

After —

(From Page 1)

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.)