

THE FAST-LANE LIVES OF CAR RACERS' WIVES (OR, LOVE IN THE PITS)

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The Deinstitutionalization of Nicholas Romeo

His case changed the fate of the retarded.

BY JOHN WOESTENDIEK

The Unwitting Revolutionary of Pennhurst

Nicholas Romeo forced changes in the way the retarded are treated that he himself can't begin to understand, and which are still going on.

BY JOHN WOESTENDIEK

THEY WERE A STRANGE BUT familiar sight walking hand in hand down the streets of South Philadelphia — Frank Romeo, the burly shipfitter, setting a steady heel-to-toe pace, and his retarded son, Nick, a gangly 26-year-old with a gait that was the opposite, toe-to-heel.

Frank knew most everybody in the neighborhood, so they'd stop a lot, popping into Claudio's, a cheese shop on Ninth Street where Nick had a habit of grabbing olives from a big jar on the counter, or into Picolli's, a bar on Passyunk Avenue where the men would talk sports and Nick would drink sodas and dance to the jukebox.

Nick was always dancing, or jogging, or jumping up and down, always headed somewhere or doing something — a perpetual child in perpetual motion. Except for the two, maybe three hours a night he slept, there was no end to his curiosity, or his energy. Even before Nick learned to walk, at 4, Frank Romeo and his wife, Paula, learned that the way to keep Nick happy was to keep him active. So they hiked around the neighborhood, and went on weekend trips to the Jersey shore or on day-long excursions to the park. At home, they would play with him until they could stay awake no longer, then sleep in shifts, driven, it seemed, to fashion a life of sorts for a son who hadn't been dealt much of one.

For 26 years, they had listened to doctors and social workers and friends tell them Nick should be "put away." Each time, it was like a slap in the face. You "put away" your socks, not your only son. With your only son — your "flesh and blood," as Frank would say — you did what you could, maybe spoiling him a bit in the process, but keeping him happy and under control. The reigns were loose, but

there was never any doubt that Frank Romeo held them. At times, when Nick's energy reached the danger level, all it took was a look from Frank to calm him down.

On May 10, 1974, Frank was sitting in his chair amid the usual spirited chaos that marked family gatherings at the Romeo rowhouse on McKean Street. Glenn Miller was blaring on the record player. Nick was on the floor at his father's feet, hollering and hammering on a Playskool peg-and-hole toy. And Paula was headed to the store to pick up some linguine for dinner. She took Nick along in the station wagon. Before they returned, Frank Romeo clutched his chest and fell to the floor, dead of a heart attack.

Death, like most things, had no meaning for Nick. When a family friend brought him to the funeral home, he grabbed one of his father's beefy hands, folded neatly on top of his best suit, and tried to tug him from the casket so they could go for a walk, or fishing, or paddle-boating, like they always did.

In the days that followed, Nick, his brown eyes bouncing back and forth between looks of anger, frustration and fear, would run from room to room of the rowhouse, groaning when he couldn't find his father. He would grab his mother's hand, pull her out of the house and lead her to all the places Frank had taken him.

Each day, he grew more agitated. He got fevers. He screamed, and broke things. He kicked and slapped, bit his hand and banged his head against the wall — things he had done only once in a while in the past, probably, his mother always figured, because he had no way to express himself. Now, though, he was doing them more frequently and more fiercely, and Frank Romeo wasn't there to

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JOHN WOESTENDIEK is an Inquirer staff writer.



Romeo, who is profoundly retarded and has never learned to speak, rests on the sofa of his mother's home in South Philadelphia at his 36th birthday party in January. Nick lived with his parents for 26 years, but when his father died, he was placed in Pennhurst. He spent nine years there, tied to a bed or chair for more than 7,500 hours. Now he lives in a group home in Northeast Philadelphia and attends a workshop, where he receives physical therapy and vocational training.

Here was Romeo, of Supreme Court fame, Pennhurst's most-watched resident, with 50 fresh welts on his back, chest and buttocks — all in the shape of a toilet bowl brush.

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help, and it was scary.

Twelve days after her husband's death, a desperate Paula took Nick to a hospital, which sent him to Pennsylvania Hospital, where doctors put boxing gloves on his hands and tied his arms and legs to a bed padded with foam rubber and sheepskin. They would list his I.Q. as 9, his mental retardation as "profound." They would note that a shortened Achilles tendon made his gait "spastic," that he had a habit of hitting himself.

Twenty-one days would pass. Nick would spend most of them in the foam-padded bed on the eighth floor. Paula would spend most of them in a teary haze. She was sick herself with heart problems, and now, with her husband's death, she was saddled with singlehandedly caring for both Nick and her sister, Frances, who, though less retarded than Nick, was still a handful. She vaguely remembers signing a form back then, after someone had filled in the blanks, but she doesn't remember exactly what it said.

The master finds Nicholas Romeo mentally retarded. Accordingly, the master directs that Nicholas Romeo be committed to Pennhurst State School and Hospital for a period not to exceed

The last blank on the commitment papers remained empty, as it had for most of the 10,433 retarded people who had entered Pennhurst before him. Most of them, since the institution opened in Chester County in 1908, had lived out their lives there and died in the hulking red brick buildings.

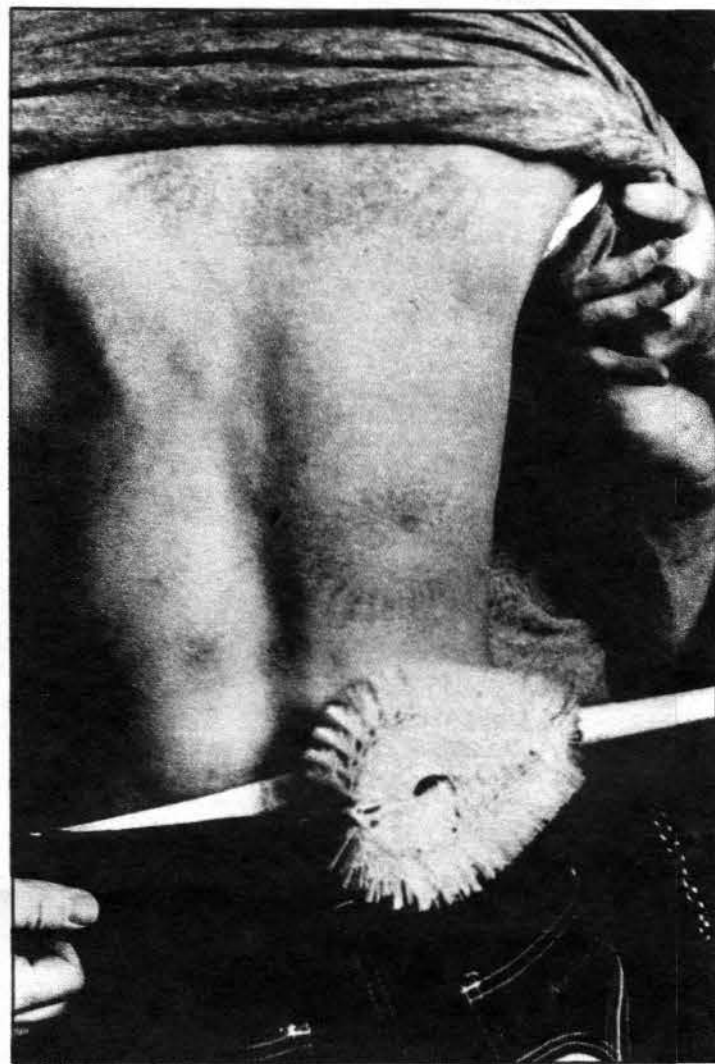
About 2,000 people lived at Pennhurst when Nick arrived in an ambulance on June 12, 1974. Like them, he was assigned a number: 10,434. His curly brown hair was shaved down to a crew cut, and he was taken to his new home — a building called Unit 7.

He would not go gently, but kicking and screaming; and though his sounds made no sense, this man who couldn't talk, and his counterparts, would be heard over the next 10 years as they had never been heard before. With the aid of advocates and lawyers, under the microscope of a courtroom, Pennhurst would emerge as one of society's more dismal failures, and Nicholas Romeo would emerge as a textbook example of why.

He would leave Pennhurst nine years later, a scarred, stitched, bruised and battered legend; a man whose injuries — 77 in the first two years, more than 200 in all — would lead the U.S. Supreme Court to rule that the retarded have a right to something more than the kind of maintenance we give an automobile. He would leave with his name in law books and special education texts, and with the promise of a better life — one in which he would not be tied to a bed or chair, like he had been for more than 7,500 hours at Pennhurst; one where he would not be sedated to toxic levels or spend hours and hours in idleness.

He would leave Pennhurst at a time when it was the most closely watched institution in America, and he was its most closely watched resident. Under that scrutiny, there would be improvements — some real, some only claimed on paper.

In the Pennhurst of the 1980s, residents would no longer labor for the state in sweatshop conditions. They would no longer sleep packed together in rows of beds, or be hosed down en masse, or get raped, or drown (as nine



did in two years) in the Schuylkill. Residents, the state would say, would no longer be left locked in seclusion rooms, tied in restraints or drugged into oblivion solely for the convenience of the staff. They would get some training rather than spend all day lying on the floor, often naked, often in their own waste.

And physical abuse of residents by staff — perhaps the most perpetual, most publicized problem in Pennhurst's 75-year history — would be fought with investigations, criminal charges and firings.

That was the new Pennhurst from which Nicholas Romeo would emerge on April 5, 1983, with 50 fresh welts on his back, buttocks, legs and shoulders — all in the shape of a toilet bowl brush.

YOU TRY TO STAY ON PAULA ROMEO'S good side. She is a tough, feisty lady, and though she never finished high school, she can verbally knock you off your feet and stomp on you.

The three ladies on Broad Street didn't know that. All they saw was a short, stocky woman trudging up the sidewalk with one end of a rope tied around her waist and the other tied around her son's. Prim and proper-looking, the ladies were whispering and frowning as Paula approached. Their eyebrows wagged, and their lips pursed. Paula couldn't hear everything they said, just the words "cruel" and "poor kid" and "like a dog." But that was enough. As her son stood by, attached

to the makeshift umbilical cord, she let them have it.

"Now look," she said. "My son just learned how to walk. He is profoundly retarded. Would you rather see him run across Broad Street and get killed, or would you rather see him tied to me so he won't get killed? What do you want me to do, huh? You tell me. Do you want me to carry a sign on my back? My son is retarded. OK? OK."

She was brassy, one of the things Frank Romeo liked about her when they met and married in 1943. He was a proud man with a jutting jaw and kind eyes; like her, he was a native of South Philadelphia. She was 18, a chef's daughter, one of four D'Attola sisters. They honeymooned at Coney Island and, by the end of 1947, after Frank returned from World War II, they were awaiting the arrival of their first baby.

On Jan. 1, 1948, Paula went into labor. Four days and four nights later, Nicholas was born; he weighed 6 pounds, 3 ounces. In three days, his weight dropped to less than half that. He would remain in an incubator for a month, until his weight reached 5 pounds, 10 ounces, and the hospital let the Romeos take him home.

They knew something was wrong, but they didn't know what. At first, he could not swallow. They fed him boiled cereal strained through cheesecloth. He couldn't roll over until he was 8 months old, or sit up until he was 9 months old. At 11 months, he first held his head up on his own, and, at 2, he crawled.

"We were half out of our minds," Paula remembers. "We had to do something. We took him to specialists here, there and everywhere. This one doctor, he should have never been a doctor. He said, 'Oh, he's only a vegetable, put him away and forget about him.'"

Although some doctors predicted that Nick would not walk, Frank and Paula kept working at it. "We'd hold him up by his hands, my husband and I, and say, 'Come on, Nicky, walk.' He'd stay with Nicky and I'd have my arms open, ready for him. And one time, he started taking steps. . . . My husband and I just hugged each other and cried all night. To us, it was a miracle."

In 1951, they enrolled Nick in a medical research project, and after three years of feeding him special powders and refrigerating his urine and feces, they learned what was wrong. He had been born with phenylketonuria (PKU), an enzyme deficiency present in one of every 10,000 births. Without the enzyme — one that metabolizes the amino acid phenylalanine — that amino acid and its by-products build up and, in effect, poison the brain. It doesn't happen, or at least shouldn't, anymore. With early detection and a restricted diet, retardation can be prevented in PKU children. Today, most states, including Pennsylvania, require that all newborns be tested for it. The discovery came too late for Nick.

Too late, too, were the community services that are now in place, but still in short supply, to help parents who raise their retarded children at home. Back then in the 1950s, there was not much choice. You could put your kid away in a place like Pennhurst, or, if you had the money, you could send him away to a private institution. The Romeos were able to find one private day school that they could afford, in 1957, but that only lasted six months. "I don't think they understood Nicky exactly — neither did we," Paula Romeo says.

Slowly, very slowly, he began to make progress at home. At 10, he was still wearing diapers, and could not

Since his release from Pennhurst — which was hastened by the toilet-brush beating — Romeo has become the affectionate, happy man that his mother remembers from a decade ago.

talk or understand words. But a year later, at 11, he would begin to use the toilet with help after his father built an additional bathroom downstairs and put a record player there to attract Nick. Paula would place plastic glasses around the house, and Nick would learn to pick one up when he was thirsty. She taught him how to open the refrigerator or stand next to the stove if he were hungry.

As a teenager, Nick still demanded constant attention. There were times when he was unusually hyper, literally bouncing off the walls. If a walk didn't work, there was a special pill. If that didn't work, the Romeos just tried to cope, and that was when it was hardest. They knew something was bothering him, but there was no way to know what. It would start with a look of anguish in his eyes, and then he would slap his forehead, or bite his hand, or bang his head into the wall. On those occasions, Frank would bring things back into control. Nick, at his father's urging, would sit down for a few minutes, then return to his father for a hug.

There was something there between them — something that went beyond words. Perhaps it was nothing more than what is between any father and son. And perhaps it is why to this day, 10 years after Frank Romeo's death, Paula says Nick still seems to be looking for him.

ON JUNE 17, 1974, FIVE DAYS after his arrival at Pennhurst, psychologists completed their first evaluation of Nick. They observed his behavior on Unit 7, where he lived with 30 other retarded men:

Upon admission, Nick was extremely disturbed and abusive toward others and himself and required two male orderlies to control him. Among his problems: handwringing, hitting head, scratching others' hands and inappropriate laughing.

He was toilet-trained, they noted, had learned his way to the bathroom and dining room, and had started approaching the Pennhurst aides, taking their hands and guiding them out of the ward.

The only way of expressing his needs and desires is one of taking another's hand and pulling him out. This seems to mean "going away" rather than going out.

In July, after a mandatory three-week waiting period, his mother came to visit. She sat with him for a while, took him out of the locked building for a walk and, before leaving, asked that Nick's hair be allowed to grow back. When she visited again on Sept. 15, she found cuts above both of Nick's eyes. He had hit himself and fallen down, she was told.

Sept. 16. Nick is adjusting to both residents and aides and there is less abusiveness on his part. Also will kiss aides on the cheek, but if you turn your back, he will hit you.

Oct. 5. Ran away after lunch. Found outside lying in the sun.

THERE ARE 400 ROLLING GREEN ACRES HERE, backing up to the Schuylkill on the Chester County side. A nice place, Nick must have figured, to lie in the sun; a nice place, the state legislature decided in 1903, to build the Eastern Pennsylvania State Institution for the Feeble-Minded and Epileptic.

It would hold 500 people — epileptics, idiots, imbeciles and the feeble-minded, to use the labels of the day. It would open its doors in 1908 and become the second state institution for the mentally retarded in Pennsylvania. At the time, institutions for the retarded were a relatively



recent phenomenon in the United States, only about 50 years old. But, already, the noble goals of their originators had fallen victim to economy and the cyclical changes in public thinking.

Until the 1800s, retarded people, in most societies, were lumped together with paupers, debtors, the deaf, the mute, the insane, alcoholics and criminals. They were viewed as hopeless and were abandoned in warehouse-like shelters. In the mid-1800s, thinking began to change, primarily because of a young man who had wandered out of the woods near Aveyron, France, on Jan. 9, 1800. He was called "a savage" and "animal-like" and, later, "Victor." The nickname that stuck, though — not unlike the words that have been used to describe Nicholas Romeo — was "The Wild Boy."

A doctor began to treat the boy, believing that he had simply grown up in the wild and had never learned civilized behavior. The training was basic, repetitious and intensive, and the change was positive. It was never confirmed whether the boy was retarded, but a student adopted the doctor's methods and applied them, for the first time, to the retarded. Special education was invented.

The student went on to open the first school for retarded people, in Paris, in 1837 and later brought the concept to the United States, assisting in opening a school in Massachusetts in 1848. In the ensuing decades, other states opened similar schools, designed to train the retarded to function independently before placing them

back in the community.

By the 1870s, slower-to-learn residents had accumulated in these schools, and demands for admission heightened. The schools grew larger, and soon emphasis was being placed on economy — training more people for less money. By the 1900s, society's pity and concern for the retarded had turned to fear. They became scapegoats — blamed for "infecting and impairing the whole social fabric," according to a pamphlet entitled "The Menace of the Feeble Minded in Pennsylvania." The answers: isolation, segregation, sterilization. In Pennsylvania, legislators responded by creating what later would be called Pennhurst.

From the day it opened, there was a waiting list. There was never enough staff and, almost from the beginning, too many "inmates," as they once were called. And, in what would remain a constant in the cyclical history of caring for the retarded, there was never, never enough money.

Over the years, Pennhurst expanded to 1,200 acres, and new buildings opened to meet the demand of an increasing population: in 1920 there were 1,200 residents; in 1930, 1,300; in 1940, 2,200; in 1950, 2,800; and, by 1955, close to 4,000.

From time to time, horror stories would emerge from the big institution in the small town of Spring City. Tales of peonage, abuse, idleness, overcrowding, filth — plenty of fodder for the media, legislature and advocacy groups. By the 1960s, those concerns spawned a national movement with a powerful and articulate spokesman in President John F. Kennedy, who called for a shift away from large institutions and toward providing retarded people with "normal" lives in the community.

Pennsylvania slowly responded. In 1966, it passed an act calling for community-based services for the mentally retarded. In the next eight years, more than 600 Pennhurst residents would return to the communities from which they came. But Pennhurst had already earned a bad name by then — as

had many of the nation's 200 state institutions for the retarded. They were viewed as necessary evils, or at least convenient evils, and despite the vile vignettes that surfaced periodically, they were surviving by sinking further behind their walls of silence and secrecy.

In the 1970s, institutions would confront a new foe, one that would force them, for the first time, to lay their cards on the table for all of the public to see. In the 1970s came a barrage of lawsuits filed on behalf of residents. They were designed, at first, to improve institutions. Eventually, they would seek to close them.

ON MARCH 12, 1975, AFTER NINE MONTHS AT Pennhurst, Nicholas got a new home: Unit 9, Ward 52. It also went by another less sterile-sounding, but misleading, name: the New Horizon building. Completed in 1972, it was the newest building at Pennhurst, constructed during a time when experts had concluded that smaller, homier environments were better for the well-being of the residents. But it was, in fact, a concrete and tile memorial to the past. Unlike the older buildings, it did not have drains built into the floors. But like them, it was big, and it offered little privacy: It held 360 residents — six wards of 60 each.

Nick and the others spent most of their waking hours in dayrooms, large glassed-in rooms with linoleum floors and plastic furniture and televisions that hung from the ceilings. Staff members could watch residents from outside the glass, in safety and quiet. Inside the locked

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doors though, the noise echoed. Some residents could speak, but most just made their own personal sounds, and the result was an echoing cacophony of guttural moans and high-pitched screams.

Terri Lee Halderman was not one of the noisemakers at New Horizon; she had not spoken since coming to Pennhurst 10 years before, at age 10. But by the time Nick arrived at New Horizon, she had become one of its best-known residents — through a lawsuit filed on her behalf.

David Ferleger, a Philadelphia lawyer, was already building a reputation through his work for the mentally ill when Terri's mother told him about the more than 40 injuries her daughter had received at Pennhurst. Once, while wandering the halls in a straitjacket, she had slipped and, unable to break her fall, broken her jaw. Aides, once they found her, had ripped dangling cartilage from her mouth, mistaking it for teeth.

The case would be Ferleger's first involving the institutionalized mentally retarded — and the first of its type in the country. The class-action suit would allege that injuries and abuse were common at Pennhurst, and that almost all residents were spending their days in idleness and boredom, deprived of the training that could teach them new skills. It would not only seek improvements at Pennhurst, but eventually demand its closing and call for its residents to be moved into neighborhood group homes.

Ferleger didn't expect the state to go to trial on the case — after all, who could conceivably defend what was happening at Pennhurst? Maybe you could explain away the photographs of adults tied in beds and chairs, or of urine and feces on the floors and walls. But how could you defend the aide who raped a female resident, or the attitude of the security guard who saw it and waited until the aide was through to confront him? How could you defend pictures of people whose bodies had atrophied because of years without exercise, or the experiences of people whose minds had gone through something very similar?

The stories touched a raw nerve for Ferleger, the son of two Polish Jews. His mother spent most of the Holocaust imprisoned in concentration camps; his father spent most of it living in a hole underneath the floor of a barn.

"I learned from my parents about the risks of what happens when people are treated as less than people," he says. "The very first people who the Nazis murdered were mental patients and people with retardation. Each method they later used to murder Jews had been tried on mental patients. . . . In fact, Germany is the only country in the world today where there aren't any elderly retarded people."

Ferleger was joined in the suit by the Pennsylvania Association for Retarded Citizens, and the suit's goal, once seen as improving Pennhurst, was evolving into closing it. Lawyers began compiling documents and depositions in an effort to show that Pennhurst was harming, not helping, its residents. In the spring of 1975, about the time Nick was moved to New Horizon, a tour was scheduled for those bringing the

Halderman suit. The U.S. Department of Justice had also joined the suit by then; one of its people was there, as well as an FBI photographer, Ferleger, a mental retardation expert from Georgia and a lawyer from the state attorney general's office.

"The typical scene on entering a ward was residents, many of them naked, lying on the floor and in corners, on benches, doing absolutely nothing," Ferleger recalled. "There were simply no programs to even keep people occupied. The smell was just overpowering."

The FBI agent, who unknown to the others on the tour had a retarded 1-year-old son, would vow that day to never put him in an institution. The lawyer from the state would not finish the tour. He ended up instead in a bathroom, throwing up.

AT NEW HORIZON, FOR REASONS unknown, injuries to Nick became more common and more serious. By the fall of 1975, Paula Romeo had begun complaining. She talked to ward leaders and city councilmen. She wrote her congressman. She filed a written request at Pennhurst: "Please, I would like to see Nicky free from cuts in and on the eyes and bruises just once when I visit him."

In November, injury reports told of him being "pushed into the dayroom wall, face first" by another resident, and later being found with a swollen and bruised nose. An X-ray showed that it was fractured. About the same time, an aide would later report in a written statement and over an anonymous Pennhurst abuse hotline, the aide saw another aide leaning over Nicholas on the bathroom floor, hitting him in the face with his fist. An internal investigation would find no evidence of abuse.

Paula wasn't notified about the minor injuries, like the 10 Nick received that December. When something major happened, she received fill-in-the-blank form letters, telling her that Nick was in the hospital for hepatitis, or, as in March, for a broken finger. By then, she was making surprise raids, sure that aides were causing some of Nick's injuries. She would drive to Pennhurst, run up four flights of stairs and pound on the thick, locked door to Nick's ward. Sometimes she was able to sneak in.

"I walked in one day and I see this here aide with his feet propped up against the wall, his chair at an angle, and with four of the clients in a small, small room. He's saying, 'You better shut up or I'll crack your heads right open, I'll beat the hell out of you.'"

In June 1976, a month in which Nicholas was injured 12 times, Paula told her story to Edmond A. Tiryak, then a 27-year-old lawyer with Community Legal Aid. Together, they met with Pennhurst officials on Aug. 10.

"They came in with a list of injuries — there had been 63 by then — and everybody treated the situation like this was the norm," Tiryak recalled. "They accepted a certain level of violence and aggression. And what they considered normal, the average citizen considered to be shocking and a disgrace. I remember sitting there thinking to myself, 'These people are crazy.'"

At the meeting, Pennhurst officials sought Paula's approval for a behavior modification program that they hoped

"It was pretty obvious why Nicky had been attacked by other people . . . It was pretty much a custodial operation."

would stem the number of injuries Nick had received and inflicted by restraining his hands in muffs. Paula refused, afraid that Nick would be left defenseless. That day, he was bitten twice by other residents, once on each arm.

More injuries followed, another hospital form letter about infected knees, and on Sept. 24, a letter saying Nick's right arm had been fractured. The injury, his 77th, occurred while Nick was "being seated." He was returned to the infirmary, where he would spend 592½ of the 744 hours in October in restraints, tied with leather straps, shackles or strips of gauze to a bed or a chair.

On Nov. 4, 1976, more than two years after the Halderman suit was filed, Tiryak filed a suit on behalf of Nick. During the next eight years, Romeo and Halderman would never meet, but their lawsuits would cross paths in the courts, and their lawyers would exchange information in their efforts to show that their clients were not receiving the training to which they were entitled.

Nick would not leave the infirmary until more than four years after his suit was filed, after more than 7,000 hours in restraints. Why is unclear. The state's lawyers, at one point, would claim that both sides had agreed to keep Nick in the hospital "pending completion of the litigation" — and that the restraints were necessary to keep Nick from injuring himself or others. Nick's lawyer would say that wasn't so, and insinuate that the restraints were a sort of punishment for filing the lawsuit. In any case, Nick remained there, often with nothing to do but try to free himself, building biceps as the months and years passed.

He would spend 298 hours in restraints in April 1977, the month the Halderman suit went to trial. He would spend 288 hours in restraints in June, the month that trial ended. And he would spend 299 hours in restraints in December 1977, the month U.S. District Court Judge Raymond Broderick ruled in the Halderman case that retarded people have a right to treatment in the least restrictive environment.

IN JANUARY 1978, A MONTH IN which Nick spent 317 hours in restraints, a psychological evaluation showed a few additions to the list of Nick's maladaptive behaviors. That was just the kind of thing Tiryak needed. After putting himself through a crash course in mental retardation, Tiryak, the son of a Turkish jeweler, was prepared to contend that Nick should be reimbursed not so much for what Pennhurst had done to him, but for

what it had failed to do for him.

"People get hurt," Tiryak said. "If Nick punched himself and broke his nose, I wouldn't say they were liable. But if he did that repeatedly, and there were programs available to teach him to stop doing that, and they don't do it, then that's deliberate indifference to his needs."

Unlike most lawsuits against institutions, Nick's would seek damages against individual employees. In a way, Tiryak was trying a little behavior modification of his own: If an aide knew that he could personally be punished, he would think twice before abusing somebody. Says Tiryak: "I want these people to be sitting there thinking, 'This guy is important, not just an animal, but an important person who can really do me harm if I don't do my best job.'"

In February, Tiryak had Nick examined by a doctor. He found that Nick could not completely extend his right arm, which had been broken. The fifth finger of his left hand, once smashed in a door, could no longer be straightened. He had become a carrier of hepatitis caused by either a dirty syringe or contact with feces. His nose was still broken and he had cellulitis, an infection from abrasions not properly cleansed.

Tiryak also called upon Dr. Richard Foxx, a mental retardation expert from the University of Maryland, who met with Nick at the Pennhurst infirmary. Nick was not the terror that Pennhurst records indicated, said Foxx, who remembers Nick kissing Tiryak on the cheek during the meeting. "He certainly wasn't aggressive. I did some things to see if he was, like blocking the door when he wanted to get out and other frustrating things. He just turned the other way."

Foxx noted that Nick, while not aggressive, did have some behavior problems. He had lost his toilet skills, and his good behavior had become extinct at Pennhurst. When he was good, nobody paid attention to him. When he was bad, they did. "After a while, regardless of your intellectual deficit," Foxx says, "you learn what pays off."

Now the director of treatment development at the Anna Mental Health and Developmental Center in southern Illinois, Foxx said he remembers being unimpressed by the programming at Pennhurst. "It was pretty obvious why Nicky had been attacked by other people — because there was simply nothing going on with the people on that unit. It was pretty much a custodial operation."

The result, according to Foxx, was that Nick regressed in Pennhurst, both intellectually and psychologically. He was prepared to say in court that it would take \$250,000 worth of therapy just to erase the damage that had been done.

IN MARCH 1978, BRODERICK, THE judge who had ruled in the Halderman case that Pennhurst was unconstitutional — that it was, in effect, incapable of providing the kind of care the retarded deserved — began ordering the release of residents into group homes. The state slowly complied, but continued to contest his decision.

One month later, the lawsuit filed on behalf of Nick, still living in the infirmary, would go before a U.S. District Court jury.

The testimony of Foxx and other experts would not be allowed. "All we could do was show all these horrible things that happened," Tiryak said. When Pennhurst officials said, "We did everything that was possible," Tiryak could not show that they hadn't.

After eight days of testimony, the jury ruled in favor of Pennhurst. For the next 2½ years, as the appeal process took place, Nick remained in the infirmary, seldom injured but frequently restrained. Finally, in November 1980, the U.S. Court of Appeals for the Third Circuit overturned the lower court ruling.

The state would appeal the case to the U.S. Supreme Court, but Tiryak, for now, had won all that he had sought. The appeals court ruling, though not addressing the issue of damages, was one of the broadest statements ever made by a court on the rights of the handicapped.

That month, Nick was released from the infirmary and assigned to an aide whose job was to never stray more than an arm's length away from him. He was enrolled in new programs, and a year later, in November 1981, he moved to No. 3 Independence Drive, one of several cottages that had been added to Pennhurst's grounds. He had his own room there, and both his behavior and toilet habits began improving. Injuries, while declining in number, continued; most were cuts and bruises. On June 15, 1982 — three days after Nick was discovered with a bruised penis, cause unknown — the U.S. Supreme Court ruled on his case.

Nick, the high court said, had a right to reasonably safe conditions of confinement, a right to be free from unnecessary restraint, and a right to treatment, if it could be shown that denying him treatment was harming him. Nick had won new rights for himself and other institutionalized retarded people — more rights than the Supreme Court had ever said they had before.

"The importance of a Supreme Court decision is that it's written in stone," Tiryak said. "Now there's a floor — a minimal amount of care, freedom of unnecessary restraint and a right to treatment — that people have to get in institutions."

Added Foxx: "A number of retarded people will be beneficiaries of the decision by not being required to spend the rest of their lives in shackles."

"It says something awfully nice about this country when a Nicky Romeo can have his day in the Supreme Court."

ON MARCH 30, 1983, A doctor summoned a Pennhurst security officer to Nick's cottage to inspect marks that she felt were a result of abuse.

The officer didn't have to be a super sleuth to figure it out, for the marks — 50 in all, on his back, chest and buttocks — stood out like black, red and blue outlines of a toilet brush in the cottage bathroom. It was not the most severe injury Nick had suffered, but to Pennhurst officials, it was the most troubling.

Here was Nicholas Romeo, of Supreme Court fame, Pennhurst's most-watched resident, a client who might as well have "handle with care" stamped on his forehead, tearing off his pajama top and

exposing wounds that could only have been administered during the night by a member of the staff. Here, just weeks before Nick was scheduled to leave Pennhurst for a group home, was the first of Nick's more than 200 injuries that could not be blamed on himself — it would have

been a physical impossibility — and could not be blamed on other residents. They were all sleeping.

And here it was at a time when Pennhurst's very future was in doubt. Its population had shrunk to about 600 by virtue of the court orders stemming from

the Halderman suit. Buildings were closing. Employees were being laid off by the hundreds.

With staff morale at an all-time low, many employees blamed the lawsuits for their problems — not making the

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distinction between the Romeo and the Halderman cases. Some saw Mrs. Romeo as a woman seeking financial gain at the expense of their reputations — even their jobs. They were on the battle lines as judges sat in their comfortable chambers, never setting foot in Pennhurst, deciding how the aides should do their jobs — or whether their jobs should even exist.

"Here comes Mrs. Romeo's million-dollar baby," some of them would say when they saw Nick approach with his aide. As one of his aides recounted, "There was so much animosity toward him it was unbelievable. It got to the point where I wouldn't let anybody go near him."

Despite constant supervision,

Nick would still be injured and some of those injuries, though never reported as such, were staff-inflicted, according to employees. "People would brag about getting away with it. There were a couple of injuries written up as him doing it himself that I know for sure staff did," said Walter Violette, who worked for almost a year as Nick's personal aide. "People didn't like him. They were either afraid of him or his reputation, and they knew his mother could have you reassigned. He was watched by a lot of people all the time. To some people, it became a challenge to hurt Nicholas Romeo and get away with it."

Of Nick's toilet brush injuries, Violette said, "I think the aide that did it cracked, but I also think she wanted to get her licks in before he left. Later on, she

bragged that she had done it."

Although his scheduled departure from Pennhurst was still more than a month away, everyone involved agreed to move him to a group home immediately. During his last three days at the institution, Nick was under a 24-hour-a-day watch by state police.

On April 5, 1983, Nicholas Romeo, under police escort, walked out of Pennhurst.

NEIGHBORHOOD CHILDREN don't know what to make of this man. They tilt their heads to the side like puzzled puppy dogs, watching with wide eyes as he walks down the street on the toes of his orthopedic combat boots, holding the hand of another man and squealing happy sounds.

Nick has stood out a bit since he came to this quiet, middle-class Northeast Philadelphia

neighborhood more than a year ago. Last summer, his screams could be heard at backyard barbecues five houses away, and for John and Diane O'Donnell, who live on the other side of the twin home in which Nick lives, there were times when it sounded like Nick was coming through the wall.

He pulled the towel racks off the walls in the bathroom. He cracked the toilet bowl. He ripped down the curtains dozens of times. Three sets of furniture have been worn out. And, although they are covered with pictures and hanging baskets, there are more than a dozen cracks — and a few gaping holes — in the wall where Nick has banged his head.

He has raised similar havoc at a workshop where he spends his days. At first, he required a special room because of his habit of throwing the various objects he was supposed to work with. Gradually, though, the new surroundings and the attention have begun to pay off.

Nick's good behavior has been reinforced with snacks, praise or pats on the hand or back for every 15 seconds he goes without hurting himself or others. His "aggressions" — hitting himself or others — have dropped from 80 an hour to 12 an hour, and now to even fewer than that. And a new Nick has begun to emerge, the affectionate happy one Paula remembers from a decade ago.

Every weekday morning, his lunch bag in hand, Nick goes to the workshop, where he receives physical therapy and vocational training. At 3 p.m., staff members of the group home pick him up. Sometimes, if he has had a toiletting accident at the workshop, he returns carrying a large Hefty bag containing his soiled clothes, but those accidents, too, have decreased. And he recently completed his first production work at the workshop (putting an auto part in a box) and was paid for the job.

It was rough for the first few months, partly because Nick arrived ahead of schedule and partly because the severity of his behavior was not always explained to the young men and women, mostly college students, who were hired to work with him. Turnover among staff has been high; some employees quit after as little as 10 minutes with Nick. Others have stayed; one lost 20 pounds trying to keep up with him.

Joe Thomas, a worker at the group home, recalls Nick's arrival. "It was weird. When he first came, whenever you held his hand you were actually able to feel the adrenalin going through his hands. He was really nervous. I think a lot of his behavior was

just because he couldn't trust anybody. That was his means of survival."

Most of the the neighbors do not know much about Nick. The rumor is that he's dangerous. Some tell their children to cross the street when they see him coming. Some do not let their children out alone anymore. They are worrying, too, about their property values going down. They have complained to city zoning officials, to their state representative and senator, only to find that, because Pennsylvania laws are quite firm on the matter, there was nothing they could do about their new neighbors.

As is the case with most group homes, the original tensions have eased. Paula Romeo brought the O'Donnells a fruitcake at Christmas, and the neighbors on the other side, the Peruginis, passed a bouquet of flowers over the fence once.

The Perugini family, like many in the area, is split on its opinion of Nick as a neighbor. "Everybody's intelligence level is different and you've got to accept them like they accept you," said father Ralph, sparking a disagreement with his 14-year-old son, Sam.

Sam: "I'm against it. There are people going in and out at all hours, and I don't like the screaming. People like that should live on a farm out in the country."

Ralph: "C'mon, does everyone in the world have to be exactly like you, Sam? Do you want a bunch of little Sammys running the world?"

Sam: "No. I just think they should live out in the country on a farm."

OUT IN THE Chester County countryside, about 500 retarded people and about twice that many employees remain at Pennhurst. Most of the red brick buildings there are empty. But renovations are being made: Workers are putting in new toilets and replacing the century-old imported Italian marble on the bathroom walls with tiles.

Though the deck is being swabbed, the flagship is sinking. Pennhurst, when it opened 75 years ago for the purpose of segregating the retarded, set a trend for the rest of the country. Today, it appears to be among the first victims of a new trend. In November, in connection with the Halderman suit, the state filed plans to close Pennhurst by mid-1986.

With its population reduced by court orders, Pennhurst, according to the state, is no longer cost-effective. Additionally, state officials say community care and

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training has proven to be both cheaper and better than institutions. Studies of the Pennhurst deinstitutionalization have shown that to be true, both through cold statistics and the heartwarming cases of former residents who have blossomed in the community — learning new skills, becoming wage-earners, even talking for the first time.

Similar findings across the country have prompted a piece of federal legislation that would divert federal Medicare money from institutions to community programs for the retarded. If approved, some say, it could mean more institutional cutbacks and closings.

Among the proponents of that legislation is Paula Romeo, who in February told Nick's story to a congressional committee in Washington. In addition to com-

munity success stories, the proponents are armed with a recent list of horrors — not the least of which is continued abuse at Pennhurst. An undercover state police investigation there last year resulted in 22 aides being disciplined. Subsequently, a federal grand jury returned nine indictments against aides on charges of violating the civil rights of 21 residents by punching, kicking, slapping, beating or intimidating them.

Despite those kinds of allegations, there still is disagreement over whether large institutions for the retarded have a place in society.

On the legal level, the Halderman suit, after 10 years and three rounds of mostly technical arguments before the U.S. Supreme Court, is still pending, its main question unanswered: Do the retarded have a right to live and learn in the community? Attorneys for Pennhurst residents say

they do, and they now cite the Supreme Court's Romeo decision as proof.

On the more emotional level, the relatives of some Pennhurst residents are opposing the closing, largely because they think their family members require that kind of secure environment. Small, supervised homes in the community, they say, are just as likely a setting — maybe more so — for abuse.

Among those opponents, ironically, is Terri Lee Halderman's mother, Winnie Halderman, who has said that she intended to improve, not close, Pennhurst by filing the lawsuit. Contending that Terri is too severely retarded to live in the community, Mrs. Halderman has said that she would kill her daughter before permitting such a transfer. (Terri Lee Halderman, after being raped at Pennhurst eight years ago, now lives in another institution operated under contract with the

state.)

Opponents point with fear to the deinstitutionalization of the mentally ill — a similar, but less-planned-for, less-monitored movement that has left many former residents of state hospitals wandering the streets, poor and homeless. Their concerns, if not based in fact, are at least worth heeding as warnings. The history of institutions has shown that ignoring outsiders — saying "we know best" and putting up walls, literally or figuratively — can ruin even the most well-intentioned plans.

Nick's story has shown that much. There are some who think that it shows more.

They remember what the Supreme Court said of Nick: that because of the "severe character of his retardation . . . no amount of training will make possible his release." Today, some would say, he shows how any person, no matter how retarded, can thrive

in the community.

By the same token, there are those who would seize upon any bad things that happen to Nick in the community — and a couple have — as examples of why severely retarded people should be kept in places like Pennhurst.

At the group home, Nick has at least once been the victim of apparent abuse, according to employees, and, as turnover continues there, he will test the patience of many more staff members. And recently, employees said, he had the second seizure of his life after a change in his medication and had to be resuscitated.

So it is, for now, a happier, if not happy, ending. But Nick's story has a long way to go before it is over. He still has a potential, however meager, to reach, and a life to live — without shackles. Retarded people have a right to that.

Without words, Nicholas Romeo said so. □