

Published on ADDitudeMag.com

Finding Stability After an Autism Diagnosis

An autism diagnosis can bring denial, confusion, or — in some cases — relief. But in order to move past difficult feelings and provide the right support for your child, you need to create and maintain a stable home environment.

by John Harrington, M.D.

The Centers for Disease Control and Prevention and the National Health Statistics Reports have estimated that a child born today in the U.S. has a one- to two-percent chance of being diagnosed with an autism spectrum disorder (ASD). Since the rates for boys are four times higher than that for girls, approximately 1 in 30 boys will be diagnosed with an ASD by age eight.

As a pediatrician and a parent of a child (who is now an adult) with autism, I have helped and advocated for others coming to terms with an autism diagnosis. The stages of grief that many of us have heard about can occur all at once on a continuum — denial, anger, bargaining, and depression. Some parents go straight to acceptance, if their child had a late diagnosis that they already suspected. Wherever you are on that spectrum of responses, the most important variable that has proved to help all children, and especially a child with an ASD diagnosis, is the stability of his environment and family.

What does stability mean? Children diagnosed with autism appreciate the consistency of routine as it relates to family members and having a daily, predictable program. Unfortunately, many things can sabotage the normal functioning of a family. One of the mnemonics that I came up with when considering stress on this stability is called IHELP2.

>Income and finances are important for families dealing with a child on the spectrum. Outcomes are improved when one parent stays home with the child, learning and performing the intensive behavioral therapies. When a family needs two incomes, supports from early intervention and special education become important in providing predictability in daily care. Support groups in the community — a local chapter of the Autism Society of America or Autism Speaks — can assist parents and help in those early days and let you know that you are not alone.

Housing in a stable location, where the child can feel comfortable with his surroundings, alleviates stress and transitional challenges that can undercut behavioral therapy. Unfortunately, this cannot always be controlled because of job relocations, deployments, or marital discord that may cause separation or divorce and the tricky balancing of two households.

An Educational setting, with appropriate services, needs to be agreed upon by the parents and communicated to the school. A school willing to collaborate with parents provides the best scenario. Battling the school to get services causes enormous stress on the family. Therefore, understanding each side's limitations allows for a happier setting for all. If the school budget cannot give one-on-one support in the classroom for your child, but the school is willing to train new staff members to help several children with autism and provide additional social skills support, this may be a nice compromise.

Language and the ability of your child to communicate directly with you is critical. If your child cannot communicate, his behaviors can deteriorate and weaken the bond between parent and child, further fragmenting a family. Parents can improve their child's rudimentary language skills by using an iPad with a computer-assisted voice or a picture-exchange communication system that uses photos and a standard sentence strip. But the goal should be the natural flow of language that allows spontaneous social functioning.

Parenting and Psychosocial components are most important in giving stability to a child with autism.

Although my son was diagnosed with regressive autism at about age three, I knew he was autistic at 15 months. He is now 20 years old and working at a paying job 20 hours a week. That outcome did not happen by accident or luck,

but through gentle insistence and persistence, mixed with some tough love, by everyone in our family, including our two daughters.

Parents Happy, Children Happy

The strength and resiliency of the parental bond sets the tone for success. Did you know that the divorce rate among parents of children with autism is 20 percent higher than the national average? So parents should be aware of stress that can undercut family stability. The primary reason for stress is the uneven division of responsibility between parents: one parent becomes the sole therapeutic agent for the child with autism, and the other parent avoids it.

Many parents develop a “silo” approach, in which one is the caretaker and the other is the breadwinner/take-care-of-everything-else person. Early on, my wife, who is the caretaker, thrust me in that role to help me empathize with her daily challenges of staying home with our son. When I was not on-call for the weekends, she planned outings for herself and our daughters. My job was to entertain my son. I moaned that I needed a break on those weekends, but I was actually scared at the prospect of trying to practice what I preached at work to other parents.

The first few weekends that I spent with my son, I drove to his favorite places — the park, the store, McDonald’s. My wife scolded me, saying that I was going to make our son obese by eating so many Chicken McNuggets and french fries. So I entertained him with sports. We played basketball, baseball, football, soccer, golf, and tennis, went biking and swimming — a different sport each weekend. I found out that he loved the latter two best. Games with rules did not fly well with him, and the freedom of riding and swimming provided sensory fun that I enjoyed as well.

Instead of being stressed about taking care of my son, I now had a way to connect and commiserate with my wife after our weekend escapades. I explained what went well (counting the numbers on the high school track) and what didn’t go well (running up the stadium stairs), how I managed meltdowns with cartwheels, and the new achievements I had witnessed in our son (throwing and catching a Frisbee).

Our ability to share the burden and joy of caring for a child with autism provided a more loving relationship with each other and our whole family. My son started to sleep better because he was tired from exercising. We found that he liked to use earplugs at bedtime because they blocked out disturbing noises. The trepidation we felt when we went out as a family melted away.

Research has shown that when parents of a child with autism fill out a Parenting Stress Index (PSI) scale, they score higher than or comparable to parents of a child undergoing cancer treatment. Unlike some cancer patients, a child with autism rarely goes into remission. Therefore, coping strategies go a long way toward keeping families together and stable.