



In Willowbrook's Wake

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January 28, 2007

I didn't know why the sparkling green-tiled hallways of Building 6 at the Willowbrook State School for the Mentally Retarded always stunk of urine, but I did know that while Mom, Dad and I took out my younger brother, Fred, weekly, most of the 50 children in his ward rarely saw their parents. They ran to grasp my legs and waist as their misshapen faces bellowed with excitement, "Daddy, Daddy, Daddy!"

This month marks 35 years since Geraldo Rivera's exposé of the infamous "school" on Staten Island, where many of the 5,300 children and adults in an institution built for 1,500 wallowed in their own feces, served as guinea pigs for hepatitis experiments and fought for attention from a staff outnumbered by a ratio of 50 to 1. Public outcry forced a court-ordered decree stipulating that every resident would thereafter live in a "normal homelike setting."

But although "Willowbrook survivors," as the families call them, are living in private group homes funded by the state and are receiving health care, they still are fighting for attention. My brother is capable of learning, as we all are in middle age. But since he left Willowbrook when he was older than 18, the state has been absolved of educating him.

Until I became re-involved in his life eight years ago, he lived with a group that attended movies together, shopped together and traveled together. Their hard-working counselors received minimal training and a state-dictated minimum wage. They were not trained educators.

I became my brother's guardian when I was 49, after our mother's death in 1998. Angered because of losing so many Sundays to Willowbrook visits, I had avoided him for years. I'd hear about him from my parents and see him only at family gatherings. Yet, when I informed my brother of our mother's death, we bonded as if connected by a taut string.

"You know Mommy has been very sick."

"Yeah." His wide-lens eyeglasses lay cockeyed across his nose, balancing the droop of his left eye.

"You saw her lots of times in the hospice."

"Yeah," he whispered.

"Mommy died."

Pointing upward with his left arm, he said, "She's in heaven. I'm going to heaven. I'm next."

"Not now," I said.

That expression of a profound abstract thought startled me: This was a man with a trapped intellect. When we talked on the phone, he could call over a counselor if I asked. When he visited me, he wondered how the radio worked - not how to turn it on, but why the sound came out.

The more time we spent together, the more questions he asked. "What's that?" he'd say, pointing at the Triborough Bridge. "What's that?" he'd ask, pointing at my foyer.

I got his residence to offer speech training, and his questions became clearer and clearer. Friends and family began a group effort to uncover his interests. He didn't just have to do the few day-program activities of tending a garden and coloring. Mopping the floor would not be the end of his world.

We could explore his enthusiasms for music, going out for coffee, working with animals. My brother's emotional intelligence defied his label of severe mental retardation. Women with and without disabilities had always clustered around him, wanting to dance with him, wanting to marry him.

But when my brother decided he wanted to learn to read and write, we were told that the day program staff didn't bother with this when a client reached his age. Shortly afterward, my brother stopped shaving, bathing and brushing his teeth. His supervisor justified this, claiming it was his choice. He'd run screaming through his apartment, and his counselor would say, "The guys get like that sometimes, and we just let them go."

At that point, two years ago, I moved my brother to a residence run by a different agency with a larger, more mature staff. His teeth are no longer crusted with food, his tantrums have ceased, and he has become a student of numbers and letters. With his speech therapist, he has created a book containing pictures and drawings so he can point to what he's saying. And he's improved his label from "severe" to "moderate" retardation.

It's sad that the anniversary of the exposure of Willowbrook is not something my brother and I can really celebrate. Certainly his life is better in many respects, especially since we switched homes for him.

But when will it be routine that those paid to work with people like him are professionals with the proper training to help residents grow their minds? When will it be commonplace for him and his housemates to have opportunities to form friendships with people other than those being paid to work with them?

My brother and I were at a baseball game. As each home team player was announced, he cheered. In the moment, I had forgotten that he was different until the teenage girl in front of us stared at him, open-mouthed. We will celebrate when the staring stops.