

'They were only guinea pigs'

Many are to blame for failure of Willowbrook 'experiment'

By SYDNEY FREEDBERG

In the winter of 1974, when he was nearly 14 and though he couldn't understand, David Amoroso was chosen for a special "experiment" at Willowbrook.

His mother, Rosalie Amoroso of Grant City, perked up and radiated hope. For the first time since 1970 (when he entered the institution), David, a "defective unlike normal children," was to be given a real chance to hold more than a nebulous place in society.

His social death, being accomplished slowly in the Willowbrook warehouse, would be turned around; his potential, hidden for all that time, would flower.

That's what Mrs. Amoroso was told by the "hot shots" from the federal government and the state and the Rockland Research Institute at a gathering called to sell the idea. And that's what Mrs. Amoroso chose to believe.

There was so much money, she thought to herself, nearly \$3 million to make her son and 58 other retarded people, all from Staten Island, better. The

"hot shots" had never before placed a price tag on the anguish the children whose brains were damaged at birth had brought to their parents and them-

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selves. No, she told herself, they wouldn't lie about this program. They wanted to help the children and they wanted to diminish the hurt.

"The researchers," she recalls, "seemed to have trust in their clinical, goal-oriented system, and I felt it too." David was going to get better. He was going to reach goal after goal set by the special clinical team.

But Mrs. Amoroso was wrong and David died at Willowbrook last winter. He was not better. He may have been worse. More black eyes than he'd ever had, just as hyperactive and frail. A 16-year-old victim of a society that finds it easier to bury its problems than to deal with them.

Mrs. Amoroso blames no one for David's death, but she regrets her son

was never given the chance. What makes her angry is that they promised David a Cadillac, and couldn't even deliver a Model T Ford.

In retrospect, Rockland's entire sophisticated research scheme was doomed from the start. The promises were just too excessive in a place where wretchedness and misery prevail to this day. As a matter of fact, maybe the state didn't want the project to work for its success would have highlighted the human waste in the rest of the state institutions.

But the federal government thought it was being good to Willowbrook by giving the \$2.6 million. "There were so many reasons to put the project there," one of the federal workers who once supervised it said. "If it worked at Willowbrook, it could work anywhere. We knew it would be tough, but there was a lot of political pressure."

The concern seemed more to placate the pressure groups than to do something tangible for the retarded. Even worse, everyone kept on promising the moon and the stars to the parents of those 59 pathetic individuals with damaged brains, organs, eyes, ears and limbs.

For any research project to work, the people in charge must be realistic and committed to it. But they weren't, not in the case of the goal-oriented program.

The Willowbrook Consent Judgment of 1975, directing radical court-ordered revisions at the institution, created a whole new set of priorities, and at once superseded the federally initiated program.

Dr. Levester Cannon, Willowbrook's most recent director, attempted in January to convert Building 29, the site for the work, into a residence for the blind.

The federal government's participation and commitment were marred by a reorganization of the Department of Health, Education and Welfare. As a result, there has been no monitoring of the program in a year and one-half.

Many Building 29 employees were ab-

sent a lot, and the Rockland researchers became discouraged.

But the state Department of Mental Hygiene might be most at fault. As one Willowbrook source explained it, "If there would have been a rose in a bed of thorns, one good building and 27 lousy ones, then the state would have been committed to clean up the rest."

If they wanted the heart of the Willowbrook project to work, they would have done it right. They would have staffed Building 29 adequately and they would have made sure the detailed plans were implemented.

As it is, they're all to blame: HEW, DMH, Willowbrook, Rockland and the Building 29 staff.

During the two-and-a-half years of the program, the lives of the 59 "subjects" never changed. They weren't tested, trained or treated. No one reached his potential.

And that David Amoroso did not have a year, a month or a day of improvement is understandably hard for his mother to accept.

"They were only guinea pigs," Mrs. Amoroso explained, her voice tapering to a whimper. "And...and...they couldn't...they can't make it work."

"I guess they have to go someplace else now and get a new bunch of guinea pigs."

This time, Mrs. Amoroso is right.

The Rockland researchers have decided to take their fancy data sheets and computerized goal-oriented system to Wassaucott Developmental Center, where the weather is a little colder and the atmosphere is "more conducive to research," Dr. Jeffrey Crawford says.

Who is going to tell that to the parents of the 58 survivors?

Maybe they'll call another meeting, like the one two-and-a-half years ago when so much hope was instilled.

Or maybe this time it's the planners turn to hope — that the whole thing will vanish without requiring an explanation, just like a bad dream.