

The Central Valley FEAT Interview

Thomas A. McKean, Interviewed by Suzanne Williams - 07/16/01

Thomas, thanks for doing this interview with me. You have an insight that parents may find helpful for their children with autism. You have written 2 books, *Soon Will Come the Light*, and *Light on the Horizon*. Your writing style is easy to read and flows well. You have three national awards, became a Kentucky Colonel, and have had a seat on the national board of ASA. You have a wonderful website with topics ranging from personal experiences, advocacy, conference recordings and the best video game "review" for children with autism. Thank you for doing this interview over the computer with me.

Do you remember how we met online? Did I contact you, or did you find me? How long ago was it?

It was about 2 years ago, give or take...

Have you ever done an interview on the computer before?

Yes. Most recently for *Esquire Magazine*. The June 2001 issue.

When did you discover that you had been diagnosed with autism?

I was diagnosed in 1979. I was 14 years old. I didn't know about the diagnosis myself until I was well into my twenties. No one bothered to tell me. My parents have told me they didn't know about it either until I told them. So I guess no one bothered to tell them, either.

I was engaged in 1989 and when we went our separate ways in 1991, I went back to the hospital to ask for my records. They gave me the admission and discharge summaries (spaced three years apart) and that's how I found out. This was 12 years after the diagnosis was made.

Do you find it easier to type, instead of speaking?

Talking is very difficult for me. Language has to go through internal translators before I can talk or understand what someone is saying to me. That's also true with typing but with typing it is easier... I have often said my favorite situation is when I am with other people and alone at the same time.

Closer friends have heard the untranslated language that is more native to me. They seem to think it is "cute," but really I don't know how they can understand it.

What age do you remember talking?

I remember sixteen. My parents tell me I was five. So I don't really know? I guess it may have been closer to five because I remember my mother telling once that the reason no one would give me a diagnosis of autism was that I was talking. But I don't remember being very chatty.

I read an article where Temple Grandin stated she believes that some children with autism learn to read before they speak. What was your experience?

I learned to read before I learned to speak.

Were you able to understand what people are saying at a young age?

Not really. They were frustrated too because they knew I heard them. I heard them but I didn't understand. I hear them and I still don't understand. I've just learned to pretend I do.

Do you have trouble now?

Yes but now it is more visual. My eyes don't process visual information correctly so I have problems sometimes even recognizing my friends. Some of them have gotten to the point now that they tell me who they are when they walk up to me. It is very sweet and I love when they do that for me, but I feel bad sometimes they have to do it.

As I have gotten older, my eyes have gotten more into interpreting people and items as clouds and random geometric shapes and shadow. There is one other person with autism I know of who has this problem and if there are two of us, there are probably others.

I have also recently been having problems with colors. It isn't that I don't see colors, it is more that I see the wrong ones. One example I can give is a couple of years back, I was still living in Columbus and I went to visit a friend. She was drinking coffee from a purple coffee mug but my eyes saw a combination of red and blue. It was quite beautiful to look at, but it was also scary because I knew that what I was perceiving was incorrect. I have a friend here in Bedford who has a good eye for color and sometimes we play color games. Recently I brought her a big pile of socks to sort for me so I could be sure that they matched when I wore them. I really love it when my friends do simple things like that for me. It makes me feel loved and special. :)

Sometimes I wonder, if these things continue to get worse, how long I have before I can't drive anymore. (Yes, I do have a valid Virginia driver's

license.) Though I have never really enjoyed driving, this is something I don't look forward to giving up. There is freedom on the open road.

I know that you were bounced around in different classes and placements during your childhood. What effect did that have on your ability to make friends?

Friends? What friends were those? *Blink*

Would it have been easier for you to stay in regular ed, or special ed? Did you notice the difference?

Oh yes, I noticed. Special ed people were not the most popular in school. We were in that "slow" classroom so you know what that meant at recess. Thank God I never had to go to high school. (But I did go on to college.)

I think, if the special ed teachers knew what they were doing, it may have been better for me in the special ed class. I am always very happy when I see the teachers come to hear me speak at conferences because it means they have an interest in learning how to better serve the students. And I always try to tell them that I like having them there for that reason.

What was your reason for writing your first book?

Originally it wasn't a book. It was a letter written to Dr. Mira Rothenberg (author of *Children with Emerald Eyes*), who wanted to know what it was like to have autism. I figured it may be therapeutic to write it out since I was wondering myself at the time she asked me. There were three letters written to her and SWCTL is an edited version of all three of them together. (The *original three unedited* letters to Mira are available from my web site, if anyone wants to read them.)

My motivation for releasing them as a book was another book called, *Children With Autism: A Parents Guide*, which you will recall is edited by Michael Powers. I read it and I didn't like it because it was very negative. It offered pretty much nothing in the way of hope for parents. In fact, if it did anything it made autism look even more hopeless! (This is not to be confused with, *A Parents Guide To Autism*, by Charles Hart, which is an excellent book.)

Granted I may not have been the best person to say there was hope, but I was able to live on my own, sort of (I was living by myself on the campus of OSU back then), so I thought I would try to write something a little more positive, right down to the title of the book, which I took from the title of a song I wrote for my nephew when he was born. The lyrics to the song open the book.

What target audience is this book best suited for?

Hmmm... Good question. I would guess maybe people who are already a little familiar with autism (the book assumes you already know a little something about the disorder and some are angry at me for that) that want a more personal view.

Maybe it is also for people who know Thomas. Or who think they do. :)

Your second book is hard to find. What is different about each book?

The second book was pulled because of mistakes. My mistakes, the publisher's mistakes, and even the printer's mistakes. I have most of the copies of it here in my closet. I have rewritten it many times but I have never been happy with it.

I am currently rewriting it again and hopefully this time I will like what I am writing. I am trying harder this time to get it right.

I am adding some things about sensory dysfunction, relationships, and the more "private side" of autism.

Look for it soon at a bookstore near you! :)

Your website has information regarding your own personal experience with sensory complexities, and helpful advice on how to alleviate sensory overload. Do you maintain your website?

All of the HTML code on the site is mine. I built it myself as an experiment. I had no idea it was going to get as big as it has. You can get to the site by going here:

<http://www.thomasamckean.com>

This site has grown considerably since I first created it. Originally I made it to promote the book(s) and to put up some articles I had written on autism for parents of kids with autism to read.

Now it has a lot of pictures, a few links, writings I have done other than autism, a few autism friendly video game reviews (try finding THAT elsewhere on the net), and several other things. If you are looking for a bear to get for your child, do check the site.

Can you be contacted directly?

[thomas \(at\) thomasamckean \(dot\) com](mailto:thomas@thomasamckean.com)

I know the color yellow is painful for you to look at. Could you explain why?

Visual distortion and light/color sensitivity is common in autism. As I am writing this, I just got back from visiting some friends. I left some sunglasses there and I went back to go get them but it was getting dark. They kept turning lights on and off for various reasons and turning them off was (and always has been) just as painful, if not more so, than turning them on. One of them suggested that I put my sunglasses on. :)

I have noticed in my travels that the color sensitivities are always either red, yellow, or blue. As anyone with a grade school education knows, these are the three primary colors from which all other colors are made. I find this an interesting coincidence.

I don't know why yellow is painful for me. I do know that looking at something that color is like looking directly into the sun. It is also my father's favorite color and the way he likes to answer the phone. He picks the phone up and he says, "Yellow?"

Is your hearing sensitive?

Very sensitive. I had the auditory training done in 1993 but it was temporary and unsuccessful. (See SWCTL or the Spring '93 *ASA Advocate* for details.)

Recently this was a problem in the church. I sit in the back on the floor and wear electronic (noise reduction) headphones. I am sure there must be people who think I am listening to the radio. This is not what you want people to think when you are in church.

Church is something that is new to me. Growing up, the church I was attending as a child did not seem to be "real" to me. Also, I was forced to go, it was not a choice I made on my own. Add to that the daily suffering of autism, and for many years I was totally turned off to the concept of God.

Now, having moved here to the mountains of Bedford County, it is much easier to be spiritual and to have faith. God will take all on amazing and wondrous journeys if only we allow Him to do so.

You know that my three boys with autism are completely different. In all of your travels, have you ever met children or adults with autism that are exactly alike?

No; and I know I won't. This is what makes autism both an annoying as well as a very fascinating disorder. It never effects two people the same way. People with autism are a lot like snowflakes.

My son Ronnie reads books like crazy! What books do you like to read?

As I write this, I have just finished the second of a *Xena: Warrior Princess* novel trilogy. (And poor Joxer!)

Years ago I used to collect comic books. Now I prefer the novels because they leave more to the imagination and I like that. Not long ago, a friend came into my apartment and stared at the *Spider-Man* and *X-Men* novels I had lining the shelf below all the same videos. I told her I had them there because "I can relate to wearing a mask."

I am not sure she understood.

I like reading the anthologies edited by Martin H. Greenberg, and Diane Duane is also an excellent writer (Her *Spider-Man* is dead on accurate). So is Harlan Ellison. I had the opportunity to talk with him once and he is nothing like they say he is.

Do you like animals?

I like animals more than I like people. I have a strong rapport with animals and they aren't always afraid of me like they are others. Even wild deer have come up to me to say hello. I once gave some serious thought to becoming a veterinarian.

My children enjoy carrying around the cat at my house. I know you have a cat named Reiki. What does Reiki mean?

Reiki (RAY-kee) is a Japanese word. It means "health" or "healing." It is also a word used to describe a metaphysical form of healing by laying on hands.

I acquired my cat back when I was deeply studying metaphysics in general. I wanted to know more about it and if it was valid and the only way I could find out was to immerse myself in it, which, upon reflection, I now believe may have been a spiritual mistake...

Still, I do believe "Reiki" is the perfect name for a cat. Felines are the ultimate in grace and beauty. Every one of them from the household tabby to the white tiger. It was suggested recently that I change Reiki's name to get away from the metaphysical references, but I want to keep her just as she is. She is very special and I love her very much. :)

Do you find Reiki relaxing?

Which Reiki? The healing or my roommate? *Blink*

Autism is a syndrome of extremes. One of the more common symptoms is a tactile defensiveness, but my tactile sense goes the other way. I crave touch. It is very calming and it takes my pain away. Maybe this is why I had a few Reiki sessions way back when.

As for my roommate, she is very relaxing. She has that cute purr thing going. (Even Spock could not resist the purr of the Tribble.) And she is soft and snugly, as a cat should be. At night when I am sleeping, sometimes she hops up on the bed, puts her head in my hand and goes to sleep.

(Sometimes I do have to remind her to help around the house though. I mean really, would it hurt her to clean up after herself? And it would be a big help to me if she would vacuum once in a while. I mean it is her hair on the floor...)

Other things that are calming for me are the pressure bracelets I designed (based on Temple's squeeze machine) and nibbling on a teething ring, which I recommend for parents whose children are chewing on everything in sight.

What other pets have you had growing up?

Mozambique comes to mind, of course. She was a terrier that followed me home from the hospital. My mother wanted to name her "Clancy," being as she was big on her Irish roots. Being rebellious, I named her "Mozambique" because that was far from Ireland as I could think of. She was also named after the song of the same name by Bob Dylan, which is off of his *Desire* album from 1976. Mozie had a cute trick where she would go to the park and climb up the ladder of the slide and slide down and do it over and over again. One time a guy brought a video camera because his wife thought he was lying about it.

Before Mozambique, the family had Tippy. Not a name I would have chosen for a dog, but she did make it to 16 years. We also had Jasmine, a dog who lived even longer, and Stormy, a husky/shephard mix who was literally thrown at me as a puppy on the OSU campus one day.

I also vaguely remember my brother had a parakeet at one time named Sneed. And for a time, I had two hamsters, Amazon and Aphrodite. Amazon died early but Aphrodite lived to enjoy over \$300.00 of habitrail.

What do you feel your parents did that helped you growing up?

Remember that they didn't know about the diagnosis as I was growing up so they were pretty much working blind. :(

But still there are two things I can think of right away. First was the music. The house was always filled Irish folk music. My mother loved it and she still does. So instead of listening to popular music, we all grew up on the *Rovers* and *Clancy & Makem* and the *Dubliners* and the *Bards* and the *Irish Brigade*.

The lyrics to the songs were very educational for me:

In the streets of northern Belfast, in the dark of early morn,
British soldiers came marauding, wrecking people's homes with scorn.
See the crying, sobbing children pull their daddys from their beds.
See the screaming, helpless mothers watch the blood flow from their heads.

What made it educational is that the history of Ireland is told in the music. These things, unfortunately, really did happen. But this wasn't all they wrote about:

Come over the hills now, my bonnie Irish lass,
come over the hills to your darling.
You choose the rose, Love, and I'll write the vow,
and I'll be your true love forever.

Red is the rose that in yonder garden grows.
Fair is the lily of the valley.
Clear is the water that flows from the boyne,
but my love is fairer than any.

And this:

She was waiting at the station, I was was rushing through the fare
when I tripped on a step and I stumbled and fell, head first, on down the stairs.

Mrs. Crandall came up to me. "Did you miss a step, my son?"
"No," I said, "my dear landlady. I hit every bloomin' one!"

I learned of the joys of love, and I learned of the horrors of war. Both in a way that only the music could teach me. It reached me when nothing else could.

The other thing they did was they seemed to understand that I needed to know how the world worked. So I was always taking things apart. Then after a while I was taking things apart and putting them back together. Then after a while I was taking things apart and putting them back together with more features than they had before I took them apart.

What do you think is important for parents to know about raising children with autism?

What is important for parents to know is exactly what autism is. They need to know what it is, and more importantly, what it is NOT. (As in: not their fault.) They need to understand that the senses are severely affected, and (unfortunately) they need to understand special education law if they want a future for their child.

Parents also need to know they are not alone. They need to attend group meetings and conferences. But along with that, parents need to understand that not all professionals are suggesting things that are good for the child.

Parents have a responsibility, both to the child and to themselves, to actively seek more information regarding treatments and therapies. Just because someone with a "Dr." in front of his name says that megadoses of certain vitamins are okay, that does not necessarily make it so. That goes for ABA, MMR vaccinations, auditory integration training, sensory integration therapies, and all those other things people are talking about. Parents **MUST** investigate these things further for themselves and make an educated decision on the best treatments and therapies for their child.

Also - it is important for professionals to know things, too. They need to know that the parents know their children. They need to remember that the parents understand the children better than they do.

Doctors and therapists need to pay more attention to the parents than they are currently. So do the schools. Everyone needs to work together for the betterment of the child. Time and time again I have heard of everyone working against each other. Due process and other arguments. Things like this need to end if the child is to have a future. The way this ends is not by doing what is best for the parent and not by doing what is best for the school. It is by doing what is best for the child, who, through no fault of his own, is caught in the middle of a battle he wants no part of.

I know you have said you would not change yourself if a miracle cure came around. Do you still feel that way?

No I don't.

Sensory pain gets worse as I get older. The day will come when it will take a lot more than pressure bracelets and nibbling on a teething ring to get rid of it. Knowing that is coming, yeah I would like to be cured. I tell my friends all the time about how I long to throw my medic alerts into the ocean. I want to get into a chopper, fly a few miles off the coast of Kitty Hawk, and toss them into the waters where they will never be seen and, more importantly,

never be needed ever again. I long for that day and I am trying to make it happen.

What do you feel is your greatest accomplishment to date?

I don't know if I have one great accomplishment. SWCTL was an accomplishment. My five years of service on the ASA board of directors was an accomplishment. (Some would disagree with that, I am sure.) Getting out of the hospital was an accomplishment. The KY Colonel award was an accomplishment, as were the other three national and numerous other local and regional awards.

There are other things that are accomplishments... Like passing that GED test first time around, I still don't know how that happened? Getting this interview written, that is also an accomplishment. Lots of questions! :)

Finding this wonderful town of Bedford, VA, to live in is an accomplishment, at least it is to me. So is knowing how to pick my friends. Okay so I learned slow, but at least I learned.

I have much to be thankful for. I have been blessed.

What are your plans for the future?

I would like to get healthy again and go back out on the lecture circuit. Except it would be different this time. Not sure how yet though. In such a way that I could still do it, I suppose.

Also I would like to write another book or two or more. Maybe publish some fiction, science and otherwise. I wrote a sci-fi novel years ago called, *Time Tapestry*, and I have several ideas for others, some of which are on the site.

And I would really like to try writing some scripts and screenplays. I wrote a short one for the *All In The Family* TV series, it is on the site as well.

Will you do another interview like this again?

I guess that depends on who was asking. :)