State officials promising retarded won't be 'dumped'

By ROBERT MIRALDI

(First of three parts)

Almost 10 years ago the state's Department of Mental Hygiene, world's largest mental health bureaucracy, made a clinical and practical decision to discharge from state centers 40,000 long-time psychiatric patients.

The mostly elderly, heavily sedated psychiatric patients were dumped into unprepared communities with little, if any, backup medical resources.

The resort town of Long Beach, L.I. was inundated—and probably destroyed by the flood of mental patients. The streets of Queens and Manhattan were filled with wandering, confused dischargees. And portions of Staten Island were targeted as dumping grounds. For now the dumping process here has been minimized.

In 1976, the same Department of Mental Hygiene, as huge and diffuse as ever, is planning a multimillion dollar five-year effort to place 8,800 mentally retarded persons in communities across the state.

Will the helpless retarded population, like the psychiatric patients, be dumped into unsuspecting communities?

"We are not going to let dumping occur again," says Alan Saperstein, a resident of the Willowbrook area who is director of the U.S. Health, Education and Welfare's Department's office of long-term care.

"No one will go anywhere unless there is a program," says James Introne, a member of Gov. Carey's program staff.

"We have to make sure," says Hugh O'Neill, deputy commissioner for the state Department of Social Services, "that we don't repeat the mistakes of the past."

"I am not going to be involved in snortcutting," says Barbara Blum, director of the Metropolitan Placement Unit (MPU), established to place in small community settings almost 4,000 ex-Willowbrook Developmental Center residents. "Quality progress will take time."

Barbara Blum does not have as much time as she would like— or probably needs to make quality placements for a population which is mostly profoundly retarded (with IQs ranging from below 20 to 35) and has multiple handicaps.

A federal court and a review panel is breathing down the collective necks of the MPU's staff; belligerent parent groups— sick and tired of inhumane care for their children—are threatening to throw top state officials in jail.

Saperstein and HEW are warning that they will cut off \$125 million in federal funds; and Gov. Carey's as-yet untarnished prestige in the health care field is on the line. A setback or taint of dumping in placement of the retarded would be a serious blow to national aspirations Carey may harbor.

The Moreland Commission on Nursing Homes spotlighted the Rockefeller Administration's dumping of mental patients. State and federal officials are asking if Carey can do better.

The state's request for a 1981 deadline is contained in a 76-page document, "New York State Plans of Compliance," and is now in the hands of HEW Secretary David Mathews who must approve the plan to ensure the flow of federal money to the state.

"As a general document," says Saperstein, the state's compliance plan "will suffice for now," but Saperstein adds that HEW "is not satisfied" with many of the plan's specifics. Critics of the plan say it offers few specifics.

In January, 1974, the federal government set March, 1977, as a deadline for the states meeting intermediate care facility regulations. New York plan now asks for an extension to 1981.

The three main elements of the plan are:

¶Eliminate 8,800 beds in the state's 21 developmental centers which now have a population of about 20,000.

¶Create 8,800 living units in the community: 4,200 in foster care; 3,100 in hostels or group homes; and 1,500 in nursing homes or small facilities which meet the federal intermediate care facility's mental retardation (ICF/MR) regulations.

¶Upgrade the remaining 11,000 developmental center beds to meet ICF/MR regulations, with \$60 million in physical renovations and with the purchase of \$5.2 million in humanizing equipment.

Practically, state officials are hoping, the plan will save money in the long run since the cost of community-based living is less than institutional living.

Pragmatism aside, however, the deci-

sion represents the bureaucracy catching up with the clinical opinion that retarded persons, no matter how handicapped or retarded, can best develop in community settings. "Normalization" is the catch word.

In his July 26 announcement of the state plan, Gov. Carey said it was the state's attempt to "avoid the mistakes of the past."

The state's largest—and most visible—mistake has been the Willowbrook Developmental Center, the 384-acre Staten Island center which houses 2,595 residents and is slated to phase down to 250 residents by 1981. Today Willowbrook is still the state's largest developmental center.

The federal ICF/MR rules are "compatible" with the Willowbrook Consent Decree, according to Willowbrook Director Dr. Levester Cannon. But the consent decree was to be implemented by last spring—it wasn't—and Cannon points to March 1978 as the target date for implementing the ICF/MR physical renovations. Programatic compliance will follow.

"It's just amazing," says one attorney connected with long-running Willow-brook case in federal court, "that the state has just disregarded the consent decree and its deadlines and set their own timetables."

The plan at Willowbrook calls for rehabilitation of seven of the present 40 buildings, making 348 beds comply with federal guidelines. By March 1976-77 the center's projected population is 1,915; by 1977-78, 1,500; by 1978-79, 1,100; by 1979-80, 700 and by 1980-81, 250.

State planners expect to spend \$2,583,003 on renovation in the next fiscal year. Statewide the cost is \$28 million.

At Willowbrook as well as statewide the success of the population reduction is contingent on the success of placement in the community. Institutional beds won't disappear until community beds appear. A task that is easier said than done.

(Tomorrow: Is the state's scheme a planner's pipedream?)