

The 'hellraisers' at Willowbrook were drugged and straitjacketed

In the fall of 1965 the late Sen. Robert F. Kennedy, responding to more than the imperatives of politics, became the first national leader who dared walk the wards of the Willowbrook State School. A week later Kennedy told a legislative committee of the glum stares of young children slipping into lifelong dependence.

One of those he described was a 15-year-old boy from Manhattan's Lower East Side named Bernard Carabello. A victim of cerebral palsy, Carabello had been mistakenly institutionalized a decade before the Kennedy visit. He was released Feb. 16, 1972, after tests showed he was not retarded.

**By BERNARD CARABELLO
as told to
Sydney Freedberg**

I live on Jersey St. now. I am lying in bed awake since 5 o'clock, my getting-up time for 18 years. Out of my bedroom window, I can see darkness turning into day.

I am a free man. I have an apartment with an eat-in kitchen, a few worn chairs and a new stereo. A full-time job with a group that protects the handicapped helps me pay my rent on time. I'm off the government rolls.

You may not think what I've got is much, but to me it's a palace. I'm still catching up on my lost years, but I can see daylight beyond the shadows.

I am a former resident of the Willowbrook State School on Staten Island. For 18 years I lived in the place like a fish on the hook.

I was what they called a "hellraiser." Teen-age hellraisers at Willowbrook got beaten, drugged, straitjacketed and secluded. Once I was thrown through a wall. When I fought with an attendant one time because she called me "animal," she gave me a shot of drugs, strapped on a straitjacket and threw me into the seclusion room at the back of Building 6.

I lost track of time in this room. It's a 7-by-10-foot box with a drop bulb, white walls and a locked door. The floor was covered with urine and cockroaches. If I hadn't stolen my clothing and hidden it under my pillow, I would have had none. No one came to see you in seclusion except when they brought you food. A per-

son died to go back to the ward even though there were 100 people jammed onto it.

Another time I got threatened with the sickroom at the back of Building 7 because I refused to tell a deputy administrator anything about my friend Dr. Wilkins. That was 1971. Dr. Mike Wilkins was raising hell, too, about conditions in the buildings. I had met him earlier in the year outside Building 21. I

was making a phone call to my mother. Dr. Wilkins came up and talked to me. He told me he didn't think I was retarded.

I thought the guy was a nut. Doctors at Willowbrook hardly ever came on the wards, let alone talk to the residents. Dr. Wilkins and I became friends. We began to exchange ideas on how to change Willowbrook, how to make it a

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Beds in tight ranks, no more than three inches between them, exemplifies overcrowding as late as 1975.
S.I. Advance Photo by Robert Parsons

decent place to live.

Then each Sunday, visiting day at Willowbrook, Dr. Wilkins would meet with the parents and tell them what was going on. The reason he did this was because the administration was lying to the parents, telling them that everything was fine when nothing really was.

Anyway, the administration wanted to get rid of Dr. Wilkins along with the other hellraising employees. Somehow, they found out we were friends. From whom, I don't know. Two administrators called me into Building 1 and interrogated me about my "relationship" with Dr. Wilkins. They wanted me to testify that he was a homosexual.

"You've been going out with Dr. Wilkins, haven't you?" one of the adminis-



trators said to me. "I refuse to answer any of your questions," I said. I understood what they were trying to do, and I also knew Dr. Wilkins' girlfriend, but it was none of their business. The administrators were furious. They said they wouldn't stand for this treatment from a resident and they would lock me up in isolation if I kept on refusing to answer. But I gave them no answers.

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Dr. Wilkins, who now lives in Kansas City, Mo., was one of the workers credited with bringing conditions at the state school to the attention of the nation. But it was Robert Kennedy, six years earlier, who had spoken of the

"snakepit."

In an address to a shocked state Legislative committee on retardation, Kennedy described the way the institutionalized were forced to sleep — "beds literally lining the floor with three inches between them" — and to live — "think of how children 5 or 6 or 9 treasure their possessions and then think of life without them" — and the lack of

staff — "there are too few attendants, they are too busy to watch carefully enough, they are too often absent" — and death — "one patient was burned in a shower by another retarded patient. . . another low-functioning boy was killed by an older, more capable boy, who was put in with the slower boys for punishment."

Willowbrook's population had doubled in less than a decade — to more than 6,000 people living in a facility planned to hold 3,000. There were pernicious consequences. Kennedy described children without adequate medical programs, supervision or a "bit of affection," and many — "far too many," he told the legislators — "living in filth and dirt, their clothing in rags, in rooms less comfortable and cheerful than the cages in which we put animals in a zoo."

The people at Willowbrook, he said, were condemned to a life without hope, without equal opportunity, without civil rights. There is "no justice," he said, and quoted Sophocles, who asked: "What joy is there in a day that follows day, some swift, some slow, with death the only goal?"

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I was admitted to Willowbrook in 1955. I don't want to get into a thing about why, it would only upset people, so let's just say that my mother didn't understand me; that she loved me but she saw me as different from her eight other children. I forgive her.

Anyway, on the day I was admitted, I remember a woman taking away the only toy I'd ever known. In return for the toy, she gave me a case number, a ward assignment and a hard rusty bed, a uniform and a word of advice: "Be a good boy," she said, "and nothing's going to happen to you." I cried anyway.

But the early years at Willowbrook were still my best years. That's because even though I was handicapped, I was still young and cute, and the attendants would come up to me and hold me and

hug me. I went to school for two hours a day, and Willowbrook had a carousel, which is more than I can say for the Lower East Side.

But as I grew older, I got too big to cuddle. People actually became frightened of me because of the way I limped and flailed my arms around. When I lost the attendants' attention, that's when I guess I became a hellraiser and started to speak without being spoken to. The more you're told you're a thing, the

more you become one. The more they made you scrub floors, or give residents baths, or carry urine specimens, the more you begin to believe you're not a human being.

The worst thing about living in an institution for 18 years is not the smell, the food or the overcrowding. It's the way places like Willowbrook strip everything away, especially a man's dignity. But I was luckier than some. I got out — with Dr. Wilkins' help. Sometimes I sit around on Jersey St. and wonder how I did it.

But there are those at Willowbrook who don't have voices to raise. These people need all the help they can get, and they can't get it in an institution — no matter how good an institution it is. Places like Willowbrook; just too big. These people would be better off on the outside, where they can get some love and attention. Human beings must learn to treat other people like human beings — not like bolts in a big machine. In an institution, no matter how kind you are, sometimes people lose sight of that. Sometimes you on the outside do.

Last week, for example, I was coming back to Staten Island from my job in Manhattan. Going to the ferry, I passed a woman with her two kids. She looked at me, the way I walked and the way I talked. It was as if she'd never seen a handicapped person before. She took her children's hands, turning quickly from me, and ran away as if I was going to eat her kids. I wasn't going to. I love children.

Sometimes I think the world isn't ready for us. Sometimes it's hard for "normal" people to accept us. But if 18 years taught me anything, it was about rights and justice and equality. I respect people now. I'm an uncle 12 times. My nieces and nephews love and respect me. They're sending the message along. And slowly the world is changing.

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The vision of the late Sen. Kennedy outreached a program for reforming the Willowbrook State School. He called for the government to intervene — to pump much-needed money into the institution, to begin jobs programs for employees and training programs for residents.

But it wasn't until a decade later, seven years after Kennedy's death, that New York State would vow to end a national nightmare, thus uplifting the people whose cause he championed into a position of hope.

(Second of three articles. Tomorrow:
Faces out of shadows.)



Young women without programs or adequate staff to care for them were condemned to a life where time just drifted, having been stripped of their belongings and their identity.



Adult residents, stripped of their hair, hide their faces. This photo was taken on Bernard Carabello's ward.