

The War Against the Mentally Retarded

By Robert Keating

“...Bomb threats, vandalism, violence, phone threats have become our newest method of treatment for the mentally retarded...”

A hidden war is being waged in New York City. Middle-class and affluent neighborhoods are doing battle against the area's mentally retarded. At issue in the conflict is the return of the handicapped population from the closing state institutions to their old neighborhoods. Instead of seedy

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hotels, they're moving into nice apartment buildings and houses on the block. And suddenly the city's concerned support of the mentally retarded has given way to a pattern of aversion and abandonment. In the words of a Staten Island woman, “We don't want them. Put them back in Willowbrook.”

In the winter of 1978 the quiet town of Huntington, Long Island, lost both

its electricity and heat. But especially cold was the new home of ten mentally retarded adults at 66 Greenlawn Road. The houseparents, Josephine and Jack Farneti, had been getting threatening phone calls for over a week. Usually a peaceful community, Huntington had turned crazy in its efforts to prevent the ten retarded persons from moving in, which was to happen any day. So on the icy evening



At home: This drawing and those on the following pages depict daily life in the hostel on 89th Street in Jackson Heights, which neighborhood groups want closed.

“...The same upper and middle classes that hollered for reform have become the problem they once fought so fervently...”

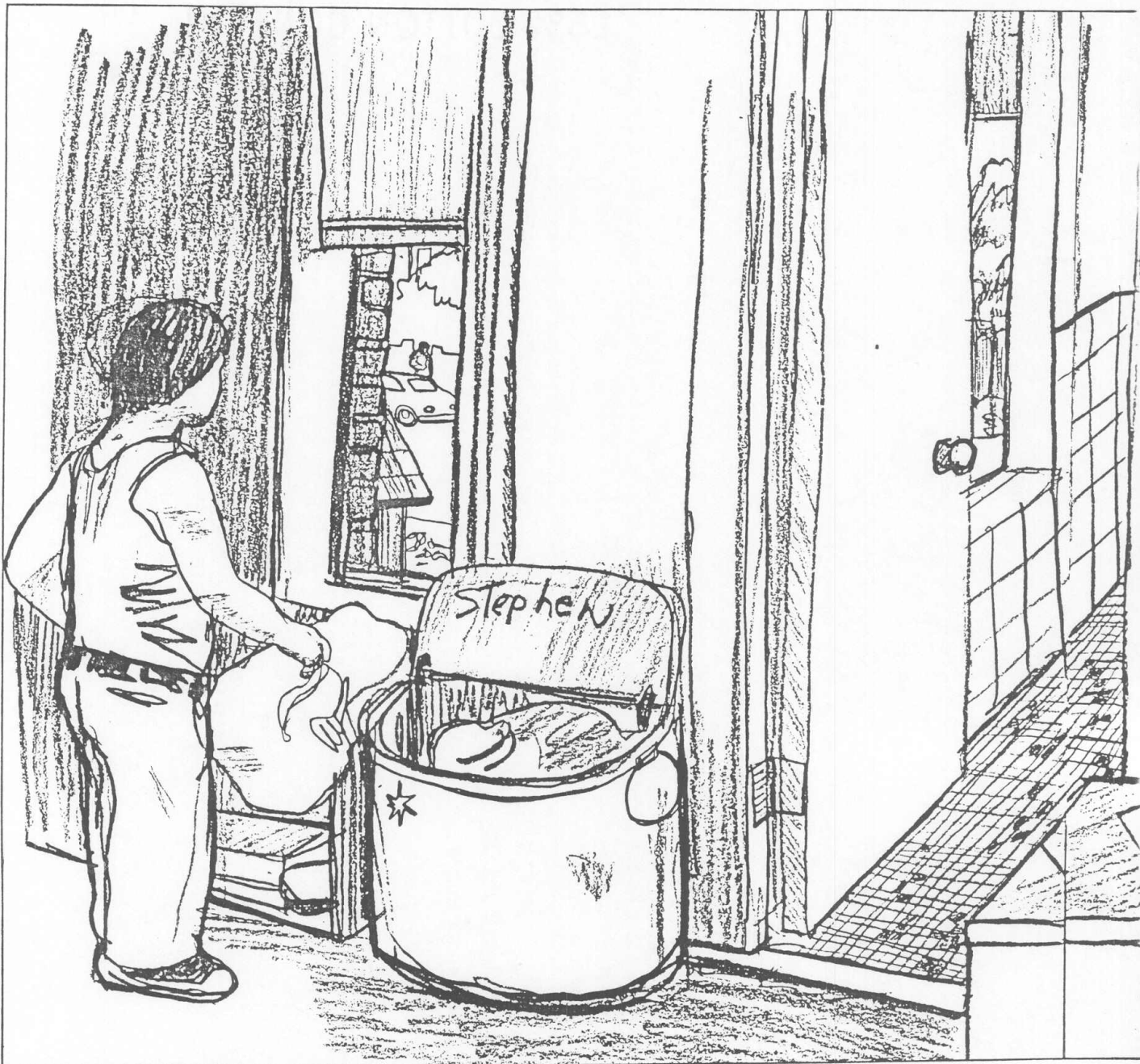
of January 15, Josephine warmed to the friendly voice with a heavy Brooklyn accent on the phone. The man claimed to be with the Long Island Lighting Company and needed to know when the Farnetis would be home so the wiring could be checked and services restored. When informed that they would be attending a wedding in Manhattan that night, the man told Mrs. Farneti to be sure and leave the vents in the three fireplaces open “to keep toxic gases from forming.” She ignored the advice. Later, when the two returned in the early morning, they

found Greenlawn Road alive with fire trucks and police, and Mrs. Farneti learned from a member of the Arson Squad that these special instructions had been made to ensure total destruction. The arsonist had, early in the night, entered the house and poured gasoline throughout the first floor. The air from the open vents fed the flames as they raged through the house. Still, with professional preparations and heavy snow slowing the fire trucks, the house was quickly lost. As was the Farnetis’ young dog.

On Staten Island the son of a home-

owner who was planning to sell a house to the state as a hostel for retarded children needed seventeen stitches to close the gash a metal pipe had opened in his head. Apparently mistaken for his father while stopped at a red light, the teenager was dragged from behind the steering wheel and brutally beaten by a small mob. The next day the car’s windows were smashed. A phone call followed, asking the father, “Have you had enough?” The man had. His offer to sell the house was quickly withdrawn.

The district manager of a Brooklyn



community board was warned that the board's approval of a proposed site would guarantee her daughter two broken legs and a bed in the home. The board voted against the site. "Definitely a vote by intimidation," said one board member, noting that others had been similarly approached.

Scot Booth, the state's community-placement specialist for Staten Island, says he needed a police escort to get him away from an angry crowd at a public hearing on proposed sites after he received threats on his life.

Bomb threats, broken windows, vandalism, violence, and early-morning phone threats have been introduced in New York City as the newest method of treatment for our mentally retarded. "It's like the Ku Klux Klan," sighed one woman after she gave in to the

pressure and withdrew her house from consideration. "And this came from people who used to be my neighbors and friends." The FBI has begun investigating such incidents.

At the root of these savage actions is a piece of paper known as the Willowbrook consent decree. When it was signed by Governor Hugh Carey in April 1975, the New York Civil Liberties Union praised it as a landmark victory for the country's most vulnerable population. The decree carries out a federal-court ruling made after the horrendous conditions at the Willowbrook State School for the Mentally Retarded, on Staten Island, became publicly known. It mandates the de-institutionalization of the facility and the relocation of the patients in home-

like settings in their original communities so as to provide "the least restrictive environment."

Even though a national Gallup poll indicates that only 9 percent of the population would object to having a supervised home for the mentally retarded on their block, the President's Committee on Mental Retardation saw fit to footnote: "Their statements may not always be reflected in their subsequent actions." Which has been proved shamefully true in New York City.

On September 9, 1965, Senator Robert Kennedy stood on the grounds of Willowbrook denouncing it as "a snake pit" with "intolerable" and "zoo-like" conditions and declared, "I think all of us are at fault. And I think it's long overdue that something be done about it." And for a while something was. Willowbrook stories filled the press for two years. Then the name slowly disappeared.

Seven years later, Geraldo Rivera brought his WABC camera crew to B Ward, Building No. 6, and for the first time a camera's eye brought the writhing forms of flesh—neglected people, condemned to filth and forgotten misery—into comfortable living rooms throughout the New York area, and soon across the nation.

New witnesses to society's crime watched with shock as Rivera said, "This is what it looked like. This is what it sounded like. But how can I tell you about the way it smelled?" After a visit to the wards, the usually creative Joe Flaherty of the *Village Voice* struggled with metaphor to describe "children with faces like twisted 8's, children with legs like rickety I's, children with eyes poked out, producing a light and a dark zero, bodies scattered over the floor like spilled bingo pills—all adding up to a hopeless naught. And the bureaucrats there want to blame it all on the cash register in Albany."

When the director of Willowbrook was asked about the frequency of "rare" deaths at the institution, his response was, "Three or four times a month."

On March 17, 1972, a suit was filed against the governor of New York and ten other state officials. One year later, on April 10, 1973, Federal Judge Orrin Judd decried the conditions at Willowbrook as "inhumane and shocking" and demanded immediate remedy. After two years of stalling, the state affirmed his decision when Carey signed the Willowbrook consent decree. The decree not only prohibited common abuses ("straitjackets shall never be used, nor shall any resident be tied, spread-eagled to a bed or subjected to . . . corporal punishment. . . .



No physically intrusive chemical or biomedical research or experimentation shall be performed"); it also mandated the relocation in neighborhood group homes of all 5,323 residents. The court ordered that at least 50 persons per month be placed in the community—which means the development of about 60 homes per year. By the project's completion in 1981 each community-planning district will have at least five residences. (Currently, due to community opposition, the state is well behind schedule and technically in contempt of court.) Judge Judd had found that institutionalized patients "deteriorate both physically and mentally."

With the consent decree, the shame of the masses had been mollified. But today, over four years later, the same righteous upper and middle classes that hollered for reform have failed to back their words with consistent actions. Rather, they have become the problem they once fought so fervently. As the head of the Department of Mental Hygiene confessed during the Willowbrook exposé: "The way we treat our mentally retarded is our last great disgrace."



"In another place, yes," says Peter Lecourezos as he sits on his front stoop two houses away from a recently opened hostel in Jackson Heights, "but not here—not on this block."

"The most logical thing to do," suggests a protester in Sheepshead Bay, "is to purchase bungalow colonies and small hotels in the Catskills and convert them into residences." One woman worries. "Their windows face my windows. I have a little boy and a daughter."

"These people are afraid of the mentally retarded because they're an unknown," says Jennifer Howse, former executive director of the Review Panel and now an associate commissioner in the Office of Mental Retardation and Developmental Disabilities (OMRDD). "The fear is based on the

belief that the retarded are dangerous, threatening, ugly, or simply that their presence will drive property values down. None of this is true." Howse supports this statement with a study by Princeton professor Julian Wolpert on the impact of group homes on their surrounding communities. Wolpert found no negative effects and noted that the group homes were generally better maintained.

Duncan Whiteside of the One to One advocacy group for the mentally retarded points out: "Fear of the retarded, whether founded or unfounded, is itself real and has to be dealt with. You're touching upon my core interests. My family. My home. My community."

Some feel that educating the community is the key. But even when efforts to educate the public are at their best—including door-to-door talks with the neighbors of a prospective site—the words tend to fall on deaf ears. "If I go over there and end up liking those people," reasoned a woman living across the street from a new hostel upon turning down an invitation to visit, "then we might never get rid of them."

These extreme attitudes have prompted one member of the Review Panel to lash out at the OMRDD for even listening to them. Murray Schneps is a lawyer who speaks with undisguised anger about the way the mentally retarded are mistreated. He was a force behind the original Willowbrook suit, in which his retarded daughter was named as a plaintiff. "The state encourages this ridiculous resistance," he fumes, "by acting as if the resisters have some rights. And this negates the rights of the mentally retarded, whom the state should be protecting. Sure I believe educating the public is important, but I can't wait for everybody's mind to change. We need improvements now. The state, every time it gives in just a little, is giving credibility to such illegal opposition."

The neighborhood opposition to the relocation project has centered in the local community boards. While the boards are typically passive when the state approaches with a proposed site, they turn into fiery forums for protest when the affected blocks find out.

State Senator Frank Padavan, not a strong advocate of group homes, saw the opportunity to become the Kissinger of the controversy by setting legal guidelines for the relocation. The Padavan law, in effect since September 1978, rules that legitimate protest can be brought against a proposed site if it oversaturates an area with social-service-related residences, thereby significantly altering the character of

the neighborhood. Confusion remains, however, in that the criteria for both are undefined. If agreement between the local board and the state cannot be reached, the case goes to a hearing. If the board is still unsatisfied, the law allows for a suit which essentially charges that the state acted improperly in the site-selection procedure.

While the law helps by providing a structure and time limitations, it often gives the boards the sense that they can and should be in complete control of the operation. In the words of one state worker, "The community boards are milking it for all it's worth."

Murray Schneps questions the constitutionality of the law and asserts that "the rights of the mentally retarded are non-negotiable" and must be enforced regardless of local opposition. "The state," he claims, "is trying



to appease everybody, and the politicians . . . well, that's obvious."

"Sue their asses off," shouted City Councilman Leon Katz over the roar of a recent public meeting concerning a site on Ocean Parkway in Brooklyn. "If this one gets through . . . Ocean Parkway isn't going to be the kind of place you wanted it to be." Local politicians have seized the opportunity to muster support by playing to the angry opposition to the hostels. "At a recent meeting in Brooklyn," notes one watchdog, "there wasn't a politician in the borough who didn't show up."

State Senator John Calandra and Assemblyman Guy Velella—the Bronx's two biggest powers in the anti-residence movement—have stated that their policy is simply "to be guided by the desires" of the neighborhoods. Calandra has gone so far as to promise that if a controversial site went through, he and Velella would "fight any appropriations of State funds" for it. Schneps took the opportunity to point out that he sees this as being in contempt of court. But Calandra's opposition is not surprising. While the consent decree was being drawn up, his firm was busy pro-

viding legal defense for what an official in Albany once called "the worst facility for the mentally retarded in the state"--the Pine Grove School. The school was finally shut down.

Assemblyman Velella's position has been: "A group home does not fit on a purely residential block." He suggests that the "least restrictive environment" be erected on the grounds of the Bronx State Hospital.

Even though the politicians are doing an excellent job of stoking the fire of discontent, they could take a lesson in inflammatory rhetoric from a man not in their field per se.

"Get Mr. King up there," shrieks a frantic voice out of a crowd of 600 protesters packed into a small Staten Island auditorium. "Let Mr. King speak!" And as the dapperly dressed middle-aged black man approaches the mike, the crowd begins to roar. King is preceded by his reputation.

"My name is Felton King," he begins in a slow, powerful voice. "I'm the president of Local 429 at the Staten Island Developmental Center [Willowbrook]. I'd like to give you some facts. . . . Approximately 88 percent of the clients being placed out in the community . . . have a severely bad behavior problem. . . . It is a fact that these kids have communicable diseases." The audience reacts with ahs and scattered whispers. King pauses after each fact.

"What we call hepatitis carriers . . . tuberculosis. . . ." (General noise and confusion.) "What would happen if they spit in your children's face? They could transmit tuberculosis . . . hepatitis. . . . If these children scratch or break your child's skin, this means your child's then contaminated with hepatitis. . . ." (Mounting chaos.)

"Last month approximately 565 of their employees went out on workmen's compensation because severely, profoundly retarded children broke their skulls, broke their legs, and fractured their ribs. . . ." (Loud applause.)

"They say they're not going to harm your kids. . . . That's a bunch of crap. . . ." King leaves the microphone while the audience extends the enjoyment of its own disorder. It is clear that one of Felton King's primary concerns is the threat of losing union jobs when Willowbrook closes.

Dr. Curt Bakal of the city's Health Department, when informed of King's claims, responded, "The guy would have a point if . . . no, the guy really doesn't have a point. If anything, the chances of a Willowbrook client transmitting tuberculosis in the community would be less than that of the general population because of better medical

“...‘Keep them in Willowbrook,’ says a woman. ‘Why tear down a neighborhood?’...”



care.” His colleague Dr. Elaine Miller notes that about 15 percent of the Willowbrook class may be hepatitis B carriers. “It’s a serious disease,” she says, “but the risk of their transmitting it is really minimal—they’re certainly not going to transmit it on the street. It requires prolonged intimate contact.”

“I guess if you got spit on over and over again, of course it’s possible,” adds Bakal, “but what he’s saying is extremely exaggerated.” Which King concedes is also true of his 565 broken bones.

More surprising than King’s inflated ravings, however, is the blatant enjoyment of the otherwise, one would assume, rational people who feed off his distorted remarks. “These retarded kids shouldn’t be made scapegoats,” states Dr. Bakal. “They shouldn’t have to suffer for someone else’s cause.”

An outraged Murray Schneps feels this is exactly what could happen. “King made an open physical threat against the residents of Willowbrook,” he recalls. “He didn’t like the attitude of the parents, so at a meeting of the Review Panel he began using the children as hostages [pointing out that they were dependent upon the care of union members]. I said, ‘Felton, are you really threatening the residents? Are you really doing that?’—fully expecting him to back down like anyone else would when confronted. But he said that was exactly what he was saying. Now if King wants to

threaten the parents, let him do that. They can defend themselves. But to get to them through their children is stupid and irresponsible.” King flatly denies Schneps’s statement, saying: “I have never stood up in a meeting and used the residents as hostages to save employee jobs.” Schneps feels the threat of institutional irresponsibility makes emptying the barracks all the more urgent. But not everyone agrees.

“Keep them in Willowbrook,” urges Olga Kudlak, “that’s the proper place for them. . . . Why tear down a nice neighborhood like this?” Olga’s “nice” neighborhood is in Jackson Heights, Queens. The people she is referring to are her new neighbors at 33-32 89th Street. It is a neat brick Tudor house unassumingly nestled into a block of the same. It is unique only in that eight mentally retarded persons call it home—the first one they’ve had in many years. One of the residents, Rochelle Grant, remembers her last home as “Building 23.” “It was a bad place,” she recalls. “They would call me a fat Jew, but I wouldn’t listen. Sometimes they would throw shoes at me and hurt, but I wouldn’t bother.” Rochelle smiles with the knowledge that this is all behind her. She doesn’t realize that Jackson Heights is battling to get her out of her new home.

Joel Levy, director of the Young Adult Institute, which runs the home, demands that the mentally retarded be

the retarded from the dangers of city living, another teenager says, "Sooner or later they gotta learn street."

The eight residents of 33-32 89th Street may soon have to learn street someplace else. In late July, too late to keep the residents from moving into the house, Community Board 3 took its opposition to the final stage of the Padavan law and sued the state under Article 78, charging improper compliance with the Padavan restrictions. The city's corporation counsel agreed for the first time to represent a local community board against the state. And one of the city's lawyers uncovered an unnoticed regulation in the complicated law, allowing the board to offer additional sites. Although the time limit for filing suit as stated in the law had expired, the judge decided that the limit did not apply. An injunction was issued restraining the state from further developing the site, but the judge has refused to prohibit occupancy, and the case remains in litigation. Should the state lose, the residents may have to vacate their home and return temporarily to an institution.

"Maybe we blew it," says Joyce Roll of CRISP, a community-service group for the state. "It was the first time under the Padavan law and no one knew. We were being cooperative, saying, 'Okay, we'll apply the law.' Now these people's home is threatened because of a technicality. It's a disgrace."

Frank Padavan, when reached, said, "See, the law works."

Paul Dolan, the director of One to One, strongly questions the legality of the Padavan law. His group has set aside funds in case a suit for the rights of the retarded becomes necessary. "It is, after all," says the mother of a retarded girl, "a question of civil rights."

Murray Schneps agrees. For him the struggle for the civil rights of the retarded is the same as the struggle for any other group's civil rights. "It's a battle," he says. "If we're going to take advantage of the opportunity given us by the Willowbrook decree, if we're going to make it so people no longer have to be destroyed in institutions, then we can't be chickening out because some nut burns a house down."

"If it doesn't work here," Schneps warns, "it won't work anywhere. No place else has the decree that we have. Nor a review panel with the power this one has. And no place in the country is funded the way this case is. It can't all be wasted because of prejudice."

"New York has a tremendous responsibility—if we fail here, we fail for everybody. No one's going to have a chance for another 50 years. It'll be back to those damn institutions." ■