

Life after Willowbrook 'better'

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On the day after Thanksgiving, Martin Siegel walks to the bank to cash his paycheck. He negotiates the pedestrian traffic on 57th Avenue in Queens with care. The 44-year-old man's purple and white baseball cap bobs softly as he looks for openings among the shoppers. Cerebral palsy slows his gait and tilts his head.

At the Whitestone Savings Bank, the teller calls him by name. Siegel folds the bills she gives him into his pocket and strolls to the pharmacy next door to purchase shaving cream. After the errands, Siegel enjoys a cheeseburger with a friend in a local coffee shop. It is a new life for him.

Sixteen years ago, Siegel could not walk on the street. He could not have cashed a check — he had no job and no bank account. No teller knew him, the outside world

What has become of the former residents of the notorious Willowbrook State School? According to one state official, "life is better for all former Willowbrook patients." But is deinstitutionalization working? Find out by reading this five-part series, "Life after Willowbrook."

resident is Isabelle Weiner, who now lives in a Canarsie house with eight other women. "I hated it there, the staff beat me up all the time," she said. "It makes you hurt when they beat you up."

Melita Diaz (a pseudonym) left Willowbrook in 1979 after 25 years. Today, she lives in a South Brooklyn apartment with her 5-year-old daughter.

"When I got out, I felt so good I wanted to throw a party for myself," she recalled. "And I said I would never be put away again."

Willowbrook is officially closed. The scandalous conditions at the overcrowded and underfunded institution were pushed into the public eye by Page One stories in the Advance that were picked up by other newspapers and television stations in 1972. Scenes of naked children lying in their own defecation galvanized public support for reform.

Three years of litigation led to

the 1975 Willowbrook Consent Decree. New York agreed to provide Willowbrook residents with "the most normal living conditions possible." The decree required that patients be moved from "more to less structured living; group to individual residences; dependent to independent living." Most of the former patients have been transferred to either community-placed programs or smaller institutions.

Siegel, Weiner and Diaz are typical of residents in community-based programs. They demonstrate how many have adjusted to life outside the institution. Their lives measure New York's compliance with the court-ordered agreement that returned the patients to society. Their lives also tell about society's compliance with its ideals for the mentally retarded.

Mental retardation is often con-

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fused with mental illness. The two handicaps affect different people in need of different treatment.

Although experts are reluctant to rely on one scale, generally a person with an IQ below 70 is considered mentally retarded. According to a 2.7 percent prevalence rate reached by the 1970 President's Commission on Mental Retardation, 6.5 million Americans are mentally retarded, with diminished intelligence and restricted ability to think abstractly.

Mental illness is a functional rather than a mental impairment. A mentally ill person may be intelligent, but does not perceive reality as most people do. The mentally ill and the mentally retarded are covered by different professions, institutions and advocacy groups.

For a century, American society put away mentally retarded people. Institutionalization, it was thought, offered justice, charity and rehabilitation. Removed from an intolerant public, mentally retarded people could live comfortably among their peers. The plan degenerated rapidly but out of sight, behind high brick walls and locked ward doors.

The publicity and court actions of the 1970s showed that the institutions had failed. Over the past decade, New York and other states have tried to deinstitutionalize mentally retarded patients. Officials were especially eager to empty Willowbrook, a process which took 15 years.

Last fall, Gov. Mario Cuomo announced at a ceremony on the grounds "that Willowbrook is officially and forever closed." The facility was renamed the Richmond Complex. About 250 patients in need of special care remain.

"It's a matter of pride for the state to say that Willowbrook is over and all the clients are placed," said Rita Martin, director of the Consumer Advisory Board, a court-created watchdog agency. The board protects the rights of former Willowbrook residents without local guardians.

'Painful experience'

"The whole case was a very painful experience and a great stigma they want to leave behind," Martin said. Critics say that in their haste, state officials put many patients into smaller institutions rather than into "the most normal living conditions possible."

"I don't think it's possible to fully comply with every nuance of the consent judgment — there are over 500 auditing standards" said Ellen Ashton, director of state operations in New York City for the state's Office of Mental Retardation and Developmental Disabilities (OMRDD).

"But in terms of basic care — meals, a comfortable place to live, no one's naked — life is better for all former Willowbrook patients."

Sociologists David and Sheila Rothman estimate in their book, "The Willowbrook Wars," that at least half, or 2,600, of former Willowbrook residents have received community placement which is safe, decent and therapeutic.

Most community residences, or group homes, are run by private, non-profit agencies established during the 1970s to accommodate deinstitutionalized patients. The return to the community would, reformers hoped, be social as well as physical.

In the early 1970s, Wolf Wolfensburger of Syracuse University developed the principles of normalization. He called mental retardation a stigmatizing label used to justify incarceration. The danger, he said, is that mentally retarded people adopt society's definition of them as subhuman and conform to it.

The self-fulfilling pattern continues in institutions where there are few models of typical behavior for the patients to emulate. In the community, Siegel, Weiner and Diaz would have neighbors, merchants, deliverymen, ministers, letter carriers, friends and relatives — in short, a whole range of "good examples" to choose from.

The question in community placement, according to Michael Kendrick, director of the Normalization Safeguards Project in Massachusetts, is how typical are the clients' lives.

"Normalization measures the extent to which the mentally handicapped person is treated as similar and is granted a valued role in the community."

For now, the state is required to get 5,400 former Willowbrook residents as far into the community as is possible. Then we can begin to accept mentally retarded people as neighbors.

(This is the first in a series of five articles. Tomorrow: Martin Siegel.)