Bernard remembers hard life on the inside

Bernard Carabello, age 34, began his life 13 years ago.

As far as Carabello is concerned, his first 21 years were wasted — times to be forgotten, or if not forgotten, at least tucked away in the outer reaches of memory.

Born in 1950 on Manhattan's Lower East Side, Carabello entered Willowbrook State School at the age of 4 because he was physically handicapped by cerebral palsy.

Willowbrook was an institution for the mentally retarded, but Carabello's family had nowhere else to send him. Moreover, doctors in those days didn't think there was much difference between Carabello and the Willowbrook residents — whether the problem was a disabled body or a disabled mind, the solution was institutionalization.

For the next 18 years, Carabello's world was the Willowbrook wards. "When you were a kid, it wasn't bad," Carabello said about Willowbrook. "They treated kids a certain way because kids are cute and cuddly."

But as Carabello grew older and moved into the adult wards, the situation became more difficult. The wards were dirtier, overcrowded and understaffed. There were occasional beatings from other residents who were violent or by Willowbrook employees who used force to keep Carabello in line. "I'd act out sometimes," Carabello said. "I was living in a frustrating situation."

By 1971, as a 21-year-old, Carabello was a resident of Building 7, considered one of the worst wards at Willowbrook. Sixty severely and profoundly retarded residents lived in a room with only two overworked attendants.

"On weekends, there were no clothes. Period," Carabello said, explaining that dressing the clients took too much effort for the staff. At mealtime, the attendants had time to spend only two

or three minutes with each client, he said. "They (the attendants) would mix all the food together on the plate and shove in the person's mouth. For showers and baths, they used the same pails that they used for morning the floor.

There were occasional beatings from other residents who were violent or by Willowbrook em
"And the smell. Have you ever been to the Staten Island Zoo? It was worse than that."

It was horrible, but Carabello coped. It says something that he was in Building 7 by choice; the administration offered to transfer him to a building with other high-functioning clients, but living with severely handicapped residents allowed Carabello to minimize his own handicap. "I guess I felt important.

"I had to compromise myself," he added. "I had no other choice. I had to tell myself that this is it, that I had to make the best of it. One thing that made it easy to accept living at Willowbrook was that I was living in a secure

environment."

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His life changed when he befriended Dr. Michael Wilkins, a Willowbrook physician who led the call for reform in late 1971. As Wilkins and Dr. William Bronston, also on the Willowbrook staff, started to organize protests against the institution's conditions, Carabello eagerly pledged his cooperation. When the doctors inspired parents of the Willowbrook Benevolent Society to mount public demonstrations, Carabello was on the front lines representing the institution's 5,400 residents.

"That's when you might say I got my basic education," Carabello said. "I was sure going through a learning experience."

Carabello left Willowbrook in February 1972; by this time, pressured by parents and the media, Willowbrook was eager to relieve its overcrowding and a social worker offered to get Carabello released.

It was a confusing transition; Carabello was thrilled at his newfound freedom, but he was also confused. Willowbrook was terrible; it was also familiar and secure, and leaving it was "scary as hell," Carabello said. "I went through a real identity crisis." For the next few years, he lived on public assistance and explored his new world. In 1978, he got a job as an advocate for the handicapped in a federal program.

He now works a full-time job at a Manhattan resource center for the state Office of Mental Retardation and Developmental Disabilities (he is currently on

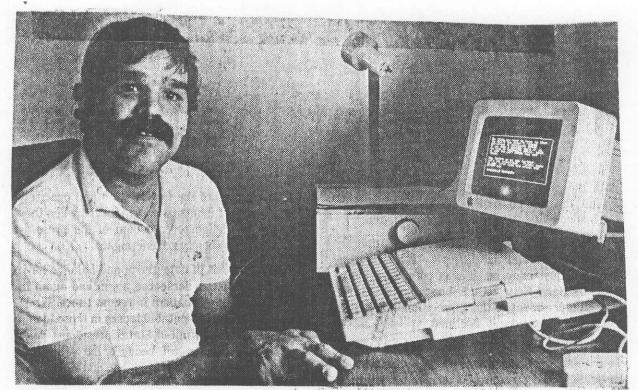
leave because of a badly broken ankle). He lives alone on Manhattan's West Side in a neatly furnished one-bedroom apartment that includes a computer and a bookcase full of back issues of National Geographic.

Despite his new life, Carabello has not put Willowbrook behind him. He is writing his autobiography. He still keeps in close

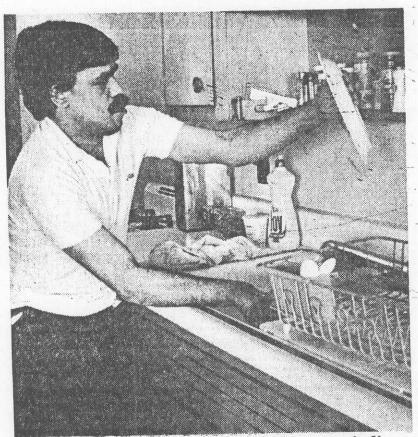
contact with Michael Wilkins, now a doctor in Kansas City. He still thinks about the people left at the institution.

"I think about them constantly," he said. "The consent decree was a victory for us, but it was not a total victory. It cannot be a total victory while people are still living in institutions."

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Bernard Carabello is writing his autobiography in his Manhattan apartment on his new Apple computer system.



Bernard does the dishes in his kitchen; he lives alone on the Upper West Side.

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