

Working at Willowbrook: 3 tell their stories

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It seems ironic in retrospect. But in 1971, a casual observer could draw marked similarities between Michael Wilkens, Kevin Sullivan and James Walsh, who worked together in the back wards of Willowbrook State School.

Then they were all young men in the 20's, just embarking on their careers. Each was fairly new to the institution, and each worked at Willowbrook because it was a "meaningful" job. All three thought the institution needed reform.

But they went about it in dramatically different ways.

Wilkens helped spawn a revolt that eventually led to the Willowbrook Consent Decree and the entire overhaul of the state's care for the mentally retarded. Walsh resolved to work inside the system; today he is director of Willowbrook, since renamed the Staten Island Developmental Center. Sullivan tried working within the state system and stayed at SIDC for 10 years, but he finally quit his job in disgust and now works for a private agency serving the retarded.

Wilkens, Sullivan and Walsh are not representative of the entire Willowbrook staff; in some respects, their experiences may have been more intense than most. But they provide an interesting study of how the events at Willowbrook in 1971-72 and the subsequent developments impacted on the staff, and the diversity of responses and emotions.

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'It was like being involved in a war'

Dr. Michael Wilkens left Willowbrook State School more than 13 years ago, but he still views his time at the institution as "sort of a nightmare."

But he also said he is proud of what was accomplished during his 18 months at Willowbrook. "I think we were effective," he said. "I think history was with us."

Along with a small group of colleagues on the Willowbrook staff, Wilkens played a central role in the uproar over conditions at Willowbrook in the early 1970s. Although the parents of Willowbrook patients eventually led the call for reform, it was people like Wilkens who proved the catalyst. Indeed, squalor was a part of the institution throughout the 1960s, and parents simply wrung their hands in frustration; it wasn't until the parents were encouraged by Wilkens and William Bronston, another doctor at Willowbrook, that they finally took to the streets in protest.

The difference in 1971 was, as much as anything, a change in the country's social climate. The rabble-rousers of Willowbrook staff were children of the 1960s and influenced by the liberal idealism of the times. They viewed Willowbrook as another example of social injustice, comparable to the Vietnam War and the civil rights movement, which could — and should — be fought through public demonstrations.

"The whole spirit was to move forward on social levels," Wilkens said, "and it occurred to Bill and I and some of the social workers and a lot of other people that pastures were a-plenty at Willowbrook as far as injustice was concerned.

"Ours was a purely professional stance, but we used social action techniques because there was such inertia."

Eventually, Wilkens' activism cost him his job; he was fired after he disobeyed an order by Willowbrook Director Jack

Hammond to stop meeting with the parents.

Ironically, Wilkens said, he was ready to quit about the time he was fired. "I was getting pretty discouraged, pretty depressed, and I was ready to pack my bags," Wilkens said. "Still, I was really surprised when Hammond fired me. I thought he was pretty ambivalent about what we were doing; he wasn't willing to do it himself, but I thought deep down he sort of approved.

"But I think he was a pretty proud guy and when he realized the parents weren't liking him, he got pretty mad."

Even after he left the institution, Wilkens continued his activism. More than a dozen times after his firing, he returned to the campus to lead television film crews and reporters who were eager to do exposes. In addition, Wilkens traveled the state to speak about Willowbrook; he was a witness at several governmental hearings, and he spoke at seminars and in front of civic groups about the changes which were needed.

But by the summer of 1972, two years after he first came to Willowbrook and seven months after Willowbrook became the object of attention, Wilkens returned to his native Kansas City.

Since his return, he has completed his residency in internal medicine and worked in a free inner-city health clinic. Now 43, he is the director of internal medicine at a Kansas City hospital and is the father of three children.

Willowbrook was another time, another world for Wilkens, but he still remembers.

"I still dream about the kids," he said, "about walking up to Building 6 and having them call to me, 'Dr. Wilkens, Dr. Wilkens, when are you going to get me out?' The whole thing was sort of a nightmare. It was a lot like being involved in a war."

'90 percent of my memories are good'

Kevin Sullivan decided to quit his job at Staten Island Developmental Center the day he walked into a building and saw a client dead on the floor.

"When I walked in, they say that he had choked on some bread," Sullivan said. "At first, I thought they were kidding. But sure enough, he was dead."

"The thing was, the body was just lying there in the middle of the room. The nurse was waiting for the doctor to come to verify that this guy was dead, and they didn't want to move him."

"But it was inhumane. People were literally stepping over the body to go about their business. I was saying, hey, let's put him in the office or something until the doctor comes. Finally I got a sheet and put it over the body."

A nine-year veteran at SIDC, Sullivan resigned in 1981, only a few months before he would have become eligible for a pension. He took a job as director of a Staten Island day program operated by Association for Children with Retarded Mental Development, a non-profit agency.

"I took a financial beating to go into the voluntary sector," Sullivan said. "But it was question of whether I wanted to do my job or not. I found you couldn't be innovative in a state institution — you had to clear everything you did with people all the way up to Albany."

But the bitter feelings are not the whole story. "Ninety percent of my memories of Willowbrook are good," Sullivan said.

He started at SIDC in 1971 as an idealistic college student looking for a job "that was something worthwhile" and was assigned to Building 9 as a recreation assistant.

It was a good building, he said. Unlike some of the other buildings, this one had a caring, dedicated staff, and superiors (including James Walsh) who Sullivan said would fight for the clients. But even so, job conditions were rough. Fifty men "were crowded into a single ward with beds were spaced only inches apart. There was a perennial shortage of supplies."

"There were times you would have 50 naked men lined up to take a shower, and the shower was a guy standing with a hose. And there would be no soap, no towels. The water might be cold. There might not have been pajamas to dress them in afterwards or blankets on the bed. At times like that, you'd say to yourself, 'What am I doing here?'"

"But I'd tell myself that maybe if I wasn't there, the men wouldn't get showers at all. And it was me who would yell at some people so the men could get clothing, get towels."

Within a few months of Sullivan's arrival at Willowbrook, the conditions were ex-

posed by the media. It was those outraged reports changed the course of direction for Willowbrook.

Like much of the staff, Sullivan was ambivalent about the media onslaught. "At first, I thought, this is good. Money will start flowing in, programs will start up," he said. But Sullivan also felt uneasy about what he perceived as the exploitive, sensational nature of the reporting.

"The thing is, if you wanted to find very negative, very unpleasant ways in which people live, you were going to find them at Willowbrook," Sullivan said. "But no one ever showed the other side of the story. There was a lot of good, caring people who worked there. The cameras never showed that, and those workers were really hurt by that. It was very demoralizing. Because of the (media) coverage, if you told people you worked at Willowbrook, it was like, 'Oh really? Who did you beat up today?'"

But if the television reports were demoralizing to Sullivan, they also were indirectly introduced him to his future wife, Jean.

Jean Sullivan was a high school student when the Willowbrook scandals flashed regularly on the 6 o'clock news, and while watching one of those reports, Jean decided she wanted to work at the institution.

She was hired and started her new job a day after her graduation from Susan Wagner High School. She was assigned to Sullivan's building, and enjoyed the work so much that her summer job turned into a two-year stint.

She and Kevin took clients on trips — shopping excursions and out to dinner. After they were married, they brought clients to their home for the holidays. "We had a ball," Jean said.

"I really believe we did have an impact on an individual basis with clients," Kevin said.

But while the couple enjoyed the one-to-one relationships with the clients, they suffered under the bureaucracy. Frustrated, Jean quit in 1976; she said there were too many people who need care and not enough staff to do the job properly. "I just felt I couldn't do it any longer. I felt like I was beating my head against the wall," she said.

"Willowbrook was not an easy place to work," Kevin said. "I've never regretted leaving."

But he still thinks about SIDC. "One thing I remember is how it was at night, when the wind was blowing and you hear it whistle in those buildings. It was a sort of scary. And especially on those nights, there was a sense that Willowbrook was a world onto itself — that no one really knew or really cared about it except for those us in there."



Kevin Sullivan, left, supervises the work of Helen Cordero and Joseph DeLillo at a workshop operated by the Association for Children with Retarded Mental Development in Great Kills.

S.I. Advance Photos by Tony Dugal

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'I decided to work within the system'

In 1969, James Walsh was a 20-year-old college dropout looking for a job.

He had majored in psychology before he left Marist College, and he liked the idea of working in human services. Someone suggested he apply at Willowbrook; although Walsh had never even heard of the institution, he followed the suggestion, took a summer job as an assistant recreation instructor and was assigned to Willowbrook's adolescent unit.

The ward was one of Willowbrook's better operations — there was not the severe overcrowding, understaffing and lack of supplies that marked the institution's back wards. It also helped that clients in the adolescent unit were high-functioning — some, in fact, weren't even retarded. "They were probably juvenile delinquents more than anything, and they didn't have anywhere else to go," Walsh said.

It was, on the whole, a positive experience. Walsh enjoyed his work, and his skills in working with the handicapped and working within the institutional system, were duly noted. Eventually, the Willowbrook administration arranged a leave of absence for Walsh so he could get his college degree and move up the

management ladder.

When Walsh returned to Willowbrook in 1971, he was assigned to the same building to which William Bronston was assigned. Like Bronston, Walsh was taken aback by the conditions. This was Walsh's first taste of the infamous back wards, and he was stunned by the contrast between this and the showcase unit where he worked before.

"My first reaction? Let's just say I had second thoughts about my career," Walsh said. "I couldn't believe that people would live this way. It was a human warehouse; there was no other way to describe it. There were no programs or anything; the residents just sat all day. The sanitation — well, it really didn't exist. And the overcrowding; well, let me tell you, we had 250 clients in a building where the certified capacity was 90 to 100. When I became a supervisor, I had to walk on the beds to go on my rounds."

Walsh said he often talked with Bronston about the situation. "We had many discussions over the way to change things," Walsh said. But while Wilkens and Bronston pushed for dissent against the Willowbrook management, Walsh decided "I was going to work within the system. I thought I could have impact by

developing programs for the clients; I knew how to tap into the system."

But while Walsh was beginning his own reforms, the public protests and media onslaught began. When Geraldo Rivera visited Willowbrook, "I saw myself on the 6 o'clock news," Walsh said ruefully.

He felt anger, but mostly ambivalence. "What was on TV was not dummy film. It was really like that, and in a way, it was bringing attention to the plight of the mentally retarded," Walsh said. "But there were some good things at Willowbrook — the staff was dedicated, they had to be — and that's where I disagreed with the coverage."

But Walsh supported the changes that were taking place — the attempts to alleviate the overcrowding, the establishment of programs for even the most disabled clients. He also began to realize that there was a limit to reforming Willowbrook; that some of the problems were inherent in the institutional system, and that the real solution was closing Willowbrook and placing the clients in the community.

His change in attitude — from supporting the institution to encouraging its closure — was

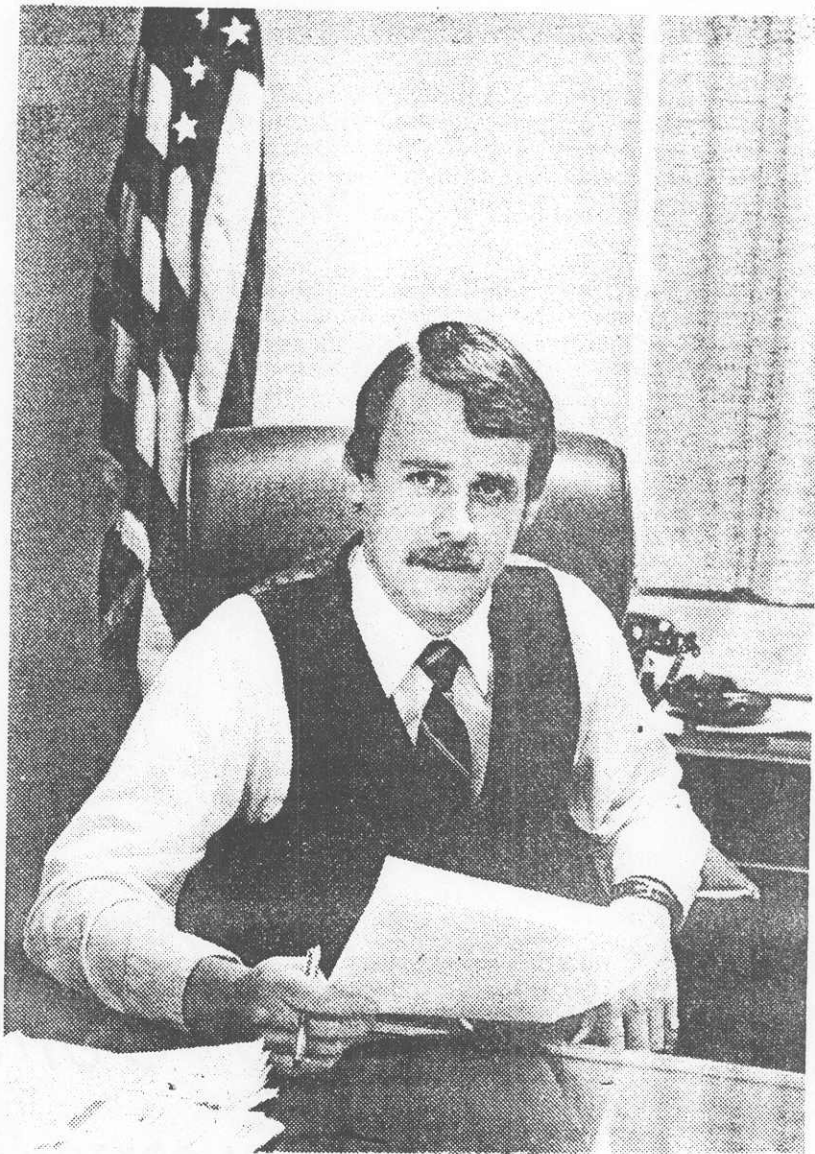
gradual, he said. "I think what changed me where the clients themselves, and seeing how well they could function in the community."

As Walsh reached upper management at Willowbrook — he has been director since 1983, and he was assistant director before that — the institution was no longer the horror it once was. "Their clothing, their hygiene, their environment has changed. Their dignity — that has been the biggest change," he said.

"I still complain now about how bad it is here. I think about where we've come from — and it's a long way — but it's still not enough," he said. "Now the real work is putting the clients into the community and that's a long process."

And so, the director of the state's most infamous institution, a man who has spent his entire professional life at Willowbrook, is now one of the strongest advocates for shutting it down.

"To me," Walsh said, "my job is to set up enough support services and enough resources to ensure that every mentally retarded person is afforded the right not to be put into a institution."



James Walsh, director of Staten Island Developmental Center, works in his office.