

# Inside the Mind of Sensory Overload

By Thomas A. McKean – 10/17/08

Years ago when I was bouncing around the country speaking at conferences, the questions parents were asking made it clear to me how very vital it is that we who are able to express our experiences with autism do so. I had, for a time, been staying away from becoming too personal because I was hesitant to reveal too much. This lack of trust was (and to some extent, still is) something that goes way back to my childhood. I had been speaking in general terms at the conferences, all the while being so amazed and impressed that some of my colleagues (who are writing articles elsewhere in this magazine) were able to open up to the degree that they have. Their insight, honesty and candor have forever changed the way we view autism. I am proud to also have the small (probably very small) credit I do in this. The following article is an update of one of my most popular published articles. It was published in the *ASA Advocate* newsletter a long time ago during one of my terms on their board of directors. It was the beginning of an attempt on my own part to learn to be more open. Though in hindsight it took me way too long, I eventually saw that it is only by close examination of autism from every angle that we will find the answers we need.

One of the many acknowledged but very often misunderstood aspects of autism is the sensory overload factor. It is common knowledge that individuals with autism have sensory problems. For example, hyper acute hearing is common, as are pressure cravings and tactile sensitivities. Another common problem is the inability to process the amount of sensory input that exists in certain situations. When this happens, the person with autism goes into "overload" and his whole sensory processing system "shuts down" because his (or her) senses cannot accurately process the rapid amount of information that is coming into them.

But what exactly does it *feel* like inside to the individual when this happens? As the new year comes, I would like to share three very personal experiences that I am hoping will help to answer this question.

One day, back in 1987, I was visiting my friend Gwendolyn in Illinois. She was living in Cicero at the time. She and her husband Michael decided to show me one of the sights of Illinois, this one being the Oak Brook Mall. One of the biggest malls in the country. Or at least it was at the time.

I was looking forward to this venture. I had a little extra money to spend and I was going to experience something new. Deep inside, I felt the fear I always felt (and continue to feel) when I am going into a new social situation, but in this particular case, I also felt that I was going to be protected. There were no people in the world who knew me better than those two. I would be okay, autistic or not.

The mall was quite the experience. Up to that point, I had never seen a mall with more than one floor. There seemed to be stores for everything. I wondered how interesting it would be to compare prices on certain items at the various shops. We walked around, did a lot of window shopping, and bought very little merchandise.

All the while, there were (in abundance) the two things that many people with autism have problems with. That of course would be sound and motion. Even just one of them can often times be a problem. Together, they are almost deadly. The eyes and ears of the person with autism just aren't built to be able to process that kind of rapid information for any period of time. So as the afternoon at the mall continued, I felt myself slipping further and further away from reality.

I vaguely remember the car ride back to the apartment. All visual input was reduced to a fragmented kind of "Picasso vision". What I saw looked like I was looking through broken glass or a cracked mirror. Some it was foggy and indistinct, mere shadows of substance. Color had no meaning and ceased to exist. My voice was completely gone. My world had become a hideous black and white horror movie distortion of reality. All auditory input was magnified in volume and echoed very painfully in my ears. Everything my hands and feet touched felt like flames. When we arrived home, I collapsed in their bedroom and started to cry.

Michael tried to console me but was unable to reach the Thomas within. Gwen came into the bedroom later and, as always, something from deep inside me recognized her touch as the gentle embrace of a friend. I had no idea who she was. I had no idea where I was. I had no idea what I was doing or how I got there. All I had left at that point were very primitive instincts and they told me I could trust her.

Michael came in and started lightly scratching my back, wanting me to feel better. I didn't know who he was and so I was very much afraid of him. My hand got tighter and tighter in Gwen's hand until she told him to stop. I mauled my friend Gwendolyn in platonic desperation until I finally fell asleep.

According to Michael, it was two and a half hours later that I woke up. He put some macaroni and cheese in the microwave but I found that I had not yet fully recovered so my skewed gustatory senses told me it tasted awful, even though it likely didn't. It took a few more hours before I was back to myself again.

It takes an incredible friendship to be able to go through something like that and I am very thankful they were both there for me.

Jump ahead now to late 1992. I am in Las Vegas, attending a board meeting of the *Autism Society of America*. I was still new to the board and I had never before been in Las Vegas.

The sensory modulation was overwhelming. Vegas, to me, seemed to be exactly as shown on television, with flashing lights outside and furious gambling inside. The stress of being new to the board combined with the sensory aspects of Vegas caused me overload during the meeting.

Sally Ramsey, who was then ASA president, asked for a volunteer to be the ACDD representative to the board. I volunteered. Part of the job was touring residential facilities and I had already had experience with these, having served three years in just such a place. Sally told me she wouldn't allow me. When I asked her why, she said (and this was verbatim, and in front of the entire board of ASA), "*Because you have no social skills.*" Now I had three situations to deal with. Not only the stress being new to the board and the sensory overload of Vegas, I now also had Sally's completely uncalled for and completely inappropriate comment. I walked out of the board room, found a nice dark corner and again began to cry.

I have since heard that two members of the board left soon after to find me. But they never found me. Peter Gerhardt (who was also new to the board at the time) did find me, though. And I must have been one sorry sight in his eyes. He talked to me and seemed to understand what was going on. Since that time, a few people have tried to cause some controversy with him. This has always angered me. Peter's difficult and controversial decision to walk out of the board meeting created a mutual trust and friendship that exists to this day. (Hi, Peter!)

There is another irony here that I would like to point out. I was supposed to be surrounded by the greatest and most knowledgeable advocates for autism in the entire United States. Why did they not see what was happening to me? Why did they not understand? Why did Sally get away with that comment?

Jump ahead again to April 22nd, 1995. I am in Baltimore speaking at an autism conference by *Future Education, Inc.* Later they would change their name to *Future Horizons*.

After the conference was over, all the speakers went out to the *Inner Harbor*, a mall along the harbor in Baltimore. Again, the sensory input was overbearing. Everywhere I looked I saw motion and heard sound as crowded people were walking by and talking amongst themselves. My eyes and ears were unable to process this rapid information. I felt my entire sensory system begin to shut down.

But it was different this time. This was many years after the "Oak Brook Incident." I had no idea what autism was back then, much less that I had it. Thus I had no idea who Thomas even was. But now I did. And as I felt myself begin to slip away, I became fascinated by the feeling. And as it happened I began to search inside for words to describe it. As long as something bad was happening to me, why not at try to make it positive in some way?

Meanwhile I latched on to another speaker's hand. I held on and I didn't let go. I knew if I did let go, I would be completely gone. She was the only thing keeping me from complete overload.

I watched with fascination as my clear vision faded to distortion. I watched as people morphed to become fragmented objects and shapes and clouds. I watched as the reds, blues and greens became different shades of gray. I listened as the volume on the universe slowly turned up. Higher, and then higher still. I had a picture in my head of Bill Bixby turning into Lou Ferrigno. I wondered if this is what it would truly be like to become a Hulk.

Then my mind got fuzzy. I felt a tightness in my chest. It was hard to breathe and I felt and thought only one thing. *"Get away. Get away. Not safe here. Go someplace safe where you will not be hurt."* I looked down at my hand in hers. Something inside told me I was not to let go. I didn't let go.

I saw another member of our group. I gazed into her eyes, going as deeply into them as I could. *"Help me. Afraid. Don't want to die. Don't want to be afraid anymore."* The message was non-verbal and she didn't get it.

Anne wanted to go inside. I pulled her away from the door. We went into a different door instead. With what little sanity I had left, I again wondered why these "experts" in the field were unaware of what was happening. I wondered if maybe they did know and just weren't able to do anything about it? I couldn't tell them; my voice was gone.

I don't remember much of what happened after that. I remember only waking up in my hotel room.

### **SOLUTIONS:**

What can be done when the person gets into this situation? What would I have wanted those people to do for me?

Michael and Gwen, despite the lack of a knowledge of autism, did exactly what they should have done. I have always found tactile input from a friend to be the most calming thing in the world. Those who are little more tactile defensive than I am might have a hard time with this. All Mike and Gwen could do in that situation was let me find my sleep (and my nightmares) and wait for me to come back to them. I am grateful for their patience.

Out in public, whether it is me or anyone, the situation is different. It is difficult to cradle someone in public. Much less an adult. And never mind that they may not want that anyway.

One solution (unfortunately perhaps the *only* solution, short of leaving the area) would be to find a quiet place in the environment. It should be not only be quiet, but also dark or at least lacking in people, motion and sound. And it should convey a feeling of safety and security. Such places may be hard to find and you may have to do some searching. Once in this area, the mind and body can process and regulate the necessary information to deal with the problems internally. The less sensory stimuli in the area, the better able the person will be to process and the sooner all of you will feel better.

If this is a chronic problem, there are some medications that may be of benefit. Consult a physician or psychiatrist for more information. And always remember to take the lowest possible dosage.

By being aware of the problems people with autism face on a daily basis, and by being aware of the possible solutions to these problems, we can improve the quality of life not only for them, but for ourselves as well. This is something we would all like to see.