

My Own Introduction to Autism

By Thomas A. McKean – 05/06/08

I was diagnosed in 1979. But I didn't know about it until 1991. This was my introduction to autism.

All through my childhood in the 70's I was seeing doctors and therapists. I would get out of school early to attend appointments. I had no idea what was going on; all I knew was on those days I didn't have to watch for bullies on my way home.

I was diagnosed in 1979 after a few visits to Upham Hall at the Ohio State University. No one thought it was important enough to tell me.

In early 1980, I was home alone (I usually stayed home while the family went out) and the phone rang. I was told there was a bed available for me at a psychiatric facility and that I could come at any time. Apparently the woman on the phone thought I had been informed that I was going to be admitted, but again, no one thought to tell me.

When my family came home, my mother confirmed that I was going.

So I packed up and moved in and stayed there for three years.

During that entire time, I was never told.

In 1990 I was engaged and when that fell apart in 1991, I went back to the hospital to ask for my records. (This was because I felt the break up was my fault, which I now know it wasn't.) They wanted over \$600 (which I would eventually give them 17 years later) for all the records. They did, however, provide me the admission and discharge summaries free of charge.

That's how I found out about it.

When I told my parents, they were just as surprised as I was. No one told them, either. What they have told me (and I really have no reason to disbelieve them) is they were told I was "developmentally delayed" and that was the only diagnosis they were ever given for me.

Once I read the diagnosis, I still didn't know what it was? I had taken a few mental health college courses and I do remember reading a paragraph or two about autism. All it said was people with autism didn't talk and were mentally retarded. That definitely did not bode well for me, especially the latter.

So I did what most of you did. I went to the library to learn more. This was a big mistake.

Even as late as 1991, there was very little written about autism. That's because it was still rare at that point, with all of 1 in 25,000 people being diagnosed. I found a book called, *Autism: A Parents Guide*, which was edited by Michael Powers.

When I was done reading, it gave me the impression that maybe the thing to do would be to crawl under a rock somewhere because autism was hopeless. I didn't want to believe that.

My real education about autism came when I was elected to the board of the *Autism Society of America* in 1994. I attended the national conference, held that year in Albuquerque. There were many who came to learn about autism and I learned right along with them.

The point I am trying to make is this: Chances are your child knows he (or she) is different from other people. I knew I was from the time I was five years old. I knew I was different, I just didn't know what that difference was.

That "knowing but not knowing" led me to some serious self-esteem issues as I was growing up. An example is above in that I felt the demise of my engagement was my own fault.

I am not saying it is appropriate to tell every child. Certainly it isn't, and this is a decision that can be made only by the parents.

Many doctors have stated they don't think telling the kids is a good idea. I disagree. I believe that if it is possible, that parents should consider letting the children know what is going on and that it is not their fault.

No one ever told me and looking back, I think I would have done much better if they did.

-Thomas A. McKean