

# 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 "total loss of the program."

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