

An Alternate Look at Autistic Perceptions

by Thomas A. McKean

About this article: This article was written as proceedings for a presentation at the *1993 International Conference on Autism*, thus there may be certain things in it that are a bit dated. Biographical information, however, is never dated, and so this article is included on the site.

Thomas A. McKean was, at the time this was written, in the middle of his first term as a member of the national board of directors of the *Autism Society of America*. He has since moved on, traveling across the USA and Canada to do private autism consulting for families and school systems. Since this was written, Thomas has (thankfully) become a better writer and has written two books on autism, one of which took a literary achievement award and appeared on the *Oprah Winfrey Show*. Thomas has an extensive website that you can visit by [clicking here](#). There is more information on autism, and on Thomas, on this site.

To see what Thomas has been up to lately, you can [click here](#) to read a recent interview Thomas did with Terri Waters.

BIOGRAPHICAL INFO:

I was born on June 18th, 1965 at the Ohio State University. Everything was fine until I was about 6 months old. I went to get some glasses. I put them on, saw the world for the first time, and I did not like what I saw.

Growing up, I thought that what was happening to me was also happening to everyone else. I thought they just handled it better. I really had no idea what was going on. Neither did anybody else. I kept bouncing from one doctor to the next, but because I could talk (though I never really said much that mattered) they refused to give me the diagnosis.

Since no one would confirm the diagnosis, acting "autistic" in any way was the wrong thing to do. I was often punished for reasons I did not understand, simply because what I was doing was being myself. It has been suggested to me that maybe this is a reason I turned out as well as I did, and that may be true. But it does not make the memories any easier to live with.

For this reason, I very strongly advocate telling your children. Since I did not know, I was under the impression that what I did wrong was my fault, and that I was basically an all around bad child.

School was pretty much the nightmare you would expect it to be. I was held back a year before Kindergarten, stayed in regular classrooms until halfway through third grade. Then I spent every half of year in a different school and in a different special ed class. If my parents or the professionals wondered why I never made any friends, maybe it was because they never gave me a chance before moving me again. Sixth grade came along, and I was placed back in the regular classroom.

Jr. High proved to be a mixture of the previous experiences. Half of the day I was in regular classes, half of the day I was in with a special ed teacher, who, like many before her, had next to no compassion and really did not understand her job very well.

Be that as it may, I was never very popular. I was an easy target, and I dreaded things like gym and recess. I would usually just walk around on the playground by myself, and watch the other kids play.

I did have a few interesting experiences in school, though. For instance, one day during recess, while I was in the third grade, a certain girl found me and told me to follow her. I looked at her cautiously, wondering what she wanted. She walked away and signaled me to follow. Following her around the corner, I was greeted by yet another girl who had pulled all of her pants down just for the occasion. I never did figure out what the purpose of that was. I was only 10 or 11 years old, and had zero interest in such things.

In the seventh grade, I had a mainstreamed math class immediately following the lunch hour. All the kids seemed to be rather pumped after lunch, and the teacher, "Mr. Dekker," never could keep control of things. One day he just gave up. Walked out on us in the middle of class, went into the office, announced that he quit, and walked out the door of the school. I never saw him again after that. Too bad, really, he was one of my favorite teachers.

Eighth grade came along, and just before finals, it was announced to me that I was going into the hospital. I had gone to see yet another doctor, and she labeled me with PDD(NOS). Why in the world they placed me in a mental institution is beyond me. Autism is not a mental illness. Nevertheless, I was rather pleased to be going, as it meant no study for finals. I was told that I would be there for three weeks, which also pleased me. I decided to look at it as a vacation. That vacation lasted all of three years.

I won't go into all the horror stories of that place. Let me just say that if I was helped at all during those three years, it was more due to the random, day to day events than it was by the doctors or any of the therapy. At least, that is the way I feel about it. I think that my values and my personality were somewhat molded ultimately in a positive way by what I experienced while I was there. You cannot watch people die and not be effected by it. I saw people in pain, heard people screaming, noticed the end results of drug overdose, helplessly observed many suicide attempts. I was there from age 14 to age 17. And even now, looking back, I still feel as though I have never had a chance to grow up. But while I was there, I learned something very important that would later help me on the board of directors of ASA. And that is the fact that there is suffering in the world, and that once in a while, if you happen to be in the right place at the right time, you can do something about it.

It was not all bad. Sometimes there was love. Usually a strong bond of friendship between the patients. We used to pass notes back and forth after hours with a remote control racer I had stashed in my drawer. Sometimes the staff caught us. Usually they didn't. When they did, we were usually punished. They seemed to not approve of us supporting each other. But with all the bad things that were happening in there, that support sure went a long way with all of us.

When I was finally released (against the better judgment of the doctors), I worked for a veterinarian for a short time. Then I left Ohio for Urbana, Illinois. I lived there for a while, attending a small, community college and studying computer science. No high school diploma was necessary to attend, so long as you studied to get your G.E.D. while you were there. And while I failed all the college courses, I did pass the G.E.D. test the first time I took it. I attribute this to divine intervention. I never studied. Even for a minute.

The school had a strong Christian Fellowship. And it was here that I met the person who would eventually go on to bring me "out of it." She seemed to want to be around me. And this was very hard at first because I could not figure out why such an attractive and intelligent girl would want to be my friend. But she did, and I owe her a lot for that. She was the first person to ever really bother to look inside. And then she taught me how to look inside. And she showed me that I was not really the bad person I thought I was all these years. Gwendolyn remains one of my close friends.

I returned to Columbus to attend another community college, this time studying mental health. Again, I was not ready to tackle the books.

After leaving school a second time, I took a job at Medicare. I processed claims for Ohio and West Virginia from 1986 to 1989. In 1989, I left to go back to college. This time to study journalism. And I got passing grades. I also "met" someone on the side. After three or four quarters, I became burned out on college. Melanie and I continued to pursue our friendship, and eventually became engaged. Friction mounted when it became obvious we had different needs. Her need for intercourse and my need for celibacy was a constant source of uneasiness between us. When she was raped several months after the engagement, she broke it off with me and pursued a relationship with someone who was more able to fulfill her needs. Last I heard, she remains happily married. Convinced that I was somehow the reason for the collapse, I began to search my past. It was there that I found the diagnosis. No one had bothered to tell me. This was kept from me for 11 years. And I had to stumble onto it on my own. Desperate to learn more about what autism was and how to treat it, and even more desperate to learn who Thomas A. McKean really was, I put my name on the ballot of the board of directors of the Autism Society of America. I was surprised to be elected. I am currently serving on the board, speaking at various conferences and seminars, and seeking employment in the autism field. My primary interests at this point are research and advocacy.

SENSORY INTEGRATION / MIRA TRILOGY:

I share Temple's need for pressure. Of all the symptoms of autism, I feel this one is the most aggravating. If I could afford one of her squeeze machines, I'd definitely buy one. Sometimes the pain is unbearable. And there does not seem to be anything I can do about it. It is like there is a part of me missing. Like I am an incomplete person. I have spent the night between the mattresses and done the shower routine, and occasionally the surgical brush, but none of that seems to really help. It is a constant, low-intensity pain that surges through all parts of my body.

It has been reported that some individuals with autism have a tactile sensitivity to certain textures. I find this to be true in my own case, though I cannot really tell you what those textures are as they vary day to day, hour to hour, minute to minute. But when this occurs, touching whatever the texture is feels quite a bit like a severe sunburn. Not a very pleasant thing. I know that I am very sensitive to cold, and that cold equals pain. Conversely, I find heat to be very comforting. When I lived at home, my parents used to get on my case for turning my electric blanket on in the Summer. They could never figure out why I did it. But to me, it was a very natural thing to do. Still is.

There are very few foods that I can tolerate eating. Usually the ones I can eat are soft textured. Italian seems to be the limit. Sometimes I think it is a wonder that I am still alive.

I have never liked the color yellow. It has always been a source of visual pain for me. Looking at something that is yellow would be like you looking directly at the sun.

I have noticed a very strong (yet platonic) need to be held. I have found that the gentle touch of a friend can temporarily drive away the previously mentioned low-intensity pain. I don't know why this is, I wish I did. I have noticed that the older you are, the more inappropriate it becomes to hold people. And this has gotten me into trouble more than once. Sometimes the need is stronger than I am.

I went through auditory training last October. I was offered auditory training over in Cincinnati, and after much consideration, I decided to try it.

It is unfortunate that the auditory training ultimately did not work for me. There were positive results for the first two or three months, then my hearing went back to the way it was before. I have heard various theories about how and why this has happened, and most practitioners I have talked to suggest I have it done again. A more detailed look at my auditory training can be found in the Spring '93 issue of the Advocate.

Sex is not important to me. It never really was. As mentioned above, this is what ultimately led to the demise of my marriage. It used to be that I felt bad about this. But that feeling has changed, possibly to reflect the times. I am now very comfortable with this. And in fact, I prefer it this way.

Since F/C has been shown to be successful (at least in the minds of the parents, which is what really matters), I would like to advocate the use of modems as a way and means of communication for those who are non verbal.

Modems are little communication devices that either plug directly into motherboard of a computer, or plug into the serial port. They allow communication by typing through the phone lines. There are hundreds of systems out there, most of them free of charge, that allow you leave messages for and to chat with other people. I feel this would be an excellent opportunity for non verbal people to learn to communicate. Especially since on many of these systems, you may remain completely unknown if you so choose. I have accounts on disability oriented systems all over the USA, plus I can be found on the Internet at this address:

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I would like to echo the words of Jim Sinclair by saying "Don't mourn for us." But by that I do not mean to say that autism is not a bad thing. I just mean to say it is not the worst thing that can happen to a person. If, for some reason, it is, it must be not because of what has happened to us, but more because of how the general population perceives us.

I have lately noticed that in many cases, those who do not need to deal with the autistic population directly have little to no interest. And I suspect this would be true of any other type of disability. They feel they have more important things to worry about, and so they let the rumors and misconceptions remain in their heads. I know of people who still believe in the cold parents theory.

I have been asked many times if I would accept a cure if one was found. The answer is: NO. Because I like who I am. Those who do not understand fear our differences. Instead, they should be rejoicing in them. I feel that the autistic population has much to offer this world. And I wish we would pay more attention to them. Sometimes, a sideways view of looking at reality seems to be exactly what is needed.

With auditory training and facilitated communication and sensory integration therapies, so many of the symptoms of autism can now be treated. But there are still many that can not. To many people, no voice equals no brains. But that is not the way it is with these kids. They have the ability of rational, cognitive thought. And I suppose, if I had one message to give to everyone, that would be it. To remember that somewhere inside each of them lies a real person. A person with thoughts and feelings, and a person who needs love just as you do. And if you do not give it to them, no one will.