teenager but there was no specific diagnosis made regarding his peculiar behavior. When I attended a conference on FASD on Oahu in 2004 I realized he had signs and symptoms of FASD and facial features of a child with FASD.

I became a grief-stricken bio-mom seeking services for my son.

He ran away at 15 years old. One night, he left the home and accidentally shot himself in the leg. I was visited by CPS and questioned. I asked the CPS worker to please take my son rather than accuse me of being a negligent parent.

> Bio Mom June 2019