Man Now Speaks For Those Who Suffer in Silence

By Dennis Fiely, Columbus Dispatch Columbus, OH - 01/13/95

A meeting with Thomas McKean is often memorable, especially for the parents of children with autism.

When McKean, 29, recently appeared before a parent's group, a mother exclaimed, "My God, it's a miracle."

The "miracle" is McKean's apparent recovery from autism. The parents of young children who are withdrawn, incommunicative and impulsive do not anticipate McKean's openness, articulation, and wit.

He gives them hope: Can their children break free from their private worlds and develop as he has?

These days, he is a speaker--earning \$500.00 to \$1,000.00 an appearance to provide insight into an illness that baffles the medical community.

McKean, of Columbus, is also among a handful of people who have had the will and skill to write an insider's view of the condition.

His book, Soon Will Come the Light, recounts his struggles and those of his family and mental-health professionals to diagnose, treat and understand his illness. It also outlines his symptoms--from voices in his head to his fascination with spinning objects--in a valiant attempt to explain the bizarre behavior associated with autism.

Like many people with autism, McKean had the abilities of a savant. He possessed a photographic memory and a musical genius that enabled him to recreate songs on a piano or guitar after hearing them once.

Such attributes have faded as he has become more sociable.

His most lasting and greatest gift, though, may be his ability to communicate what being autistic is like.

McKean recently talked about his life to commemorate national Autism Awareness Week, which runs through Sunday.

Speech, however, remains difficult.

"I can make people think I am normal," he said, "but it takes much effort and energy."

Autism, a lifelong developmental disability that appears during the first three years of life, is a neurological disorder that affects brain function. Autism, or autistic like symptoms occur in about 15 of 10,000 births.

People with autism share many symptoms, but reveal individual differences. Thus, to expect recoveries as complete as McKean's is unrealistic.

"There are all sorts of degrees of autism," said Joan Fechter of the Central Ohio chapter of the Autism Society of America. "It's hard to predict which kids will do OK."

Because of McKean's high level of functioning, some parents think he is not truly autistic.

He didn't learn of his autism--from a psychologist from the Ohio State University-until 1991.

McKean's book describes his symptoms in graphic detail.

He hates change, lacks an appetite and--because of his overly active mind--has trouble falling asleep.

He tells about his "dead" nerves ("I don't know the meaning of the word *calm*."), his need to wander and withdraw, and his craving for isolation. (He happily lives alone in a condominium on the North Side.)

He also writes of his "low-level pain," relieved by rubbing his arms, legs, and back with a soft bristled surgical brush.

"I wish I could run to someone every hour," he said, "and have them brush me down."

Autism is "primarily a sensory disorder," McKean is convinced. A heightened sensitivity to sounds, voices, textures, sights and smells sparks unusual behavior.

His earlier attitudes and actions, he said, made life "a living hell" for his parents-and hindered professionals who tried to help.

"I must have been to every psychologist in the city of Columbus," McKean said. "I kept taking the same tests. It was so boring I eventually manipulated the doctors with my answers--which may be one reason they were so confused."

After years of special education classes, he was admitted to Worthington's Harding Hospital at age 14.

His book details three years at Harding. "No one gave us enough credit," he said. 'People assume, if you can't talk, you don't have a brain. But that's not true."

When McKean left Harding, he attended a junior college in Illinois that accepts students without high school diplomas.

He met a woman he said turned around his life and his illness. He has dedicated the book to classmate Gwen Bossingham Jebb.

For most of his life, McKean's treatment had consisted of "aversion therapy-being trained to stop certain behaviors." It made him only more rebellious, he said.

Unwittingly, Jebb helped him with a simple formula: love and acceptance.

"She was the first person," McKean said, "who treated me with dignity and respect, like a real person."

They remain close friends.

Another breakthrough occurred after McKean's return to Columbus: He became involved with the Central Ohio chapter of the Autism Society of America, where he found further acceptance.

"What I was being hated for and punished for my whole life were the same things I was now being praised for," he writes of his first meeting. His participation in the group launched his career as an advocate for people with autism. It encouraged him to write his book and serve on the board of directors of the *Autism Society of America*.

Soon Will Come the Light, published 10 months ago, has sold 3,000 copies. A second printing is planned.

The book concludes with lyrics from many of McKean's musical compositions.

As others have come to terms with his illness, so has he:

For it has taken
Twenty years
For Mother Wisdom
To teach me her
Most valuable lesson
And I no longer expect
What life cannot give me.