

Willowbrook, the institution that shocked a nation into changing its laws

Patients needing “tenderness and affection” got the opposite



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When World War II ended, a large Staten Island facility on 375 acres of land faced an uncertain future. Some believed that Willowbrook should be used for the care of disabled veterans, but ultimately the preferences of New York governor Thomas Dewey won out. Dewey argued that there were thousands of children in the state who were “mentally and physically defective and feeble minded, who never can become members of society,” who needed to be cared for with a “high degree of tenderness and affection.” On this last matter, the institution would utterly fail: In the coming decades, Willowbrook would become synonymous for social injustice, moral abhorrence, and the glaring failures of the state psychiatric system.

The Willowbrook State School opened on October, 1947, admitting 20 mentally disabled patients from upstate institutions. In only a short time, Willowbrook was overfilled and understaffed. By 1955, it had reached its full capacity of 4,000 occupants. Around that time, hepatitis infections ran rampant among patients and staff. Only a short time later, in 1960, an outbreak of measles killed 60 patients.

Yet these snapshots fail to convey the wretched and abhorrent conditions Willowbrook patients lived under. Despite its name as a “school,” there was barely any educational structure at Willowbrook. When teaching did happen, it was only for a handful of cooperative students, and only for around two hours per day.

Most of the Willowbrook experience was defined by constant neglect, a condition that the overstressed and underfunded staff were not necessarily responsible for. In some buildings, the mentally disabled were let to huddle in rooms, moaning, fidgeting, meandering, all with little care or resources. Many went naked for lack of clothing and supervision. Others sat drenched in their urine and feces, and some smeared them on the walls and on their clothes, with no available garments to replace them. Sexual and physical abuse at the hands of fellow patients and employees was common, as was disease.

By 1969, Willowbrook, designed with a capacity for 4,000 patients, reached its peak of 6,200. It was the largest mental institution in the United States, and host to some of the country’s most deplorable living conditions.

The first the American public heard of the horrors of Willowbrook was from a speech made by a promising young politician. Speaking of systemic failures in mental-health care, Robert Kennedy said

“I’ve visited the state institutions for the mentally retarded, and I think particularly at Willowbrook, we have a situation that borders on a snake pit.”

Yet this alarm went unheeded for seven years, that is, until two people, print journalist Jane Kurtin and an ambitious 29-year-old local news reporter named Geraldo Rivera, decided to cover the story. Tipped off and given a key by a disgruntled and soon-to-be dismissed Willowbrook employee, Rivera snuck into Building Six with a cameraman. They acquired quick evidence of an overpopulated and squalid facility, at the time filled with 5,400 patients.

Scenes from inside Willowbrook were shocking, and the local news story on WABC-TV was watched by millions. Viewers saw scores of mentally disabled patients huddled in anxious aimlessness. With exceptions in the warmer months, they were not allowed outside. Middle-aged patients slept on seats. Others crouched and rocked back and forth on the floor. Some child patients went without clothes. Such neglect was especially significant in light of a patient population in which 60 percent were not toilet-trained and 64 percent were incapable of feeding themselves. The stench in these rooms, coming from the unclean, unattended, and disregarded patients, to Rivera resembled “disease” and “death.”

As a feature of the times, all who ended up in Willowbrook were treated more or less the same, despite differences in needs and the common reality of early childhood misdiagnosis. In his exposé, Rivera interviewed Bernard Carabello, a 21-year-old patient with cerebral palsy and 18-year resident of Willowbrook, whose intellect was sharp, though he suffered difficulty speaking and moving as quickly as others. He eloquently explained the environment he called a “disgrace.” “I got beaten with sticks, belt buckles. I got my head kicked into the wall by staff,” Carabello recalled, “most of the kids sat in the day room naked, with no clothes on. There was a lot of sexual abuse going on from staff to residents, also.” For all of the horror of this injustice, today, Carabello is in his late 60s, and is retiring from his job as a state employee in Manhattan.

Progress came slowly, though for long it appeared not to come at all. A year after Rivera’s expose, a Harvard student wrote about his summer job at a ward in Willowbrook, where every day he witnessed a situation more or less identical to the one Rivera found. The student saw 45 adolescents huddled into a room, given no structure and little companionship, “moaning and screaming, rocking back and forth, stinking of urine and feces.” The job, it turned out, was symbolic, too. The student, along with around 300 people his age, were hired as “recreational aides” without an interview, for the ulterior purpose of making Willowbrook appear as if the patient-to-staff ratio was a more adequate nine-to-one.

Around two months after the television special, residents of Staten Island filed a class action lawsuit against Willowbrook. It would mark the beginning of the long end for the institution.

Lurking beneath the negative publicity was an even more heinous contour to the story of Willowbrook. In 1955, New York University Dr. Saul Krugman began using patients as human experiments for the treatment of hepatitis, as he would continue to do for about 20 years. Krugman’s research at Willowbrook extended medical knowledge of the disease, especially in providing evidence for the effectiveness of a gamma globulin as a treatment. At the same time, Krugman’s methods have become among the most remembered among American cases of bioethics.

Krugman deliberately infected the mentally disabled patients of Willowbrook with samples of hepatitis, synthesized from the stool of six infected patients and incorporated into patients’ food and chocolate

milk. Krugman argued that rates of hepatitis infection ran 90 percent within Willowbrook, so the chances his human hosts would never have come down with the disease was very low. He also contested that it was the best health scenario for these non-consenting patients, as they were to be under close supervision and care they would not find elsewhere in his ward.

Now in the annals of controversial American medicine, the Willowbrook tests were unearthed not on TV but in the medical community. "It was indefensible," argued Dr. Stephen Goldby, "to give potentially dangerous infected material, particularly those who were mentally retarded, with or without parental consent, when no benefit to the child could conceivably result." Krugman found defenders in high places, like the *New England Journal of Medicine*, whose editor advocated for Krugman over a "zealot ... blind to the fact that his one-track efforts to protect the rights of the individual are in fact depriving that individual of his right to good medical care."

Krugman, who died in 1995, defended the ethics of his studies to the very end, and was only so inhibited by the controversy. Upon his death, he was lauded for his essential work on not only hepatitis, but the rubella and measles vaccines.

The success of the class-action lawsuit brought in 1972 gave way to New York state's 1975 consent decree, making the state find alternatives to Willowbrook for the mentally disabled to live. It was a daunting task. Barbara Blum, who led the Metropolitan Placement Unit, the agency in charge of finding new residences for the mentally disabled, was reviled in neighborhoods where she was bringing former Willowbrook patients. She was pelted with eggs, and in one instance, her nose was broken.

The decommissioning of Willowbrook went along slowly and behind schedule, with its overdue closing happening in 1987, several years past the projected date. But along the way, the lessons learned from Willowbrook influenced policies engineered to protect the disabled, as they do to this day, like the Protection and Advocacy System of the Developmental Disabilities Assistance and Bill of Rights Act and the Education For All Handicapped Children Act, both passed in 1975, along with the Civil Rights of Institutionalized Persons Act of 1980.

Today, the buildings once part of Willowbrook are now part of the College of Staten Island. They stand as artifacts of a time when American society more clearly failed its mentally disabled citizens, and treated them so brazenly as less than human. "Everyone knew that the institution was no way to care for this population," Geraldo Rivera reflected about the subject of his exposé just last year. "It absolutely began the end of the institutional era that had existed since Bedlam and the United Kingdom in the 19th century."