

Private palsy group may handle some Willowbrook cases

By SYDNEY FREEDBERG

Late in the fall of 1956, Elizabeth Tracy was born into a doctor's promise of early death. Of the two most prized gifts of mankind — good health and happiness — she had neither. Elizabeth was pale and impossibly vulnerable at birth. Her eyes, luminously green as mint jelly, were always kindled with tears.

For months, Elizabeth (not her real name) remained secluded in the sterile room of a Manhattan hospital, clinging precariously to life. But because of a lack of oxygen at birth, her brain and limbs would be damaged always and she'd continue to weep for comfort.

Though Elizabeth eventually made it home to Rosebank, that didn't work for the Tracys. The seizures and feelings of sadness grew worse; each voluntary act Elizabeth tried was marred by intense involuntary movement.

By the time she was four, she'd fallen well behind and could not eat, walk or toilet herself. So, in the winter of 1960, with some words about "curiosities" and "chances," Elizabeth was set aside in Willowbrook, becoming one tarnished fixture in a tent of thousands.

Deemed retarded, difficult, temperamental and self-abusive, there she remained for 15 years, emaciated, sometimes curled fetally on a ward floor, but most often just ignored.

The gloominess of her case, oddly, led to a chance for something better, and in 1975 Elizabeth and 49 others, all judged to be among the most physically and mentally disadvantaged at Willowbrook, were chosen to take part in a new private residential program, to be operated by the state United Cerebral Palsy Association as a model for the public Willowbrook Developmental Center.

It was the first facility of its kind. Although the private palsy group had operated day programs for the physical-

ly handicapped throughout the country, never before had the organization received state funds to attempt a residence for an institutionalized population.

The Nina Eaton Center, located in Building D of the South Beach Psychiatric Center, opened June 16, 1975, when 50 of the "worst possible cases," director Fred Stein recalls, "were transported to us in little yellow school buses."

"We were shocked at what we saw," Stein says. Elizabeth and the others "were virtual unknowns, flat on their backs, bird fed and neglected for years. Never were they encouraged to use their limbs or to gain any degree of independence."

At once parents and advocates of the handicapped and mental health experts across the country dubbed the new residence "the center of hope," a dramatic proving ground against those who saw the disabled as a basket of vegetables.

Unlike Willowbrook, the privately run UCP center specialized in what Stein calls the "interdisciplinary team approach," where a therapist, for instance, could perform the tasks of workers in any number of fields. Stein sees this treatment approach as the most important factor in UCP's success.

When Elizabeth was transferred to the center, Stein explains, her programs, hand-tailored to meet her capabilities, were necessarily on the most basic level. Training in infant stimulation, toileting and self-feeding was followed by involvement outside the building in a sheltered workshop experience in Queens.

And now, there is Elizabeth, a smiling, strapping young woman of 21, asking a visitor to come see her new apartment in the Coney Island section of Brooklyn, and then proudly showing her

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favorite sights. She can move around at ease in her wheel chair, and though her arms and legs still flail aimlessly sometimes, Elizabeth has learned to use them to her advantage, showing a remarkable talent in communicating by gesture. And perhaps most importantly, especially to her mother for whom she once cried constantly, Elizabeth no longer recoils at the thought or act of touching.

"She is really a perfect example of what we can and need to accomplish," Stein says. "We are not looking to prove something to Willowbrook, and we're not looking at the improvements in terms of miracles. Sometimes they can be measured in feet, and sometimes only in inches. But they do happen."

The palsy residence, which operates with Medicaid money and costs approximately \$29,000 a year for each client (Willowbrook costs \$35,000), points to some hard-line data, which indicate that nearly all of the Eaton residents have improved markedly since moving away from Willowbrook.

Many of the center's clients, all diagnosed at the state institution as having some form of cerebral palsy, were discovered not to be retarded or mentally deficient at all. Elizabeth, for example, was measured to have an intelligence quotient of 16 on a standardized test administered at Willowbrook. "Our tests showed her to be in the normal bracket," insists Stein. And she certainly wasn't 'self-abusive.'"

In addition, statistics provided by UCP show more than half of the center's clients, who range in age from 21 to 50, today need only minimal or no assistance in daily living skills, compared with zero in the same category two years ago.

The program's success, heralded by both proponents and foes of institutionalization, now has led to a second precedent-setting project, larger in scope than anything like it ever attempted by a private organization.

Last March, following years of broken promises and bureaucratic delays preventing adequate care for their children, parents turned to UCP and asked the private group to take over part of Willowbrook from the state.

An agreement to do just that is in the

works, and Robert Schonhorn, executive director of UCP, says his privately-hired staff will be ready to begin operation at Willowbrook soon, taking over the treatment of 641 individuals with a host of physical and mental disorders.

"If it works," Schonhorn said recently, "it may change the nature of public institutions for good."

"We're using Nina Eaton as the model, and we think we're going to be able to show we can do a much better job than the state," Schonhorn added. "And then, I think we'll see more" private operation of formerly public facilities.

Although most mental health experts familiar with Willowbrook won't say so publicly, they confide that the major difference between a public and private Willowbrook would be the quality of the staff.

"Good treatment," contends one attorney involved in the Willowbrook case, "comes from interested and caring workers, and the state employees at Willowbrook have shown they're neither."

The workers, on the other hand, argue that budget cuts have destroyed the possibility of effective programs, and say the Department of Mental Hygiene bureaucracy is so vast that it is impossible to know what to expect, when to expect it, or whom to expect it from. Willowbrook, they charge, has been run by an administrator sitting at an Albany desk for years now, ever since the scandal about conditions there unfolded.

What seems clear is that no one — not the state administrators, the parents or the Willowbrook Review Panel members — is completely happy about the prospect of a UCP takeover of seven buildings at Willowbrook.

Jerry Gavin, a spokesman for the court-appointed review panel, charged with overseeing conditions at the state institution, admits the major concern is that "UCP has not proved it can get large numbers of retarded persons back into the community," which is seen as the way to reduce Willowbrook's population, now at 2,500 to 250 by 1981.

The Nina Eaton Center, according to Gavin, has graduated only two young women, including Elizabeth, to an independent-living or group-home environ-

ment. "That certainly isn't conclusive," he says.

Another question raised by parents is whether the private organization, which in the past has worked exclusively with a cerebral palsy population, will be able to adapt its specific mode of treatment to fit the needs of 641 persons with a variety of physical and mental disabilities.

Finally, in addition to the questions concerning 600 civil servants' role after the takeover, there remains the moral dilemma raised by the prospect of giving private groups control over governmental functions. Could that mean more of the same for the future? Or could such an eventuality lead to the state's complete abandonment of the handicapped?

Stein may offer the key to the answer, when he says that "the only regret I have is that we didn't get the (50 Willowbrook residents) when they were younger. Maybe we could have done even more."

For now, the state, in concert with the private group, has chosen what will be the UCP-run buildings at Willowbrook. And among them are the baby complex, representing the heart of Willowbrook's future.



Lorraine Kendel, left, and Iris Zohler aid two of the Nina Eaton Center's 50 residents, making sure they receive the personalized care they need. The question remains: Can it happen at Willowbrook?

S.I. Advance Photos by Robert Parsons



Regina Favors, a staffer at the center, helps a young man with a new skill — writing — in what will lead to rarer goals and milestones.

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