

Millions of \$\$ down the drain at Willowbrook

By SYDNEY FREEDBERG

The heart of the three-year \$2.6-million "Willowbrook Project" — inaugurated with high hopes in 1974 to improve conditions and combat criticism at a beleaguered Willowbrook Developmental Center — is being phased out with many of those promises dashed.

Once heralded as a progressive alternative to the misery and neglect that became synonymous with Willowbrook in the early '70s, the federally initiated program has fallen victim to severe neglect itself.

Life for the 59 Staten Island residents selected for the program has been unchanged despite \$2.1 million of federal and state funds pumped into a special "goal-oriented" system.

Under the plan, even those mentally retarded individuals referred to as "total care cases" were to be improved. Their potentials, said to be hidden under the warehouse concept of institutionalization, were to flower with the aid of a regimented program of testing, record-keeping, training and treatment made possible by the federal grant.

It did not happen.

But documents relating to the program's checkered two-and-a-half-year history indicate the concept was never proved wrong; what they show is a Willowbrook project tangled in an intricate web of impediments — left to fend for itself without adequate enthusiasm, guidance, timetables for contractual compliance or monitoring by any federal or state agency.

An advisory panel of experts in the field of mental retardation and Willowbrook parents, once charged with overseeing the operation, was canceled mysteriously in early 1976.

A private educational firm contracted with to evaluate the program has refused to produce all of the required reports, although the reasons why are unclear.

At least 23 state and federal workers from five separate bureaucracies were at one time or another, "in charge" of the Willowbrook project. But they all insist now their relationships to it are merely "quasi official."

For the past year and one-half, according to state and federal records, the U.S. Department of Health, Education and Welfare, which funded 75 per cent of the demonstration project, and the state Department of Social Services, the technical recipient of the funds, were aware of ongoing problems in implementing the detailed proposals.

In February, for example, a federal official expressed the urgency of the situation in a letter to a colleague in Washington, D.C., saying that the project had not been evaluated in a year and a "site visit was long overdue."

Another regional HEW official wrote six months ago: "We must get a (regional) staff member to work with Larry Plumb (in HEW's Washington office) in overseeing the project. We should be on top of these activities."

But the record also shows that each time HEW or DSS questioned the program's progress, the state Department of Mental Hygiene, which funded the remainder of the work, allayed their fears and doubts in letters that appear to obscure the facts.

For example, one DMH commissioner wrote to an HEW official in January, "I want to assure you," he said at the time, "that the Department of Mental Hygiene is committed to a full test of the goal-oriented medical record system."

"I want to stress with you that the activities you encouraged at Willowbrook have already borne considerable fruit," he said.

DMH officials categorically deny having misled anyone as to the Willowbrook project's successes or failures, but some do admit that the core of the program is "sadly lagging."

HEW chooses to characterize the goal-oriented program as "chaotic" and "disorganized" and that the \$2.1 million implies a "void" and "lack of direction."

But where that \$2.1 million has gone is not entirely clear either.

The original contract, signed in September 1974 and given to the Information Services Division of the Rockland Research Institute, a unit associated

with a public upstate institution, calls for the testing of 11 automated and computerized recordkeeping systems.

Of those, two were scrapped by project designers early in the grant period. In the past two and one half years, five systems — regarded by some Willowbrook associates as the simplest and most fundamental — have been installed at the Staten Island developmental center.

They include an admission/census system, which can be used to determine where the residents are and where they are receiving service; a drug system, which captures data on residents' drug utilization; a physical examination system, which gathers medical information on residents; a personnel system, which facilitates the management of Willowbrook staff, and an inventory control system, which calculates the commodities the facility needs.

But what the contract refers to consistently as the "core" and the "heart" of the goal-oriented approach — the clinical system that was designed to aid the 59 pre-selected residents — was never implemented, nor did it receive a thorough test.

By January, 1975, five months after the program began, the Rockland group and Willowbrook administrators had chosen a building at Willowbrook to

PAGE 1 OF 2 PAGES

serve as the base for the clinical system's testing.

DMH spent \$78,000 of its own non-grant money to "humanize" Building 29. The renovation, completed quickly, transformed an austere, cavernous structure into new compartmentalized living units, alternating soft and rich pastel colors.

Willowbrook and Rockland thought the newly designed interior necessary for the type of therapy that was to be given, and DMH gave the money to show "the department's commitment to the federal computer project," a memo of Feb. 10, 1975 states.

Under Rockland's plan, the 59 Staten Island residents chosen for the project were to be observed carefully, with every activity recorded.

A team of specialists was to judge each individual's abilities, listing the area where help was needed. A rehabilitation plan was then to be spelled out that included timetables and milestones for reaching goals in personal hygiene, vocational skills and self care.

In turn, that information was supposed to be fed into the computer. As the resident met his goals, new ones were to be set until he developed to his full potential.

But a recent visit to Building 29 showed that the brightly colored therapy rooms go largely unused, and residents are not receiving the precedent-setting goal-oriented treatment.

Rather, Building 29 is much like the rest of Willowbrook, where passivity remains the key to therapy and residents sit idly, staring blankly into thin space.

A reporter was told by the acting team leader that only four out of 16 staffers were in the building.

She said some of the others were "using up overtime," "absent for two months with asthma" and "on an interview in Manhattan."

In apparent violation of the New York State Health Code, a clerk, instead of a registered or practical nurse, was administering medicine to residents.

Dr. Jeffrey Crawford, Rockland's project director, stresses and Dr. Lester Cannon, Willowbrook's director, admits that the staffing of Building 29 is a different problem — Willowbrook's responsibility and not Rockland's.

But perhaps more importantly, the building's team leader said the therapists assigned to Building 29 "have no knowledge of the special funding or its purposes.

She said, "If you mention the Rockland program, one or two of them will tell you they were trained by them a long time ago, but if you ask about techniques, they'll say, 'I don't know.' The rest of the people would be in the dark."

The team leader added she knew of six residents who at one point received "special tests," but said she is not sure if or when the practice of recording their behavior was discontinued.

Asserting there are "many problems" with Willowbrook's administration, Dr. Crawford now says the clinical portion of the project has been moved to Was-saic Developmental Center north of the city,

But the associate director of that facility said he has "no knowledge" of the move. "We are negotiating with the Rockland group, but have not come to any terms or agreement," he explained.

Dr. Cannon, Crawford insisted, was "unsympathetic" to the program.

That appears to be true to some extent.

In January, for example, although the project was still officially being conducted at Willowbrook, Cannon sent mailgrams to the relatives of Building 29 residents, saying that all of the persons were to be moved and Building 29 converted into a home for the blind.

But confronted by irate parents whose hopes had been raised by the program (predating and above and beyond the requirements of the Willowbrook Consent Decree), Cannon backed down.

The whole matter is now being reviewed by HEW's Washington office because Rockland and the Department of Mental Hygiene have asked for a 10-month renewal of the contract to "finish" the project with \$400,000 of unexpended funds.

One of the questions to be decided in the review is the site, according to Gates L. Plumb, HEW's Washington director of Section 1115 project grants.

DMH and Rockland said they don't want the program at Willowbrook, even though the federal government admits the reason it approved the \$2.5 million in the first place was to quiet the furor that once arose over that besieged institution.