

“Autism is Not Me”

Donna Williams' Courageous Search for “Self”

After reading Donna Williams' two books about her life as an autistic, Elaine Vanstone stands in awe of this woman who has pulled herself from the depths of painful, misunderstood isolation. Based on her years spent working with autistic children, Vanstone doubted that a true autistic could reach such a level of achievement. Now, she believes that Williams is not only autistic, but also a savant—someone who possesses unique brilliance or genius. We stand to learn much from Williams both about autism itself and humanity as a whole.

***Nobody Nowhere* and *Somebody Somewhere* by Donna Williams. Doubleday, 1992 and 1993. \$26.95.**

by Elaine Vanstone

Until her mid-twenties, Donna Williams thought she was crazy. At the end of her rope, she decided to write down her life story in a diary and took it to a psychiatrist to diagnose what kind of madness she was suffering from. It was then she discovered that she was autistic.

That diary took her four weeks to write and eventually became her first book, *Nobody Nowhere*. The narrative begins with her earliest childhood memories and recounts her life to the time when she was 25 years old. Williams' second book, *Somebody Somewhere*, covers the next four years of her life.

A misunderstood syndrome

Autism is a life-long information-processing disability which affects approximately four in 10,000. Four out of five autistics are male. Caused by an unknown abnormality in brain development which occurs either before birth or in early childhood, autism does not necessarily mean mentally handicapped.

Much has yet to be learned about autism. Though autistic people do not interact with the world around them as “normal” people do, they possess an internal logic and rationale for all that they do, feel or express. Though autistic people may differ greatly from one another in the symptoms they exhibit and in the severity of their expression, there are three constant disorders which are found in nearly all cases.

First, autistics experience severe communication problems, affecting their ability to interpret and use words, gestures and facial expressions. Abstract phrases are especially confusing, as autistics tend to understand words literally. Many autistics do not acquire verbal language and may never speak. With those who are verbal, echolalia (the repetition of words heard from others) is a common speech trait.

Difficulties in developing social relationships is another barrier commonly faced by autistics. Often in childhood, this symptom manifests itself as a lack of interest in the attention paid to the child and unresponsiveness to people around them. Some autistics may retreat into a solitary world, while others appear overly outgoing with strangers and family alike.

Finally, autism is usually associated with ritualistic or compulsive behavior. Often this involves a strong preoccupation or obsession with a particular object, action or routine. Repetitive movements such as rocking are also common.

Other characteristics of autistic people may include detachment, fear of physical touch, self-injurious behavior, and



Donna Williams: shattering the myths of autism and rising above its challenges.

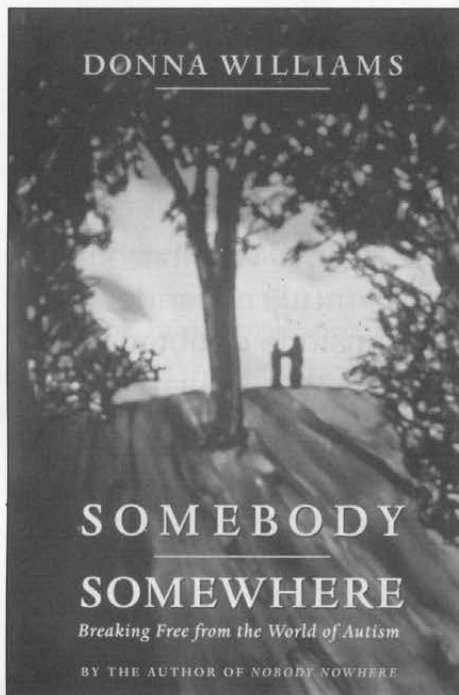
unusual anxieties or fears.

Reclaiming her “sanity”

Although Williams was diagnosed as being autistic at the age of two, she was never told what her condition was. Instead, she was mistreated. Her mother had no idea of how to cope with a child who had special needs, and so turned to verbal and physical abuse to deal with her daughter.

Williams' stories tumble from the pages at great speed—perhaps mirroring the frantic pace at which she originally recorded them. *Nobody Nowhere* sucked me into her vortex of confusion, and

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forced me to experience her world firsthand. Through the telling of childhood events, Williams defies the misconception that autistic people are mad and conveys the inherent rationality of their actions—actions that usually elude the empathy of those around them.

For instance, Williams provides insight into why echolalic speech is common among autistic people. She says she immediately repeated everything that her mother said because she did not understand what was being stated in the first place. She only gave back what she had been offered, and would be further confused when these dialogues would lead to her being berated or beaten. I had been taught that echolalia was just something autistics do; now I have a fresh perspective through Williams' eyes.

She also tells other stories of how she was punished for swatting at "nothing" in the air. As with many autistics, Williams was hypersensitive to her surroundings and was trying to catch the dust particles that were visible in the rays of sunlight. Again, what many shy away from as abnormal antics are reasonable when explained in context.

Elaine Vanstone is a mother of four children, one of whom is mentally challenged. She worked for ten years with the Vancouver School Board with children displaying behavioral problems—many of them autistic—and says they taught her a tremendous amount about life.

Nobody Nowhere ends where Williams' new life began: with the confirmed diagnosis of autism. The doctor who read the diary was amazed that the world of an autistic could be communicated so clearly. He showed the diary to colleagues, and because of the uniqueness of Williams' story of survival and her ability to relate it to others, numerous publishing houses were eager to buy the rights to the diary.

Joining the "real" world

Somebody Somewhere begins with her brave decision to attend university in order to obtain a teaching degree. In return for her courage, she endured open ridicule from her classmates and subjected herself to situations that were more frightening than we can imagine.

For Williams, attending classes at a regular university would be for us like teetering on the edge of a steep cliff. In a classroom, the ultraviolet lights aggravated her eyes. Her hypersensitive hearing made the noise of her classmates almost deafening. She had difficulty taking in the instructor's information because autistics like to listen to low-level monotone speech. The enclosed area and lack of windows in many of the lecture halls made her feel suffocated, and the entire situation would become intolerable if one of her classmates touched her in any way.

It is a truly remarkable moment in her life when one is reminded that Williams has not recovered from this syndrome—and never will. She struggles only to control it.

The senses and feelings involved in the daily activities of most people are beyond the capabilities of autistics. Williams still lacks an understanding of basic human emotions. For instance, she feels no anger toward her mother who constantly abused her. Instead, she objectively says her mother simply lacked the skills necessary to raise an autistic child. Williams does not like to be touched; she has no interest in sex. She cannot carry on a normal conversation with people.

To obtain an interview with Williams, one must send her all the questions in advance. The actual meeting must take place in an open area that is quiet; preferably the interview is conducted while walking; and she is not to be looked at in the eye.

The tenacity of the human spirit runs deeply through the pages of Williams'

heart-rending autobiographies. She vividly describes her struggle to leave her inner world—"my sanctuary and my pain"—to become an active part of the "real world," with all of its relationships and emotional connections.

Relying on her extraordinary strength and courage, Williams subjects herself to intensive therapy sessions in an ongoing ordeal to "become real." She has been able to leave behind her alternate personalities: Carol, a smiling, social imp "who could hide the child who should be put to death" and Willie, with "his hateful glaring eyes, pinched up mouth, clenched fists and corpse-like stance." Williams marches on alone and finds she is not "mad or bad," but rather, is afflicted with one of the most misunderstood syndromes.

Bridging a great void

Williams' unique ability to reach through the barriers of autism is apparent in her practical teaching experience. One autistic boy she worked with was more intent on using his hands to tap his chest than on feeding himself. Williams started tapping his shoulder in the same pattern the boy was using on his chest. He then started to feed himself while Williams continued rhythmically tapping him.

Williams is not currently teaching and is living quietly in England. I am sure we will hear from her again. The medical world would be foolish not to learn as much as they can from her. She represents an invaluable bridge to the inner world of autism.

Both books should be read by educators, caregivers and people who are related to an autistic person. But most of all, these books should be read by everyone else. Who has not walked down the street and been intimidated or annoyed by someone who appears abnormal? These books give a better understanding of the person inside the body that does not conform.

Williams' honesty in recounting her daily—and lifelong—struggle is inspirational to us all. By sharing her innermost thoughts with us, Williams has opened the door a little wider on our understanding of autism and its different way of ordering the universe. We come away from her books better equipped to extend the boundaries of how we perceive "normal" and "rational" human behavior. Donna Williams is more than somebody somewhere. ●