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Yvette Adam, a therapist, working with a retarded child at Flower and Fifth Avenue Hospitals

For the Retarded, Despair Is Lingering

By RONALD SULLIVAN

"They were the most profoundly retarded and severely handicapped patients ever assembled. You could work in this field for 40 years and never see anything like them. They were the hidden cases, the ones that no one ever wanted to see, the victims of years of neglect."

The words poured out slowly from the lips of Dr. Erwin Friedman, the director of the Manhattan Developmental Center, the New York State facility that cares for the mentally disabled and handicapped in Manhattan. He was describing a group of former Willowbrook patients who had been removed from the huge state institution for the retarded on Staten Island under Federal District Court order in 1975.

The 160 patients were originally sent to another state facility in Old Gouverneur, a rundown former municipal hospital in downtown Manhattan that was being condemned at the time as a firetrap.

Last May, they were moved from Gouverneur to a new private rehabilitation facility operated by the New York Medical College in Flower and Fifth Avenue Hospitals. And if a special Willowbrook Review Panel established

by the Federal Court in Brooklyn prevails, the patients will be moved again.

The panel, which was created by the court to make sure that the 5,000 patients who are or were in Willowbrook receive optimal levels of care, contends that the Flower and Fifth Avenue facility, on Fifth Avenue at East 106th Street, continues to violate minimum-care requirements of the court-ordered Willowbrook Consent Decree signed by Governor Carey in 1975.

Last Sunday the panel met to discuss a new deadline for evacuating the remaining 132 patients from Gouverneur, perhaps as soon as September, 18 months earlier than projected. No decision has yet been reached.

In a letter last month to Thomas A. Coughlin, Commissioner of the state's Office of Mental Retardation and Developmental Disabilities, the panel charged that Flower and Fifth "has failed to respond to the extensive needs" of the former Willowbrook patients.

Moreover, the panel said, the panel's medical consultant had determined that some of the six patient deaths at

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the hospital last year "were avoidable" and had been caused by "improper feeding techniques" that caused some patients "to strangle on their food."

The hospital, however, contended that the deaths were not unusual, said the patients had died from pneumonia and other complications and offered autopsy reports as evidence.

The panel's chairman, Dr. James Clements, the director of the Georgia Retardation Center, said in an interview that the hospital was guilty of both "an administrative and programmatic failure" despite the "terribly high costs" of \$245 a day for each patient, all paid with Medicaid funds.

'A Good Idea Gone Wrong'

In response, Commissioner Coughlin contended that the panel's criticism was outdated. While Mr. Coughlin conceded that the initial care provided by Flower and Fifth represented "a good idea gone wrong," he insisted that the hospital had corrected its administrative and therapeutic failings and was now providing good care.

Other state officials said that the alleged failings at the hospital had resulted from several factors. One, they said, was the fact that Dr. Margaret Giannini, the initial head of the program, left last October after only six months on the job and that her replacement was not hired until last month.

Another factor was the problem of re-training nurses and aides who remained in Flower and Fifth after it closed as a private voluntary hospital. Most of them had no experience, either professionally or emotionally, in rehabilitation therapy for the retarded and handicapped, particularly for patients as severely afflicted as the Willowbrook evacuees.

"Even though they had the best of intentions, no one knew what to do," Dr. Friedman said in his office at 75 Morton Street in Greenwich Village. "There was

not another group like this in the world. They never saw people like this in their lives."

Virtually all of the 132 patients are immobile. According to one state official, they would have been written off years ago as "institutional basket cases." They suffer from gross deformities, multiple sensory handicaps and profound retardation. Their bones have become brittle and their limbs gnarled askew from years of neglect.

They must be hand fed. They are all incontinent and must be cleaned and turned in their beds. Their average age is around 20 and authorities attribute their longevity, compared with a lifespan that was once five times less, to modern drugs and better care.

Dr. Friedman said that last year he had warned Dr. Giannini, who heads the medical college's Mental Retardation Institute, against "taking all of them at once with a staff that had never worked with the handicapped."

Dr. Giannini Cites Pressure

In an interview, Dr. Giannini conceded that Flower and Fifth was not ready when the patients moved in last May. "But the important thing was to get them out of Gouverneur, that terrible place, that firetrap," she said. "The real problem was that the review panel expected overnight, instant success."

John Keane, the hospital's executive director, said in an interview that the facility "probably opened too soon." But he added that the panel's criticism had been based on observations it made last October and did not reflect the progress that had been made since.

Msr. James Cassidy, who oversees the hospital as director of hospitals for the Roman Catholic Archdiocese of New York, which took over the medical college last year, said: "The real tragedy is that we did not get these patients years earlier. If you can get them young enough, you might have a chance."

When the patients arrived a year ago they were silent and motionless. There were no smiles, no tears, no hope. The morale of the therapists-in-training was regarded as dangerously low.

"Just look at the difference today," said Dr. Alphonso Sorhaindo, Dr. Friedman's former deputy who recently took over as director of Flower and Fifth's rehabilitation programs.

"First, listen," he said. "You can hear them — they're making noise when they never made a sound."

"Now look," he said as he walked through a third-floor therapy room where patients were being turned or having their limbs moved. "See the smile on Lisa. Look at her smile — isn't she beautiful?" And indeed, Lisa smiled and smiled.

"More than anyone else," Monsignor Cassidy said, "these patients are entitled to a chance no matter how hopeless it may seem. Society owes them that much."

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