

# Decree changed view of care for retarded

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In April 1972, 5,343 mentally retarded persons were living at Willowbrook State School under conditions so intolerable that the New York Civil Liberties Union filed suit to get them out.

The plaintiffs represented people like Lara Schnepps, a severely retarded 4-year-old who — according to the lawsuit — almost died because of inadequate medical care; 10-year-old Nina Galen, who was given tranquilizers instead of toys; and Evelyn Cruz, 13, who lived on a ward with 100 other children staffed by only four attendants.

There was little doubt that Willowbrook (since renamed the Staten Island Developmental Center) was a terrible place to live — “It was so bad it was off the end of the spectrum,” as one person put it — but the validity of the lawsuit was questioned by many.

Willowbrook was not a prison, but an institution; its residents were not forced to live there. If the parents and the NYCLU didn't like the conditions there, the residents could go home. The situation was maddening, but was it a violation of civil rights?

The NYCLU wanted the state to close Willowbrook and put its residents in group homes, but plenty of people thought that was stretching the United States Constitution too far.

There were indications that even Judge Orrin Judd of the U.S. District Court in Brooklyn had his doubts. Yet on April 30, 1975 — 10 years ago this Tuesday — Judge Judd signed the Willowbrook Consent Decree, a landmark document which settled the lawsuit and marked a new beginning in New York

State's concept of care for the mentally retarded.

Most of the 29-page consent decree outlined standards of care for Willowbrook residents. But the real bombshell, although only vaguely outlined in the document, was an agreement that Willowbrook would reduce its population to 250 by 1981 and transfer all the remaining clients into community residences.

Moreover, the state indicated that the deinstitutionalization would not be limited to Willowbrook, although those clients covered by the lawsuit would get first priority. Through the consent decree, the state government essentially agreed to at least partially dismantle its institutional system for the retarded and establish community-based services.

The implications were staggering — not only for Willowbrook residents, but for all mentally retarded persons in New York State and even extended by implication to the rest of the country. It was the first time New York State acknowledged that retarded persons do not belong in institutions; that retardation is not a disease requiring lifelong isolation from the rest of society, but a condition which can permit a happy and productive life in the mainstream community; that the state had a responsibility to provide the services which would allow the retarded to live in the “least restrictive setting” possible.

Certainly, the transfer of clients from the institution to the community is what made the Willowbrook case a landmark. While it was not the first class-action lawsuit against an institution for the retarded, it was among the first that went beyond demands that an institution be merely upgraded.

“It (the Willowbrook Consent Decree) was the single most important action which brought change in the field of mental retardation,” says Arthur Webb, commissioner of the state Office of Mental Retardation and Developmental Disabilities (OMRDD). “Its magnitude in terms of effect on social policy was unprecedented.”

In fact, the year the consent decree was signed, New York State supported less than 6,200 retarded persons in the community (the majority in family care, which resembles foster care), while more than 20,000 resided in institutions. Today, the institutions house fewer than 11,000 — and the number is still declining — while more than 18,000 are living in community residences financed by the state.

Not surprisingly, the exodus out of the institutions has been led by clients at Staten Island Developmental Center (SIDC), although the original timetables set down in the consent decree proved to be wildly optimistic. By 1981, when the institution was supposed to have only 250 residents, there were still almost 1,500 living in the facility; community placement proved to be much more difficult than anyone had imagined.

There are still about 600 clients at SIDC. Of those who have left, about 1,100 are now living in

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