

A look back

Not 'Willowbrook,' SIDC still plagued

By JULIE MACK
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Many people connected with Staten Island Developmental Center — supporters and detractors alike — will tell you that SIDC has improved since 1975, but that its quality of care still falls short.

The question is a matter of degree — how significant the improvement has been, and the extent of the problems that still exist. And the issue has been recently muddied by an announcement from the Health Care Financing Administration (HCFA) that the agency plans to yank SIDC's federal share of Medicaid funding — \$21 million, half of the institution's operating budget — for failing to comply with federal standards on quality of care.

Alan Saperstein, regional associate director of HCFA, says that while conditions at the cen-

ter have not deteriorated, "in view of the circumstances, we would expect much more to have been done."

His comments are supported by attorneys with the New York Civil Liberties Union, which represents past and present SIDC residents in ongoing litigation. "Except for the fact that (the institution) is less crowded, I don't think the clients are really any better off now than they were in 1972," says Chris Hansen of the NYCLU.

These charges are angrily denied by Arthur Webb, commissioner of the state Office of Mental Retardation and Developmental Disabilities, which operates SIDC. He says the institution does meet federal standards (his agency plans to appeal the federal decision to cut off Medicaid funds), and

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Peter Montessani and activity therapist Joann Parker walk down the corridor of the Richmond Complex of United Cerebral Palsy.

maintains that the institution has made substantial improvements in almost every respect.

Yet even Webb admits that the SIDC's problems are such that he plans to shut down the institution in 1987.

The facility has been a headache for the state for years. In the early 1970s, SIDC was widely regarded as a horror among institutions for the mentally retarded. Overcrowded and understaffed, filthy, incapable of providing almost anything beyond basic custodial care (and even that was questionable), the conditions inspired the civil liberties union to file a class-action suit against New York State in 1972. The case was settled 10 years ago this week with the signing of the Willowbrook Consent Decree, which promised full-scale reform.

The implementations of those reforms have been the source of constant battle between the NYCLU and the state for the past decade, with the NYCLU insisting that fundamental change has been sorely lacking.

"It's just appalling," Rob Levy, the NYCLU attorney currently assigned to the case, says about conditions today at the institution. "At best, it's basically a warehouse. At worst, it's a place where bad things still happen to people."

Among those who agree with the NYCLU's assessment is Tony Pinto, president of the Willowbrook Benevolent Society (a parents' group), and members of the Consumer Advisory Board (CAB), an independent state agency that serves as an advocate for past and present SIDC patients.

"The facility is better (than it was in 1975), but it still leaves a lot to be desired," says Anne Thompson of the CAB. "But a lot of the implementation is on paper."

The NYCLU, Pinto, the CAB and federal officials point to the same issues. Training programs for the clients are considered the biggest problem; 30 hours of programming is mandated for each client every week, but critics say the programs exist only in theory.

"The programs are meaningless or nonexistent," Levy says. Notes Ms. Thompson: "You walk into a (program) room and everybody's doing nothing." The federal surveyors from Health Care Financing cite lack of "active treatment" as one of the facility's most serious deficiencies.

Ray Gannon, also of the CAB, noted that the vast majority of SIDC residents are profoundly retarded and many are multi-handicapped, which means they need highly innovative, individualized programs. "But the kind of sophisticated programs that are needed don't exist here," he said.

In their most recent survey of SIDC, Health Care Financing officials cited the institution as failing to meet federal standards in 55 categories — ranging from meal service and nutrition, sanitation and safety, to "philosophy, goals and objectives."

SIDC Director James Walsh says he recognizes that there are

problems. "I wouldn't say that this is a bad institution, but there's no way it's a good institution," says Walsh, who has headed the facility for two years. "It doesn't meet my expectations."

He points out the inherent difficulties of administering the facility — he's not trying to make excuses, he says, but there are problems at SIDC that other facilities do not face.

One major issue is the condition of the buildings. Most were built in the late 1930s and early '40s, and all were constructed in a time when the philosophy was to provide the mentally retarded in a restrictive, sterile, hospital-like environment. Although attractive on the outside, the buildings are gloomy and dingy inside. Exposed pipes run along the ceilings. Lights cast eerie glows. The paint is institutional green.

And while much cosmetic work has been done on the wards — walls have been erected to create more private bedroom space, colorful pictures have been posted, centerpieces are put on the table — it is almost impossible to get away from the dreariness.

Genevieve Benoit, a former SIDC supervisor, noted that while she was at SIDC "my job was to do anything I wanted to

the buildings to make them more comfortable and more attractive. But soon I realized that no matter how many pictures I put on the wall or how fancy the bedspreads go, it was never going to be enough to give that place a homey feeling."

Walsh and Levy agree that the gloominess doesn't affect just the clients. "No question, it affects the employees, and if it affects them, it affects their treatment of the clients," Walsh says.

Levy is more succinct: "The same environment that dehumanizes the clients also dehumanizes the staff."

Walsh says it would cost up to \$50 million to renovate the buildings to create the kind of atmosphere he would like to see. But the state budget office is understandably reluctant to spend any kind of big money on a facility scheduled to close in two years.

Another issue is the staff. SIDC has traditionally experienced high absenteeism and, until recently, high turnover. As for morale, many employees say it's the pits — it's not easy to work at a facility that has been

degraded by the media and by courts for the past 13 years.

Layoffs at SIDC — it was recently announced that 80 percent of the staff will lose their jobs over the next two years, as the institution phases out its operation — have further eroded morale. "We're asking everyone to give 110 percent, but it's tough," said one supervisor.

There is another factor. The salaries paid by SIDC are not great by New York City standards, and working with such severely disabled clients is both physically and emotionally demanding. Considering the salary and the nature of the work, it is not surprising that SIDC — along with developmental centers in elsewhere in New York City — have had difficulty attracting highly skilled, motivated workers.

Yet, Walsh says: "The services

we offer now are adequate. And I do think we have certain sections that are good, sections that show we are capable of providing quality care."

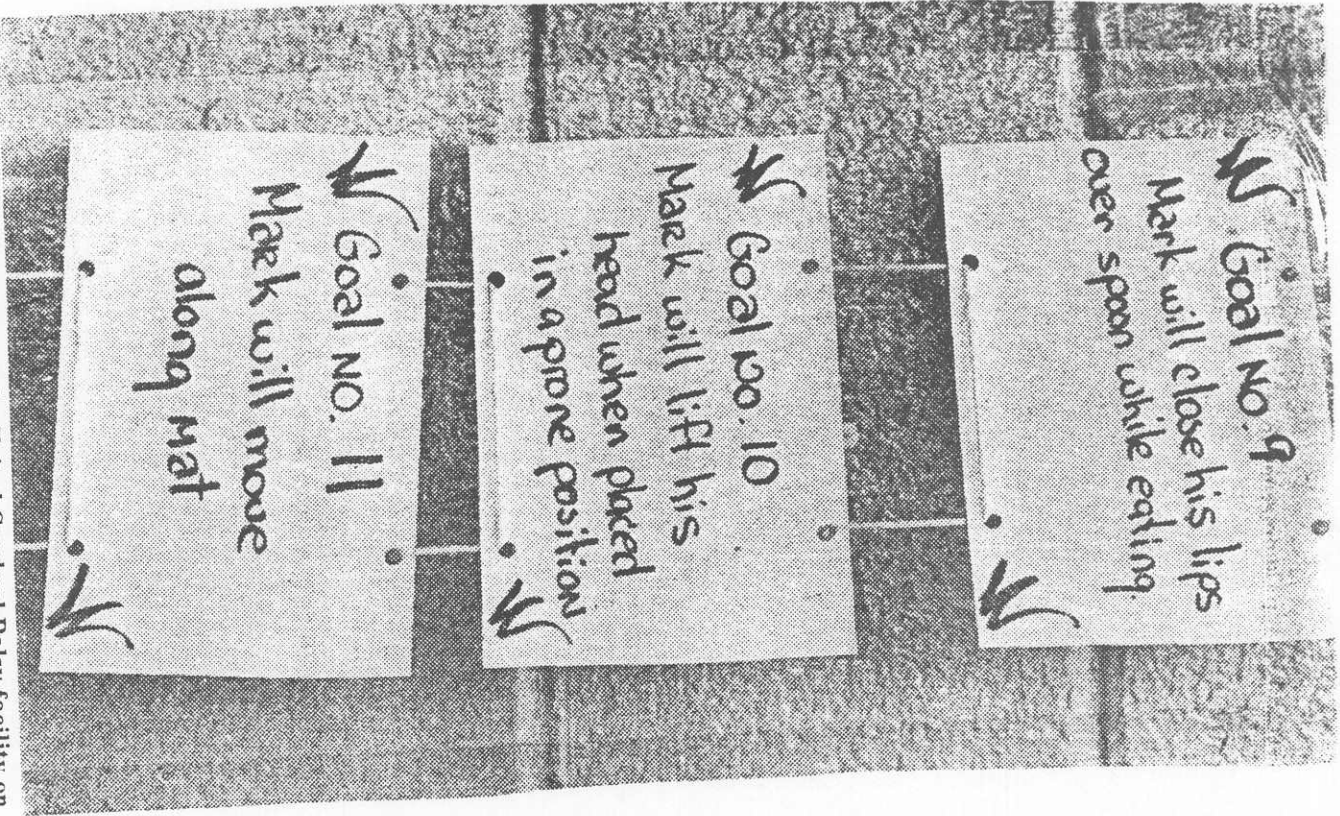
Saperstein, who has reviewed federal audits of SIDC for more than 10 years, says he is baffled and frustrated by the facility's apparent inability to improve to what Saperstein considers acceptable levels.

"I've met with Jim Walsh and he seems to be a real dedicated spirit. I would guess that what he is going through is the worst kind of frustration you can experience in a bureaucracy. I know he has union problems. I know he has staffing problems. Yet I also now that he feels gratified over the improvements that he feels have occurred," Saperstein said. "But they still haven't come up to federal standards."

The question now is how much the institution can be upgraded before its closing in two years. Walsh says that improvement will occur as the client census continues to decline, allowing for more personalized care. But he adds that the real solution to the problem is shutting down SIDC as quickly as possible. "I took this job with that understanding: I said I wouldn't take it otherwise," Walsh says.

"One problem is that the situation here is so protracted; it's such a slow-death," says Gannon of the Consumer Advisory Board. "The best for SIDC is for it to close."

(This is the fifth in a six-part series on the Staten Island Development Center and what has happened to it since the consent decree was issued 10 years ago.)



Goals are simple for clients at the United Cerebral Palsy facility on the grounds of the Staten Island Developmental Center. As many SIDC clients as possible have been transferred to UCP programs in an effort to improve the quality of therapy and care.

S.I. Advance Photos by Tony Dugal



UCP aides have clients roll on an airbag and then roll a huge ball over them for physical therapy — and just plain fun.