

Open minds opened doors of Willowbrook

In 1973, as a result of a good deal of publicity, interest was sparked regarding a snake pit on Staten Island known as the Willowbrook State School.

Its huge landscape housed innumerable buildings, which held hundreds of human beings in indescribable misery.

Many good people — doctors, therapists, aides, administrators — tried to provide services, but the odds were against them. Years of thoughtless overcrowding, cut-to-the-bone budgets and public apathy prevented them from offering anything other than limited services.

Once the scandal was uncovered in a series of articles by the Advance, it was seen by the entire nation, even the world, for months. Finally, the New York State Legislature, in an attempt to cleanse itself of the stigma, passed a bit of legislation called the Willowbrook Consent Decree.

This was, in essence, a bill of rights addressed to the developmentally disabled. It spelled out not only the responsibility of the state to these individuals, but provided the funds to give them their rights.

The Assembly in Albany added another component to this piece of paper. Under pressure from parents who were vocal and persistent, and professionals who had worked within the system, services that were mandated to be provided for this population were directed in two ways — 50 percent to those already suffering in Willowbrook and 50 percent to those who lived in the community.

The concept, we were told, was to prevent Willowbrook from ever happening again by making services available in the community.



Beatrice Victor

AS WE ARE

All of us involved were ecstatic.

We were further mandated to form a council made up agencies and parents or parent groups to propose and monitor services for our population. We did. We took ourselves very seriously. We were aware of our obligations and of the budget dollars available. Volunteer hours every week were given freely to make certain that duplication of services, a waste of taxpayer's money, was prevented. Reported infractions in service by any agency were immediately investigated. We believed in our goals.

One of the first priorities was to set about providing group homes for our clients.

It is important to say that when the Willowbrook scandal broke, many on Staten Island were so shocked, they immediately offered whatever they could to help the unfortunate scapegoats. Food, clothing, volunteer time were offered freely. Newspaper pages and television broadcasts were full of photos of neighbors doing their thing. It was nice.

But then came the search for group homes for Willowbrook patients. The NIMBY — Not In My Back Yard — syndrome developed.

In all fairness, we could understand the community's fear. After all, it was only logical to assume that if these folks had to be locked up, they must be dangerous. The fact that many were not disabled but had become so as a result of the nightmare they lived in, did not count.

Everyone had heard the stories, myths of how a retarded individual performed. We all had read the book or seen the movie "Of Mice and Men," in which a retarded man commits murder. How could people be expected to welcome such dangerous individuals into their neighborhoods? How effective would be the comment "That is just a playwright's vivid imagination."

Disfigurement resulting from cerebral palsy, or some other neurological defect, was not a familiar sight, because for years such individuals were kept away from the gazes of others. How many would bother to get beyond the twisted limbs to find out about the beautiful human inside?

There was a great deal of fear. We would have to deal with it.

So we began. If I start to list names of those agencies and individuals who were such a big part of the effort I will run out of space, so I won't. But we all pulled together, the staff of the Staten Island Developmental Center (the new name for Willowbrook), the New York City Department of Mental Retardation, the State Commissioner for Mental Retardation and the Staten Island Retardation and Disabilities

Council. I am proud to have been a part of the effort.

What I am about to tell you is not hearsay. It really happened.

From 1973 to 1977, we attempted to find appropriate living quarters for no more than eight individuals in one setting. The consent decree was very specific as to staffing, living space, work and recreation availability, health care services, education and supervision.

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First, we could not find real estate firms that would take us as clients. Once we finally overcame Realtors' fears, we would go to the community to ask permission to move in. Inevitably, we were told, "it is a wonderful idea, but not here."

Sound familiar?

Then the list of excuses would come.

"There are too many; they will cause sanitation back up."

"There is a brook nearby; it is too dangerous."

"The coming and going of the staff will cause traffic jams."

"We have too many welfare people already."

"Our property value will go down."

I even had a group at a church meeting tell me, "If you come here we will burn you down."

However, in July 1977, under the auspices of the Volunteers of America, we opened the first group home in Mariners Harbor.

We were able to open because a group of seniors supported us. They were led by a woman known as Sophie Wolfe who had been in a concentration camp during World War II.

"I know what not being wanted means," she said. Supported by her friends, she stood with us and faced the community.

She and her friends came into the home. They worked alongside our tenants.

The seniors taught our tenants that the world is not totally hostile. They helped them to learn to cook and to deal with their medical problems. They served on our advisory board. They ran our cake sales and celebrated the holidays with us. They became our friends.

The complex was new when we moved in. As soon as the other tenants arrived, vandalism began. The elevators were covered with graffiti; locks were continually broken. This was not done by our supervised tenants.

In 1979, we approached the management of the complex.

"We would like to open some independent apartments. Would you consider letting us do it here?"

We were told that management would be pleased, but that we would have to speak to the other tenants.

We went to Sophie and asked what her senior group thought. They took a vote. It was a unanimous "yes." The success of the project was impressive.

In 1983, shortly before I decided to resign, management approached the Volunteers of America and offered the use of a townhouse for our clients.

We immediately sent a proposal to the proper sources and I am delighted to say eight very happy men are living productively and comfortably in those quarters.

When we were trying to educate the community as to who and what a developmentally disabled person is, we spent many weeks in schools with young people, hours with service clubs, their auxiliaries, and PTAs. We thought that young people listened and heard what we said.

It is 17 years later. They are the adults now, and each time I read of another group home being rejected, accompanied by the same tired litany of complaints, I wonder if they did hear us.

Perhaps it is not that "a child shall lead them."

Maybe it is the seniors who will have to do it.

(Beatrice Victor was the chairwoman of the Staten Island Regional Retardation and Disabilities Council).

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