

Willowbrook: A struggle lost in a fight over a battle

By SYDNEY FREEDBERG

A parent with a child at the Willowbrook Developmental Center insists the place is plagued by a terminal form of bureaucratic cancer: The more the confusing cast of players struggles to improve conditions there, the more impossibly debilitated the place becomes.

It's not that these somewhat tragic-

Analysis

omic protagonists don't try, this mother explains. It's just that the point and meaning of the fight, as in existential drama, often seem to get lost in the fighting itself.

What's being fought for, we must occasionally be reminded, is the right of a faultlessly helpless people — the retarded of Willowbrook and other state institutions — to more meaningful lives through special treatment, activity and love.

The most recent controversy at Willowbrook, then — over the surrender of seven buildings to the private United Cerebral Palsy Association — is just another in a long list of attempted trial remedies to achieve that stubbornly elusive goal.

The takeover itself stemmed from a court-invoked plan in March, more than four years after the federal court system took the matter of "Willowbrook warehousing" into its own hands.

And today, after years of delays and broken promises, Willowbrook, which once packed away more than 5,000, has at least reduced its population to 2,380 residents.

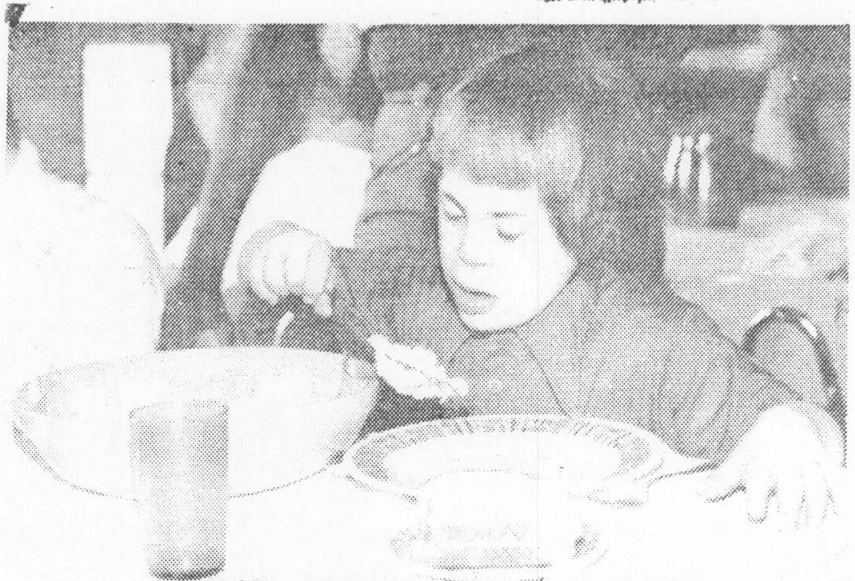
But while many argue that Willowbrook must be expunged, the official goal remains to get the census down to

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Willowbrook workers protest...

S.I. Advance Photo by Robert Parsons



...and a Willowbrook child learns to feed himself.

S.I. Advance Photo

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250 by 1981, by discharging residents to less restrictive community group homes.

How to achieve this, quickly but not rashly, with due process and consideration for individual need, has resulted in a gumbo-melee of conflicting thoughts by as many as a dozen vested interest groups, all of which proclaim they are thinking "only about the residents."

That may be true. But it is also sadly apparent that the residents of Willowbrook sometimes become the unwitting victims of a system mired in paperwork, number games and the following factions at work:

Parents

Plaintiffs in Willowbrook's ongoing federal court case, the parents of the institutionalized retarded attempt to correct what they see as persistent abuse and neglect of their children.

They are far from a united group, often at odds on the issues, but the activist parents speak for the rest and cast blame on the state or the union for Willowbrook's lingering woes.

Twice now, since the April 1975 signing of the precedent-setting Consent Decree, the parent groups, led by attorneys from the American Civil Liberties Union, have marched back into court, charging state officials with contempt and incompetence over alleged failure to implement basic terms of the judgment.

It was these desperate and saddened parent groups, which include the Willowbrook Benevolent Society and the New York Association for Retarded Children, that sought the UCP takeover in the first place, as a way to achieve the long-sought goal of better care for the institutionalized retarded.

If the parent groups are criticized at all, it is for their oversensitivity when it comes to approaching Willowbrook's perennial crises.

For in their zeal to right the years of wrongs at the institution itself, occasionally some of them lose sight of the future — and the all-important task of seeking homelike settings for the retarded, back in the communities where they were born.

State

Gov. Carey, as the state's chief executive, is a named defendant in the federal court case, responsible himself for effecting change at the beleaguered public institution.

And under him is the Department of Mental Hygiene, the massive state agency with a budget of \$1 billion plus, that actually operates Willowbrook as well as dozens of other institutions for

the retarded and mentally ill.

As Willowbrook loses an average of one director every seven months, there is often a vacuum of leadership there, leaving Thomas A. Coughlin, a deputy commissioner of DMH, to attempt to maintain order from his Albany office.

And Coughlin, Carey and others, as typified in their handling of the UCP affair, receive the brunt of the criticism from all sides.

The parents took them to court in the first place, making them agree this latest time to the private takeover or face the prospect of sentencing on contempt charges.

The federal court and its appointed arm complain of foot-dragging by state officials, who seem reluctant to comply with a number of key pledges.

And the federal government, too, gets its licks in, saying the institution — the recipient of millions of dollars in U.S. aid each year — is not up to an additional set of federal standards.

The state's on-again, off-again style of negotiating with UCP over a takeover agreement was questioned by the palsy group, whose officials maintained they were kept in the dark for months.

And the union of public workers — a formidable opponent with 4,000 members at Willowbrook alone — has filed lawsuits, conducted demonstrations and is now threatening to strike the management's massive home for the retarded over the fear and unhappiness that accompanies unsettled futures.

But state officials nevertheless contend the UCP takeover is what they want and must do, because it will afford them the opportunity to reduce Willowbrook's patient load — to approximately 1,750 residents — making the institution a more manageable size.

And the numbers game continues. Just this week, for instance, Coughlin, who had been saying there'd be no layoffs as a result of UCP's presence at Willowbrook, said there will be layoffs because of the reduction in population.

He doesn't know how many or when, he says. And at a paranoid moment, one wonders if that just might be the case — that no one really does know what is happening.

But the memos, recommendations, meetings and telephone calls continue to filter across a top-heavy bureaucracy, consuming hours of a single working day — all (and too often, not) for the residents.

Courts

The federal courts changed the nature of Willowbrook in April 1975, when a Consent Decree, signed by parents and state officials, established the rights of the retarded to equal protection under the law.

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The sprawling Willowbrook Developmental Center: Are the residents becoming part of a system of paperwork and numbers games?

S.I. Advance Photo by Frank J. Johns

It also established timetables, guidelines, committees and paperwork.

The most important of these committees — (as well as the primary source of the paperwork) is the Willowbrook Review Panel, composed of seven experts in the field of mental retardation.

The panel, forever keeping an eye on community placement goals, makes recommendations to the state and informs the court of progress and stalemates, but it is not empowered to run Willowbrook.

It's a puzzling, adversarial relationship that has developed between the panel and the state, with panel members questioning state management and state officials criticizing the notion of federal intervention into their affairs.

On the UCP issue, however, the review panel has remained strangely silent, refusing to affirm support of the private group. Saying the plan was agreed to by the state and the parents, panel members insist they can do nothing to assist or assure an easy transition to private operation.

In fact, some members express

doubts about the takeover, feeling UCP has not proved it is willing to work vigorously toward the panel's primary concern — the development of group homes and the eventual abolition of institutions like Willowbrook.

Public workers

They constitute an army at Willowbrook, 4,300 strong. They're concerned more and more about a smaller institution and what that will do to their numbers.

Many feel they've developed a certain degree of expertise in dealing with their residents and see the prospect of deinstitutionalization as a sticky, insurmountable problem.

Worker opposition to the UCP agreement was born in this realization — that the future holds more and more relinquishing of state mental health care to local governments and private groups.

And with a good 70 percent of the Willowbrook work force minority and 65 percent women, the state policy dictating smaller institutions will doubtless eventually leave many of them looking.

A fraction of state employees at Wil-

lowbrook is criticized, too, by parents and administrators who say these workers are over-concerned about pension and under-concerned about the retarded.

And as permanent civil servants, these few "rotten apples" come armed with tenure and an organized union, making it difficult, at best, for them to be fired.

Unanimously, the threatened strike by the union representing everyone from treatment staff to kitchen workers is being viewed with despair, because the takeover is a court-mandated, not management-ordered, prescription to Willowbrook's woes.

But the workers say it won't work because UCP doesn't have the years of experience they do. And besides, the workers are angry — because they never had a say in the decision, because the state never made clear to them their future and perhaps most importantly because the state has made no commitment to re-train them once Willowbrook is expunged.

UCP

United Cerebral Palsy Association of New York, with the Willowbrook project budgeted for millions, wants to prove a point, though its executives are squirmish about comparisons between private and public care.

The group's connection to Willowbrook stemmed from a 1975 contract to train state workers through a "mini-team" approach in the art of complicated therapy techniques.

Now that little contract has led to an unprecedented surrender of state business to more than 1,000 privately hired employees.

UCP has begun to operate seven center buildings, with 640 residents mostly children, and will attempt, it says, to get them to be active and involved people.

But an adversarial relationship already exists between UCP and the state over the private group's boisterous proclamations that it will succeed where the state has failed.

And the public workers, clearly, have nothing good to say about their successor for the deal is resulting in the dislodging of 600 state employees, and even possible layoffs.

In addition, there are already signs that UCP, which must, like the state, become a defendant in the federal court case, will refuse to be bullied into strict compliance with the mandated community placement timetable.

A new party to the consent decree, it remains to be seen how much the private organization will buckle under to the courts, or if it will, instead, choose to operate as an island smack in the middle of state grounds.

Most important, it remains to be seen if this somewhat amorphous, unproved notion of a private takeover will work, and the answer to that will be measured in terms of human lives, not in numbers games or in weight of papers amassed on some Albany administrator's desk.

Each and everyone of the 2,380 residents at Willowbrook will benefit in some way from this takeover, we've been told.

Some of the improvements will be measured in inches, others in feet. Programs throughout the institution will pick up, and each resident shall have a right to grow to his potential.

And then, and only then, will the cast of players in this dense Willowbrook saga be able to smile and say with a clear conscience, "The years of fighting were worth it."