

Breaking down the walls

New trends emerging in care for the retarded

By PHIL ARKOW

Bitter demonstrations erupted last year when the New York State Department of Mental Hygiene ordered the Sampson State School closed during a continuing financial crisis. One school employe set himself afire to protest the transfer of hundreds of mentally retarded patients to other schools already overcrowded and understaffed to a point of despair.

In Harrisburg, Pa., a federal court ruled that 14,000 patients in 18 Pennsylvania mental hospitals had been denied the rights of due process of law. In Montgomery, another court ruled that patients committed involuntarily to Alabama's mental institutions have the right to adequate medical treatment. In July, New York State will begin administering a civil rights law requiring that mentally retarded patients be notified of their rights and how they can challenge their commitments.

In Connecticut and California, millions of dollars were trimmed from state mental health department budgets last year, as lawmakers decided that the retarded could be treated with a little less care in efforts to balance tight state budgets.

Residents of schools for the retarded "don't vote, they don't speak, they have no control over the legislature," says Robert Wertz, a New York State Assemblyman, chairman of the Assembly Committee on Mental Hygiene. "Even their own parents have forgotten them, and it's just so easy to dump them into a corner."

Across the country, the status of America's care for its millions of mentally retarded citizens is coming under a social crossfire unequalled in the history of state and local institutions. From all sides,

fiscal, ethical, legal and emotional — the need to improve the situation for brain-damaged children and adults is caught by binding financial crises, labor disputes, social changes, tuition increases, and just the boggling size of the problem.

WILLOWBROOK NAMED

The world's largest institution for the retarded, the New York State School at Willowbrook on Staten Island, has been referred to as "the last outrage" and "the big town's leper colony." The school has been under investigation for several months, following recent media disclosures of death, filth, and a lack of even minimal custodial care as patients outnumber the staff by up to 30 to one.

At Willowbrook, more than 5,000 residents, mostly those in the "severely" and "profoundly" retarded categories, were in a statewide freeze on staff hirings. More than 100,000 of Willowbrook's residents are not toilet trained and cannot feed themselves. Thirty-nine per cent cannot walk. More than half cannot speak.

Willowbrook is an institution of virtually all custodial care. The major break in the routine of boredom and apathy, say legislators and newsmen who have toured the school, are the deaths that occur three or four times a month when a patient chokes to death in his own vomit before an attendant can reach him.

There are about 30,000 residents in New York State's 37 schools for the mentally retarded, and hundreds of thousands more who receive out-patient services. The state's Department of Mental Hygiene had felt itself strapped with a \$600-million budget, and had

been forced to leave almost one-fifth of its hospital staff positions vacant during the employment freeze.

There are an estimated three million patients in schools and hospitals for the retarded across the country.

Care for the nation's mentally retarded is often nothing more than a holding action until death. Depending on the severity of the brain damage, rehabilitation can at best be a borderline with normality.

SLOW PROGRESS

Rehabilitation for the retarded is measured in agonizingly slow, gradual steps. For the 95 per cent that will not "graduate," being able to hold a spoon, or feed oneself, or become toilet trained, is the most that may ever be learned.

Dedication and depression seep from the walls of the infirmaries of the nation's schools for the retarded. The moans and shrieks of children incapable of speech cry out for love and attention. The smells of urine, feces and antiseptic are pervasive. And the devotion of the ward attendants is admirable.

At the Wilton State School, located in a former sanatorium atop Mount McGregor in the foothills of New York's Adirondacks, children pad along the cold infirmary floor because they cannot walk on their club feet. Boys wear football helmets, not to idolize star quarterbacks but because; they are compulsive "head-bangers," self-abusive children whose only forms of communication are to hurt themselves in moaning cries for attention.

Wilton is the fourth smallest of New York State's schools, and it is more typical than Willowbrook of the trends and future for mental health care.

It was once a small town's "leper colony," perched atop a mountain where no one could see inside. It is now being brought down the mountain to help break down the fears and the stigmas imposed upon the retarded for generations.

"For years and years, institutions were left out of the mainstream of the community," says Dr. Emanuel Rechter, the soft-spoken Viennese psychiatrist who directs the Wilton school, and who always has a kind hand and a smiling face for its 410 residents. "No one wanted anything to do with them. It's not by chance that they were built away from the centers of towns. There was always a certain amount of apprehension and fear — and no one wanted to look at someone who was disfigured."

For generations, the mentally retarded were quickly confined to private and state institutions, without any thought that they might be able to lead useful lives within the limits of their intelligence.

One former Wilton resident spent 32 years in various state schools, the victim of an age when the retarded were not given a chance. He is now working and paying taxes to support the school he used to live in.

Wilton represents a trend that has spread across the country in recent years, to eliminate the large, walled-in institutions with their condemning custodial care, replacing them instead with smaller, regional centers with an emphasis on community care. Wilton receives patients from a three-county area of upstate New York. It works with area municipalities and educational facilities in combined projects.

"All our construction projects

are aimed at reducing the resident population of our large institutions," says Dr. Alan D. Miller, commissioner of the New York State Department of Mental Hygiene. "Our new, small facilities are designed to develop a new model of services, including residential and out-patient care, which integrate their services with all other community services."

"Lifelong institutionalization will no longer be the pattern of care, and the retarded person, whatever his level of disability, will have his rightful place in the community."

But the new trend is not finding its way out of society's closet easily. The task of shifting years of health care from custodial treatment of outcasts to a coordinated effort of community interaction, and to break down psychological barriers, is almost as formidable as finding a cure for mental retardation.

"Thousands of children labeled 'autistic' make up only a fraction of the handicapped patients who have been deprived of essential services in the shuffle of diagnostic con-

fusion and through the misguided efforts of an unwieldy bureaucracy," Dr. May Goodwin, a consultant with Miller's department, told a joint legislative investigation subcommittee. She also charged that New York State's mental hospitals are just as "intolerable" today as they were in 1965, when the late Sen. Robert F. Kennedy said

Willowbrook "bordered on a snakepit."

"I don't think the attendants are at fault," Kennedy said then. "We're all at fault."

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