Speaker Puts Face on Autism

Cynthia T. Pegram, Lynchburg News & Advance Lynchburg, VA – 1999

Unless Thomas McKean tells you he is autistic, you won't know.

Smart, funny, complicated, and irritated about having grey hair at 34, McKean is doing what every parent of an autistic child hopes for his own child--succeeding at things he is interested in.

McKean has authored two books, is a board member of the *Autism Society of America*, and a frequent public speaker.

"Thomas has been a lot of encouragement in my life," said Theresa Vincent, a board member of *Advocates for Special Citizens* and mother of an autistic child. "I hope my own will do as well."

McKean, interviewed on a recent visit to Lynchburg, will speak at Lynchburg College at 7:00pm tonight in the Hall Campus Center. The free program is open to the public and is sponsored by the Bedford Advocates Group, Lynchburg College, and the ARC.

Autism is not clearly understood. It is best described as a developmental disability in affecting sensory processing. Some autistic children never speak or communicate and are hypersensitive to sound.

McKean, from Columbus, Ohio, was diagnosed as autistic at age 14, but he did not know of his diagnosis until he was 25.

He knew when he was five that something was different. "I wondered which planet I was from. That is common in autism, to for people to look up at the sky and wonder which planet they are from."

He was in special education. From ages 14 to 17, he was in a mental health institution.

In the 1970's, autism was associated with mental illness and bonding problems with the parents.

"They called them refrigerator parents because they were cold," said McKean. "It took a long time for people to accept it after it was proven to be a neurological disorder."

"My own theory is that it is mainly a sensory disorder. I've had people agree and disagree on me with that," McKean said.

"What one perceives through the senses is distorted either on the way to the brain or in the brain itself, so what you perceive as reality, is in fact a distortion."

In some autistic people, the sense of hearing is affected. The problem is not that they don't understand the words, it is the way they hear.

McKean describes it as "a hypersensitivity that has more to do with frequency of sound than with volume."

When he looks at something, McKean said he has to translate what he thinks he sees. In his book, *Soon Will Come the Light*, he describes what he sees as "clouds and shapes and shadows of substance."

Some estimates are that 1 in 500 people have some form of autism.

"It has a huge spectrum," said Vincent, who adds that many people think of it only in terms of "Rain Man and mental retardation."

McKean, for example, said he understood what the teachers were instructing but, "I never did the work."

"Why should I write down the answers for some teacher when I already know them? Why should I prove I know the answers, I'm satisfied I know the answers."

Once he got into college, he said, "I finally figured that out...that you *do* have to prove it to the teacher."

McKean went to college in Illinois, which allowed him to attend without a high school diploma and let him earn his GED while taking college courses.

In 1992, he put his name on the ballot for the *Autism Society of America* board of directors.

"Because I was elected, they requested I attend the annual conference. I didn't want to but I agreed to it."

He went ahead, and now says, "I've discovered that if you do certain things, you can be wiser for the experience."

He agreed to speak on a panel at the conference. "Then all of a sudden the requests to speak started coming in."

"I find it rewarding. I didn't at first. It was stressful at first."

Now, he says, "I try to keep my life simple. I've been thinking about going back to school--for a journalism degree. Writing is really the only thing I know how to do."

McKean will answer questions from the audience as well as give insights into the therapies that have benefited him.

Dorothy Narodny, a teacher and a member of the Bedford Advocates Group, said that the book "gives you a lot of insight into his experience as an autistic person."

Because autism has so many variations, especially in social relationships and communication, Narodny said, it is very illuminating "when someone with autism is able to communicate how they got from where they were to where they are."