

Willowbrook:

How does it serve today?

By JULIE MACK
A decade after the Willowbrook scandals, the state's care of the mentally retarded is undergoing a dramatic evolution, but the success are pockmarked by disappointments.

"The dream remains unfulfilled," as one parent of a mentally retarded client put it.

Reforms were pledged by the state eight years ago, in the wake of charges of inferior care for thousands of clients housed at the former Willowbrook State School.

The facility has since been renamed the Staten Island Developmental Center, the clientele has been spread among many facilities, and most parents and professionals readily acknowledge that treatment of the mentally disabled has improved in the last decade.

Yet many claim that not enough has been accomplished, particularly within the past few years. There is genuine concern that the state government is stagnating or even renegeing on its promises.

"I think the state has withdrawn its commitment to deinstitutionalization, to put it politely," said Keit Penman, regional director of United Cerebral Palsy of New York State, a

non-profit group contracted by the state to provide services for the retarded.

Among the specific complaints:

- Frustration from those who feel that the quality of care is still deficient at state-run institutions.
- Concern about the shortage of supervised community residences for the retarded.
- Bitterness among parents of retarded children who were never institutionalized and who claim their children are being short-changed in the present distribution of services.

The problems now facing state officials are an outgrowth of the Willowbrook Consent Decree, signed by then Gov. Hugh Carey in 1975 as settlement of a class action lawsuit representing Willowbrook patients.

Major reforms were promised on all aspects of care — therapy, clothing, medical care, patient-staff ratio. The biggest effect of the consent decree was moving people out of the institution and into community residences.

While the consent decree covered only Willowbrook patients, it inspired hope that the state would overhaul its entire service system for all the mentally retarded. In fact, the state has

worked closely with voluntary agencies to create a new network of support services.

Yet the new system is experiencing growing pains, and old issues refuse to go away. It doesn't help that the mentally retarded population, and its advocates are factionalized, with sharp divisions between "class clients" represented in the Willowbrook Consent Decree and community clients who have always lived at home. Each client group has its own set of problems, its own priorities.

SIDC remains at the forefront of controversy, fueled by concern that the state is not fulfilling the

1975 agreement. Indeed, the state has already violated one of the main tenets of the original agreement, which was to reduce the institution's population (which numbered more than 6,000 in the early 1970s) to 250 by April 1981. A new deadline has been set for 1985. Meanwhile, more than a 1,000 clients still remain on campus.

Moreover, advocates for Willowbrook patients say they are still getting inferior care.

"The quality of life in institutions, including the cleaned-up Willowbrook, is still lower than

Page 1 of 3