

Autism: Our Journey and What I've Learned

By Holly Hickok-Kearns

My purpose in writing this article is to share some of the insights I have learned as a parent, a former autism consultant, and a current special education teacher. I have been on this journey for 29 years and while I hope my experiences can be helpful, I also firmly believe that autistic individuals are more different from one another than are neurotypical people. No, they aren't all like Rainman! I also realize that many of you parents have been in the trenches long enough to have come up with your own insights and problem-solving techniques, so please realize that I am in no way saying I have all the answers, but if only one of the tools I've used is helpful for you, I will feel this has been worth sharing. We all do the best we can!

Ross was born in 1989 and he wasn't diagnosed until he was 3 ½ years old. The incidence of autism that year was about 1 in 10,000. Because he had a good vocabulary, was relatively bright, and most doctors did not know what autism looked like, it took over a year and a half to get a diagnosis. Even living in the large city of Atlanta, GA, we did not know any other families who had an autistic child until we were linked to a support group at a local hospital where we met FOUR families. Now the incidence is about 1 in 59.

What is autism? Autism is a neurological disorder characterized by communication problems, a lack of social awareness, sensory issues, a tendency to engage in repetitive activities, and a resistance to change in daily routines. Twenty-five percent of autistic people are non-verbal. Interestingly, this has decreased in the last decade, possibly due to earlier diagnosis rates and earlier intervention. Sensory issues may include an oversensitivity or an undersensitivity to touch, noises, and light. People often become less sensitive as they age thanks to therapy and experience. Ross used to scream when he heard a leaf blower and as a young adult he has used one for his job at the city park. However, as a baby and toddler, he loved being held and wouldn't let me put him down, another reason I had ruled out autism because every article I found in the library said that autistic babies stiffen and pull away when held. Autism is called a "spectrum" disorder because the range of ability and function varies from individual to individual to relatively mild to severe.

Thoughts for Parents and Guardians

1. Accept your child 100%.

Shortly after Ross' diagnosis I went to a lecture about autism. I can't remember who gave the lecture, other than it was an autism parent, but the main takeaway was to accept your child 100% where they are now in order to move forward and make progress in the future. This was a relief to me and helped me a lot over the years. Acceptance doesn't mean defeat. Acceptance

doesn't mean the grief disappears completely, but, for me, it made our journey more peaceful, productive, and joyous. I chose to 100% love and accept Ross for who he was while celebrating every milestone, no matter how minor. And there were many milestones.

2. Fight for the realistic dreams for your child.

I wanted Ross to read for pleasure. After his first grade year he was still struggling to read fluently. At the end of the year IEP meeting I requested he repeat first grade. The entire team was dead set against it. I persisted and he repeated 1st grade and became a good reader. Ross owns hundreds of books and enjoys reading daily. It has truly enhanced the quality of his life. The key is being realistic though. If he hadn't become a fluent reader after repeating 1st grade, we would've moved on to a different goal for reading, e.g., reading safety signs and other functional words.

3. Use your child's strengths and interests to develop leisure and employment opportunities. Have your child volunteer to prove their employability.

The Robinson School District has top notch special education programs across all grade levels. Transition planning (planning for life after high school) begins at age 14 for students with an IEP. It is important for parents to be as involved in this process as possible as you know your child's strengths and interests best. Ross was always obsessed with trash and recycling. At the beginning of his 17th summer, dreading another summer of Ross spending most of his time on the computer and watching television, I approached the city park superintendent and asked if Ross could volunteer to pick up trash at the city park. I told him that I would initially train and supervise Ross. He agreed and Ross worked 2 hours a day that entire summer. He did such a great job that he was hired the next summer and has worked for the Robinson Parks Department every summer since. Sometimes you have to anticipate an employer's need and volunteer your child.

4. Don't be afraid to ask for your child to be included in extracurricular activities.

It can be a challenge to find recreational opportunities for children with autism, especially living in a smaller town where there aren't organized community recreation programs specifically for students with disabilities. One advantage of living in a smaller town is that people know one another or are at least acquainted so it's easier to ask for favors. My eldest child, Kendra, was on the LTC swim team when Ross was about 7-8 years old. The swim team practiced every morning for an hour. Ross loves swimming, and while I knew he would never compete, I asked the coach if Ross could swim with the swim team every morning, under the conditions that I would pay the swim team fee for him, and that I would stay in case there were issues. The coach agreed and Ross got a wonderful opportunity to swim and get some socialization.

Ross also enjoys bowling but could not tolerate the crowds during regular business hours. I asked the manager if Ross could bowl right before they were officially open on Saturday mornings. Of course we would pay. He agreed since they were just vacuuming and getting things ready for the day. Remember the worst thing that can happen is that you will hear “no”, but in my experience people want to help and are happy to be asked.

5. Use visuals to help structure your child’s day.

Since this is emphasized so much in special education classrooms most parents have probably heard this, but it is easier said than done at home. People with autism, even those with good verbal skills, process visuals such as symbols, gestures, and pictures, much better than words, especially when they are in a stressful situation. Since Ross was little before we had cell phones I took pictures of familiar places such as grocery store, bank, park, home, etc., had them developed and put them in a mini photo album so he would know what the order of daily errands was. You can also use photos or symbols to create a home schedule. I recently searched and found an app that costs \$3.99 called “Visual Schedule-PCM” that looks promising but I have not used it. The technology available today makes things so much easier! You can also ask your child’s teacher or SLP for resources and assistance.

6. Use calendars to help your child understand time.

The first time I realized Ross didn’t understand time was when he was about 3 years old, about 6 months before his diagnosis. I told Ross that we were going to north Georgia the next day to visit some friends at their cabin. Ross LOVED this place and he immediately got into the car. I kept telling him, “Not now Ross, tomorrow.” But he didn’t know what tomorrow was and he sat in the car for well over an hour before he finally gave up. The concept of time is a tough one to teach, but if you are able to consistently use a calendar to help your child cross off the days and put stickers or pic symbols to represent specific activities, your child will eventually get it!

7. Take care of yourself!

This is a tough one. Ross didn’t sleep through the night until he was about 11 years old. Life was stressful. Back then people were afraid of autism so no one volunteered and we lived nearly 1,000 miles away from family. He didn’t go to parties or sleepovers, so we never had a break. These days, nearly everyone is familiar with autism or knows someone who’s autistic, so don’t be afraid to ask for help and get a break now and then. And those of you who don’t have a child with a disability, offer to help often.

In conclusion, the hard work and sleepless nights pay off. Things do get easier over time. In my experience, as autistic children grow and experience the world, they adapt and we live in an era when, just as importantly, the world has adapted. There are sensory friendly theaters

and shows and I do think people are slowly beginning to understand autism. As to Ross, he is doing great! He is a happy, polite young man who works two part time jobs, one as a custodian at Robinson High School and another as a trash picker upper at Robinson City Park. He is so passionate about recycling that he has a recycle center in the park named after him. Your child will grow up and things will get better!