



Autism: A Family Perspective

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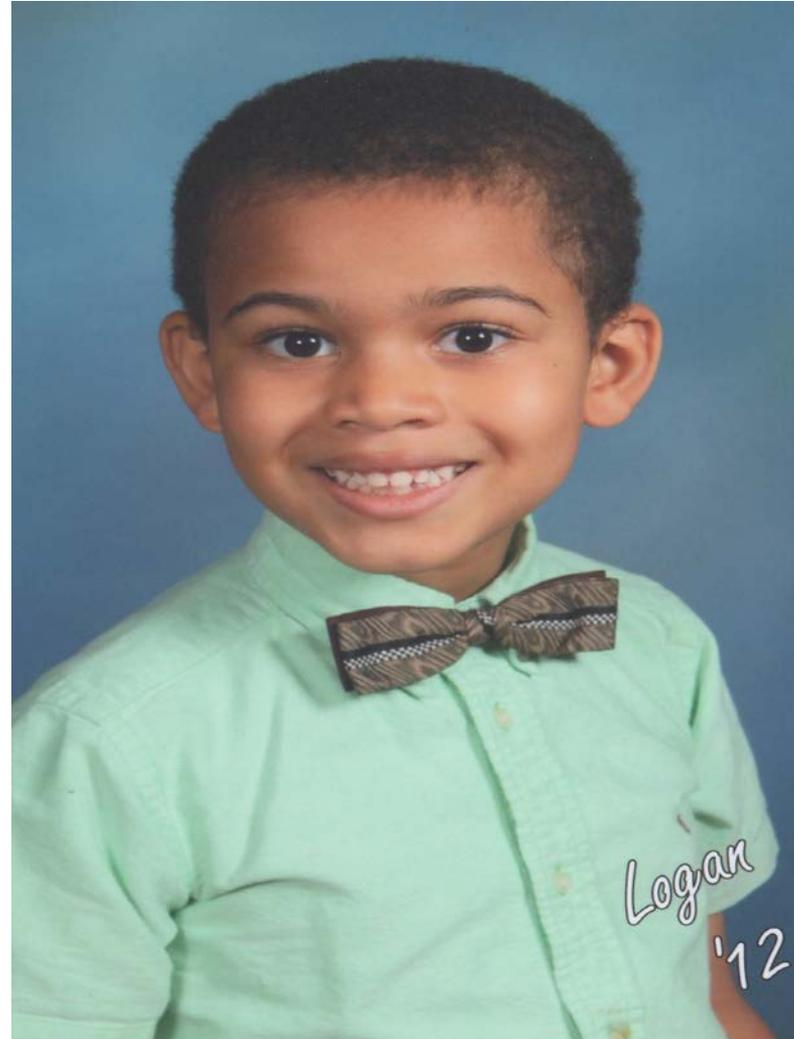
Family Discipline

Background

- Mother of a child with Autism Spectrum Disorder
- Former VA-LEND Trainee, Family Discipline
- Behavior Analyst – Recent graduate with MA in Applied Behavior Analysis
- Chose this field because of my child, and our challenges, to help other families
- Family advocate- help other families with children like mine, treat children, educate the family
- Do not want them to have to struggle to get a diagnosis, or receive services like we did



Logan



Our Story

- Logan , 7-years-old diagnosed with autism and speech delay
- Normal birth, short hospital stay
- Noticed he was very serious, did not smile until almost 6 months





He will be fine

- Had babbling, cooing, could say 1 word at about 12 months, but not much progress
- First child, inexperienced, but had a feeling something was not quite right
- Pediatrician did not entertain the thought of autism “too soon to tell, just a speech delay”
- Early intervention (NE) – Speech and OT consult at 18 months
- Took him for Autism Evaluation Omaha– speech delay. “He’ll be fine”
- Still had a gut feeling, not progressing well
- Continued speech and OT, PT
- Behaviors started around 2- temper tantrums
- Enrolled in a day care and Head Start program for socialization with typical peers at 3.

Early School Days



- He had behaviors in school and day care, aggression
- Like he could not control himself
- Speech increased tremendously, but so did behaviors
- Pediatrician did not mention autism or to get tested
- School did not think it was autism

Finally

- I was afraid of my own child
- Dreaded bedtime- things thrown at me
- New this was not normal, had a feeling
- Moved to VA
- Federal Programs Preschool
- Aggression issue, behaviors, really bright
- I had him reevaluated in September 2010
- I was hoping it was just ADHD
- PDD-NOS, ADHD
- Told to see the Social Worker on the way out, given phone numbers, papers to read and left
- Now What?????
- By this time he was 4 years old
- That's when my world fell apart
- Picked up the pieces and started educating myself advocating



Finally

- By this time he was 4 years old, which is still earlier than most
- On average African American children are diagnosed about 2 years later, often diagnosed with conduct disorder



Endless Appointments and Meetings

- Seemed like there were endless meetings IEP meetings, Eligibility, FBA's, BIP's
- Doom and gloom
- Intervention in school
- Intervention outside of school
- Speech, OT, PT , Psychology, ABA therapy, etc.
- Could not work, had to be a case manager
- Load on me – I'm just a mom what do I do
- Joined Autism Society, every list serve I could, hours doing research
- Felt Isolated and alone
- Closed off as a family
- Behaviors kept us prisoners





It Gets Worse?

- In Kindergarten he was in general Ed
- Could do all the work, ahead of the class, seemed okay
- Went to work as an Instructional Asst. at Public school
- Behaviors worsened, suspensions, sending him home disguised suspensions
- Had Manic episode
- Not many places will take a child with autism unless verbal
- Hospitalized for almost 2 weeks for med adjustment
- Had to resign from job missed too many days
- Stabilized enough to finish school- don't have resources to help him
- Started first grade – new school Autism Room part of the day
- Suspension, attorney, endless meetings again



Life Goes On

- Child was hospitalized 4 times in 1 year
- Seemed like we always in crisis
- When will it end?
- Stabilized- new meds
- I was accepted to VA LEND
- Started graduate school at another school
- I wanted to know what others knew, and to help other families
- That's what I could do
- I am still his advocate
- After a 2 year fight he is in special education with an Aid
- Doing well- on or above grade level
- Has Medicaid waiver and attendants who care for him
- ABA Therapy, Speech, OT, Play Therapy
- Behavior Analyst, took my exam to become BCBA
- Work with families who have children with autism

His Future

- What do I want for him?
- Independent, meaningful work, friends
- Have some form of a life
- Advocate for him until he can do it himself
- What about other families who cant stay home with children
- What about other families that don't know how to advocate for their children
- What for those who are not educated
- I can be their voice, unique perspective
- Parent/Professional





Barriers We Faced

- Felt my concerns were not valid
- Long time to get a diagnosis
- Lack of resources and treatments
- Had to move for better services
- Endless meeting at school
- Hard to find Child Psychiatrist, long waiting lists
- Could not work – had to be case manager
- Financial hardship
- No time for self care
- Isolation- friends and family
- Marriage difficulties
- Hospitalizations for co-morbid conditions
- Lack of school resources, support
- Middle class, educated what about other families



Barriers to the Diagnosis of Autism

Reasons for Diagnosis Disparities

- Parent education level can determine the knowledge of developmental milestones, and the ability to advocate for ones child to receive a diagnosis.
- Racial differences in diagnosis can be due to institutional factors like limited access to health care, prejudices and beliefs of the clinician, and the families interpretation of the child's symptoms.
- Clinicians may be more likely to diagnose autism in White children and intellectual disability in Black children due to research that suggests a lower prevalence of intellectual disability in White children.

Barriers to Autism Treatments

Culture

- Culture can influence how the family perceives treatment options. Families may base the choice of treatment for a child on the belief of the cause of the diagnosis, and this can vary across cultures.
- African American families may be hesitant to attribute symptoms to mental health issues and therefore not seek this type of treatment. Stigma on mental health issues in the African American community may also play a role.
- Expectations of the role of the parent and provider may vary across cultures. In some cultures parents do not expect, or may not want to have a role in the treatment of the child. They may expect therapists, doctors, and schools to be the primary providers of the treatment plan, and therefore lessen their involvement.



Barriers to Autism Treatments

The Cost of Autism Treatments

- Due to the high incidence of co-morbidity with other disorders, children with autism have higher health care costs since they must access more healthcare services than children with other health problems or those without health problems.
- Medical expenditures for children with autism are up to 6 times higher than medical expenditures for children with other health care needs.
- Even with insurance, public or private, there are significant out of pocket costs for autism treatments. This is especially true for in-home behavior therapy (Figure 1).



Barriers to Autism Treatments

Limitations of Public School Systems

- Special Education services and treatment services for children with ASD differ by race and ethnicity. There is also a disparity in the use and quality of services in predominantly minority school systems.
- Staff at schools, and the money associated with caring for children with ASD in school programs are a consideration. Significant time by staff implementing interventions may not always be possible because of school system limitations.
- Poor African American parents have no choice but to send their children to dilapidated schools, where the teachers may lack experience, and they are less involved in the neighborhood school activities, including activities that would help improve parent involvement and awareness.
- Because school systems for minority children often do not have appropriate staff numbers or skilled staff to implement intensive interventions, many parents may be forced to seek a combination of public and private funded interventions for their children.





How I Help Families

- My journey through autism has made me a strong advocate for my child and other families
- Getting a diagnosis, treatment, paying for treatments
- Getting the school system to listen – We do know
- I can be a voice for families – parent/professional
- Parent/ treat children with autism, research
- Disparities- need for equality in access, diagnosis, treatment for children from ethnically diverse cultures, lower socioeconomic status
- Sharing my story- to spread the message...
- Professionals- we love our children, we are not lazy, but overwhelmed. Have mercy on us when we don't follow through on treatments or appointments – meet them where they are
- Listen to our concerns and value the “parents truth”, we know our children -Family centered care, Person first language
- Families that you are your child's greatest advocate and hero. Not the end- Beginning of “new normal”
- You know your child- listen to your inner voice- advocate

Thank you



Questions?

