

RESEARCH ARTICLES

Willowbrook State School: Institutional Abuse, Medical Ethics and the Rise of Disability Rights in the United States

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On Staten Island, at the cusp of New York City's bustling, postwar metropolis, once stood an institution whose name would become synonymous with one of the darkest chapters of disability care in United States history. The Willowbrook State School, closed permanently on September 17, 1987, had been conceived in 1947, opening its steel doors during the fervor of wartime public health expansion as a progressive facility for children labeled "mentally defective" by the state. Within a decade of opening, however, Willowbrook began to suffer. Designed for approximately 4,000 residents, it would soon hold over 6,000, adults and children alike crammed into lightless wards without sufficient food, attendants, or sanitation. A place just 17 miles away from the center of the nation's wealthiest city had, in practice, become its moral periphery.

Introduction

On Staten Island, at the cusp of New York City's bustling, postwar metropolis, once stood an institution whose name would become synonymous with one of the darkest chapters of disability care in United States history. The Willowbrook State School, closed permanently on September 17, 1987, had been conceived in 1947, opening its steel doors during the fervor of wartime public health expansion as a progressive facility for children labeled "mentally defective" by the state.¹ Within a decade of opening, however, Willowbrook began to suffer. Designed for approximately 4,000 residents, it would soon hold over 6,000,² adults and children alike crammed into lightless wards without sufficient food, attendants, or sanitation. A place just 17 miles away from the center of the nation's wealthiest city had, in practice, become its moral periphery.

This moral failure was deceptively hidden from parents and visitors of patients via organized visitation hours and limited viewing access to most buildings and sanitary facilities, concealing the horrific truths of Willowbrook until it was filmed in secret and publicly televised. In 1972, a 29-year-old journalist named Geraldo Rivera, working on a tip and spare key provided

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¹ New York City Government. "Our History." NYC Mayor's Office for People with Disabilities. <https://www.nyc.gov/site/mopd/events/our-history.page?slide=10>.

² Rivera, Geraldo. *Willowbrook: A Report on How It Is and Why It Doesn't Have to Be That Way*. Vintage Books, 1972.

by ex-employee Dr. Michael Wilkins, rolled his film crew into Willowbrook unannounced and left with footage that would obliterate blissful national assumptions about institutional care.³ The resulting exposé, *Willowbrook: The Last Great Disgrace*, aired on WABC-TV and later ABC's national broadcast, stunned the country. Of particular horror were images of children lying nude in pools of their own waste, moaning and rocking in overfilled rooms, left alone by staff. These pictures were so abundant, so representative of everyday scenes, that viewers were left in disbelief. Rivera chillingly remarked, "There are no civil liberties here. The children are rotting."⁴

The exposé prompted an immediate wave of public outcry and, in the long term, helped accelerate a growing national disability rights movement that had already been underway for over a decade. Rivera's footage, though journalistic in form, functioned as legal evidence in the class action lawsuit filed later that year by the New York State Association for Retarded Children (NYSARC), a statewide organization founded by parents to advocate for their institutionalized children.⁵ That suit culminated in a 1975 consent decree in *NYSARC v. Stanley Brezenoff*, mandating the systematic improvement of conditions and the gradual deinstitutionalization of Willowbrook's residents by 1981. A 1993 injunction in *NYSARC v. Mario Cuomo* made the terms of this reform permanent, codifying the state's obligations to ensure individualized treatment, protection from abuse, and integration into the community.⁶ Around the same time, a federal court in Pennsylvania ruled in *Halderman v. Pennhurst State School and Hospital* (1977) that institutionalization itself violated residents' rights under the Eighth and Fourteenth Amendments, establishing a landmark precedent that reinforced the national movement toward deinstitutionalization.⁷

The story of Willowbrook is neither a tale of clean-cut reform, nor is it a closed book. What makes the institution and its history remarkable is its literal and symbolic tie to visibility—what was seen and what remained hidden. As Rivera's camera swept across filthy tiled floors and emaciated bodies, the public encountered the physical manifestation of what had always existed out of view: a system built not to rehabilitate but to contain. Historian David J. Rothman, reflecting on Willowbrook a decade later, observed that "such institutions did not fail, as they functioned precisely as

3 Wilkins, Dr. Michael, and Bernard Carabello. "Remembering Willowbrook." YouTube, posted August 18, 2022. <https://www.youtube.com/watch?v=CM9fnwUp2iU>.

4 "1972. Willowbrook: The Last Great Disgrace." YouTube. <https://www.youtube.com/watch?v=5F7CrMAwCw4>.

5 Rivera, Geraldo, and Bernard Carabello. "Remembering Willowbrook." YouTube, posted 2023. https://www.youtube.com/watch?v=9_4nYMu1IE0&t=122s.

6 *New York State Association for Retarded Children, Inc. v. Stanley Brezenoff* (E.D.N.Y. Apr. 30, 1975); *New York State Association for Retarded Children, Inc. v. Mario Cuomo, et al.*, 393 F. Supp. (2d Cir. 1993).

7 Paul J. Castellani, *From Snake Pits to Cash Cows: Politics and Public Institutions in New York*. State University of New York Press, 2005, 60–64.

they were intended to.”⁸ Instead of being seen as a singular twisted exception, this injustice should be acknowledged as the consequence of the norm. Emerging from a historical lineage of backward institutions, Willowbrook thrived under a political system adamant to hide the disabled and collapsed only when media, law, and survivor testimony consolidated to bring the institution’s abuses into plain sight. Willowbrook’s exposure intensified legal and ethical scrutiny, but it did not originate the disability rights movement. Years before Rivera’s exposé, institutions like Pennhurst were being challenged by families and regional journalists. In 1968, reporter Bill Baldini’s *Suffer the Little Children* series revealed similarly horrific conditions at Pennhurst⁹, while *Christmas in Purgatory* documented Willowbrook itself and four other institutions using covert photography.¹⁰ These early revelations, though less nationally visible, helped lay the groundwork for public revulsion. It is undeniable, however, that the events of Willowbrook continue to haunt present-day systems of care, an imposing warning that institutional cruelty, once sanctioned by silence, inevitably returns through indifference.

Institutionalization and the Founding of Willowbrook

The Willowbrook State School was authorized by the New York State Legislature in 1938 as a residential institution for children vaguely labeled “mentally defective”, a loose term assigned by a combination of IQ scores, perceived “social competence”, and broader biases concerning race, class, immigration status, and eugenic ideology.¹¹ The institution’s completion was delayed by the exigencies of World War II, hence it officially began accepting patients nine years later. The site—formerly Halloran General Hospital, a U.S. Army medical complex—was returned to the state in the late 1940s and formally reopened on October 11, 1947, as the Willowbrook State School. Located on a 375-acre campus in Staten Island, the institution was intended to house up to 4,000 residents. It was established to provide long-term custodial care, meaning individuals would live there permanently under supervision, with minimal emphasis on education or therapeutic support.¹² Although the rhetoric surrounding its opening promoted Willowbrook as a step forward in disability care, the institution ultimately followed older models. It was built for long-term confinement, managed through complex state systems, and designed to keep disabled individuals physically and socially separated from the general population.

8 Rothman, David J., and Sheila M. Rothman. *The Willowbrook Wars: Bringing the Mentally Disabled into the Community*. Aldine Transaction, 2005.

9 Bill Baldini, *Suffer the Little Children*, NBC10 Philadelphia, 1968, YouTube, <https://www.youtube.com/watch?v=Bh2VkhXjSA&ct=706s>.

10 Burton Blatt and Fred M. Kaplan, *Christmas in Purgatory: A Photographic Essay on Mental Retardation* (Syracuse, NY: Human Policy Press, 1966).

11 Castellani, Paul J. *From Snake Pits to Cash Cows: Politics and Public Institutions in New York*. State University of New York Press, 2005.

12 New York City Government. “Our History.” NYC Mayor’s Office for People with Disabilities. <https://www.nyc.gov/site/mopd/events/our-history.page?slide=10>.

In the years following World War II, institutional care expanded rapidly across the United States as state governments invested in large residential facilities they believed could efficiently manage growing populations of people with mental illness and developmental disabilities. In New York, the Department of Mental Hygiene oversaw an expanding network of more than thirty institutions by 1950, all fueled by appropriations that prioritized occupancy over quality of care.¹³ State funding increased with the number of residents housed, creating a financial incentive to admit more patients while neglecting investment in staffing, treatment, and infrastructure. Paul Castellani, a scholar of New York's disability policy, identifies this funding model as the cornerstone of systemic dysfunction: State institutions like Willowbrook were financially rewarded for high patient loads and nothing beyond that. Unsurprisingly, by 1955, the population at Willowbrook had ballooned to over 6,200 residents—more than 50 percent above its intended capacity—and state officials, rather than intervening, continued admissions apace.¹⁴ Internal memoranda, which were flagged by staff but ultimately ignored, described failing hygiene systems and dangerously low staffing levels that reflected deeper structural neglect.

Beneath these fiscal motives ran a deeper, more insidious current. The founding of Willowbrook was inseparable from the legacy of American eugenics. In the early 20th century, numerous U.S. states enacted laws permitting the sterilization and institutionalization of individuals deemed “unfit” to reproduce, often based on pseudoscientific beliefs. A significant example is Virginia's 1924 Eugenical Sterilization Act, which authorized the compulsory sterilization of residents in state institutions considered to have hereditary forms of mental illness or intellectual disability. This law led to the sterilization of Carrie Buck, a young woman institutionalized at the Virginia State Colony for Epileptics and Feeble-minded after being deemed “feeble-minded” and “promiscuous.” Her case culminated in the 1927 U.S. Supreme Court decision *Buck v. Bell*, where the Court upheld Virginia's sterilization law, with Justice Oliver Wendell Holmes Jr. infamously stating, “Three generations of imbeciles are enough.”¹⁵ Decades later, Geraldo Rivera's 1972 exposé drew a direct comparison, documenting California's ongoing recommendation of therapeutic abortions when prenatal testing suggested fetal disability.¹⁶ Dozens of patients in the California clinic were filmed receiving such guidance, reflecting a persistent eugenic mindset that viewed disabled people as burdens on humanity unworthy of inclusion. Though the ideological fervor of eugenics waned after 1945, its eugenic classifications and diagnostic assumptions remained embedded in state

13 Castellani, Paul J. *From Snake Pits to Cash Cows: Politics and Public Institutions in New York*. State University of New York Press, 2005, 33.

14 Castellani, 45.

15 Holmes, Oliver Wendell, and Supreme Court of the United States. *U.S. Reports: Buck v. Bell*, 274 U.S. 200. 1926. Periodical. <https://www.loc.gov/item/usrep274200/>.

16 “1972. Willowbrook: The Last Great Disgrace.” YouTube. <https://www.youtube.com/watch?v=5F7CrMAwCw4>.

institutional policy. Willowbrook's admissions framework in the 1950s and 60s continued to classify children using categories such as "idiot," "moron," and "imbecile," terms that conferred permanence and eliminated hope of eventual release.¹⁷

Reflecting its history, the Willowbrook campus was modeled on military architecture: an array of pavilions, regimented in cold, spatial geometry, connected by locked corridors, flanked by staff checkpoints.¹⁸ The wards were entirely unsuitable for adult rehabilitation, let alone for young children. There were no mainstream classrooms, no transition programs, and no meaningful mechanism for community reintegration.¹⁹ According to the NYC Mayor's Office for People with Disabilities, the original plan envisioned an innovative education-treatment model. In reality, by 1969, fewer than 15 percent of residents received any form of specialized instruction, and most daily schedules revolved around group feeding, toileting, and passive confinement.²⁰ Castellani reports that the average direct-care worker was burdened with the impossible task of supervising over fifty residents during each shift, many of whom required continuous assistance with mobility, hygiene, and feeding.²¹ Rivera noted that Willowbrook's emphasis on "specialized training" was a linguistic sleight of hand, masking the rote, dehumanizing routines that governed everyday life.²² The average length of stay for residents extended well beyond a decade. Unknown to many patients, Willowbrook was not a waypoint. It was the endpoint.

Despite promotional language about progress, institutional failures had long been visible. Castellani notes that by the mid-20th century, public trust was wavering but the state's financial and logistical priorities made alternatives rare.²³ To contain further upset, the state managed its image through calculated PR efforts. Parents were allowed access only to select, pre-sanitized areas, and official tours avoided the overcrowded and dilapidated deep wards. Complaints filed by conscientious staff and concerned family members were typically rerouted, buried in administrative files, or answered with vague reassurances. In 1948, the Hollywood film *The Snake Pit*, based on Mary Jane Ward's semi-autobiographical novel, exposed the brutality of American psychiatric facilities and helped establish the "snake pit" metaphor in public culture.²⁴ Senator Robert Kennedy's echoed this trope in 1965

17 Rothman, David J., and Sheila M. Rothman. *The Willowbrook Wars: Bringing the Mentally Disabled into the Community*. Aldine Transaction, 2005, 24–25.

18 "1972. Willowbrook: The Last Great Disgrace." YouTube. <https://www.youtube.com/watch?v=5F7CrMAwCw4>.

19 Castellani, Paul J. *From Snake Pits to Cash Cows: Politics and Public Institutions in New York*. Albany: State University of New York Press, 2005.

20 New York City Government. "Our History."

21 Castellani, 74–76.

22 Rivera, Geraldo. *Willowbrook: A Report on How It Is and Why It Doesn't Have to Be That Way*. Vintage Books, 1972, 14.

23 Castellani, Paul J. *From Snake Pits to Cash Cows: Politics and Public Institutions in New York*. SUNY Press, 2005, 60–64.

24 *The Snake Pit*. Directed by Anatole Litvak. 1948.

when he conducted a surprise visit to Willowbrook and issued a blistering public rebuke, stating: “At Willowbrook, we have a situation that borders on a snake pit.”²⁵ His condemnation briefly pierced public apathy but did little to reform the institution’s operations. Patient admissions continued unchecked.

Internal Conditions and Abuse

Photographs taken by Eric Aerts in 1971 were among the few visual records preserved of the state school before the scandal broke. A Belgian-born photographer working throughout the 1960s and 1970s to expose social inequalities in New York, Aerts captured the overcrowded dormitories, where residents were captured lying on bare mattresses or directly on the floor, often minimally dressed and unsupervised.²⁶ Rivera’s on-site investigations in the early 1970s uncovered similar scenes: children tied to furniture with strips of torn sheets, limbs bound and contorted for restraint.²⁷ Several images depict unsanitary conditions, such as severely soiled floors and walls, emphasizing the institution’s inability to keep up with the overadmission of patients exacerbated by a \$20 million funding cut amid financial troubles in the state.²⁸ As policymakers rationalized these cuts as economic necessities, administrators and staff within Willowbrook adapted by lowering expectations for care, allowing neglect to become routine practice.

Many parents believed institutionalization was their only responsible option. In the mid-20th century, professionals often dominated decision-making, steering parents away from alternatives and framing institutions as medically necessary.²⁹ This dynamic created and continually fed into a phenomenon called civil disability, where both disabled people and their families were treated as outside full civic belonging.³⁰ Thus tragically, many families placed their children in Willowbrook not because they wanted to, but because they were told it was the only safe choice.

The gradual collapse of care within Willowbrook can largely be attributed to the financial and political infrastructure that sustained it. Under New York State’s reimbursement model, institutions were funded per capita, not per service rendered,³¹ effectively rewarding overcrowding and penalizing individualized care. The practical impact was stark: after a twenty-million-dollar budget reduction—from \$600 million down to \$580 million during a statewide fiscal crisis—patient-to-attendant ratios surged from 4:1 to

25 Rothman & Rothman, 22.

26 Aerts, Eric. *Children at Willowbrook in 1971*. Photograph. College of Staten Island Archives & Special Collections.

27 Rivera, Geraldo. *Willowbrook: A Report on How It Is and Why It Doesn’t Have to Be That Way*. Vintage Books, 1972, 12.

28 “1972. Willowbrook: The Last Great Disgrace.” YouTube. <https://www.youtube.com/watch?v=5F7CrMAwCw4>.

29 Valerie Leiter, “Parental Activism, Professional Dominance, and Early Childhood Disability,” *Disability Studies Quarterly* 24, no. 2 (2004).

30 Beth Linker and Nancy J. Hirschmann, *Civil Disabilities: Citizenship, Membership, and Belonging* (Philadelphia: University of Pennsylvania Press, 2015), 117–19.

31 Castellani, Paul J. *From Snake Pits to Cash Cows: Politics and Public Institutions in New York*. SUNY Press, 2005, 47.

approximately 40:1.³² Average feeding times dropped from 20-30 minutes per resident to an impossible 2-3 minutes, depriving severely disabled residents of any chance to learn basic skills, oftentimes leading directly to fatal pneumonia or choking. Janitorial and direct-care positions remained vacant for months, leaving residents who could walk to perform tasks such as cleaning bathrooms and mopping floors, while essential supplies like soap, towels, and medical equipment remained inaccessible, locked away from staff and residents.³³ Conditions became not only unhygienic but pathogenic. By the late 1950s, hepatitis was endemic, transmitted easily through unsanitary toilets, unwashed hands, and shared utensils.

While statistical accounts of disease outbreaks, understaffing, and mortality at Willowbrook paint a damning picture, survivor accounts provide critical insight into the everyday realities of institutional life that statistics alone cannot convey. Bernard Carabello, admitted at the age of three for an intellectual disability despite truly having cerebral palsy, spent eighteen years within the institution. Though the average life expectancy for residents was just twenty-five to thirty years, Carabello survived and later became a leading voice in the disability rights movement.³⁴ He received only five years of education and therapy before being deemed “overage” and removed from all instruction. For the remainder of his time at Willowbrook, he was left largely to his own devices in Building 6, without stimulation or assistance³⁵. In a rare and trusting interview with Dr. Wilkins—a compassionate staff member who worked in Building 6 and developed a close, mentoring relationship with Bernard after hearing the young man converse with and humor fellow residents despite their collective circumstances—Carabello recalled his time there with horror, describing in detail a memory he had never previously shared: “They used to give out cookies and candies but throw it on the floor and watch the kids get down on the floor and grab at it... I never told anybody that. I remember that horrible day. It happened. It happened.”³⁶ For years, he had suppressed it: “I tried to block it out of my mind. I never talked about it, never told nobody about it.” His recollection, shared only decades later, reflects the extent to which everyday humiliations were normalized and left unaddressed.

Testimonies from the PBS documentary *Uncovering Willowbrook: 50 Years Later* deepen Willowbrook’s record of abuse by documenting the lingering emotional and psychological toll inflicted on residents and their families. Deborah Weissbach’s brother, Robert Weissbach, was institutionalized at Willowbrook in 1958 at age six and died years before Rivera’s exposé.

32 “1972. Willowbrook: The Last Great Disgrace.” YouTube. <https://www.youtube.com/watch?v=5F7CrMAwCw4>.

33 “1972. Willowbrook: The Last Great Disgrace.” YouTube. <https://www.youtube.com/watch?v=5F7CrMAwCw4>.

34 Rivera, Geraldo, and Bernard Carabello. “Remembering Willowbrook: A Conversation.” YouTube, 2023.

35 “1972. Willowbrook: The Last Great Disgrace.” YouTube. Posted by Geraldo Rivera.

36 Wilkins, Dr. Michael, and Bernard Carabello. “The Path Forward.” YouTube, August 18, 2022

Deborah described her horror upon seeing the facility exposed in the news: “I secretly watched the news. I secretly peeked at the newspaper. We never ever discussed it at home, and I was confused and angry... I spent years being angry.”³⁷ Robbie returned home nonverbal, emotionally distant, and deeply traumatized. In the end, Deborah’s long-suppressed grief resolved into quiet insistence: “He meant something. He meant something to me. I know now that he mattered deeply.”³⁸

Jose Rivera, another participant in the documentary, recalled a similar story. His brother Louie Rivera, also institutionalized at Willowbrook, regressed dramatically under its care. “Louis was not getting what they (his parents) were led to believe... people like my brother were isolated and hidden away from society,” he eloquently stated.³⁹ Their family was left not only with grief but with guilt, having been misled by professionals who insisted Willowbrook was the only option. “That caused significant trauma, emotional damage to my parents, and I think to the family.”⁴⁰ Only a small number of survivors and families have come forward, but their experiences reflect those of thousands who were similarly harmed by Willowbrook and its underdeveloped system of psychiatric care.

Those inside Willowbrook who attempted to intervene were met with swift and deliberate suppression. Dr. Michael Wilkins, a pediatrician working in Building 6, was dismissed after encouraging parents to visit the neglected wards concealed from official view where residents were abandoned by staff.⁴¹ His termination was a clear indicator that transparency was incompatible with Willowbrook’s preservation. In the wake of his dismissal, efforts to discredit him intensified. Bernard Carabello, the previously mentioned former resident with whom Wilkins had formed a sustained and respectful bond, was publicly confronted with invasive questions about the nature of their relationship, including insinuations of sexual misconduct.⁴² Carabello later recalled the indignity of being forced to defend one of the only humane connections he experienced at Willowbrook.⁴³ Such tactics reflected a broader institutional norm in which neglect could be absorbed, whereas resistance had to be discredited. Willowbrook’s internal structure was beyond merely ill-equipped to handle reform—it was deviously built to withstand it.⁴⁴ That

37 PBS, *Uncovering Willowbrook: 50 Years Later*. <https://www.pbs.org/video/uncovering-willowbrook-50-years-later-pecma5/>.

38 Ibid.

39 Ibid.

40 Ibid.

41 Rivera, Geraldo, and Bernard Carabello. “Remembering Willowbrook: A Conversation.” YouTube, 2023.

42 Ibid.

43 Ibid.

44 Kristen S. Addressi, “*How the Willowbrook Consent Decree Has Influenced Contemporary Advocacy of Individuals with Disabilities*,” Master’s thesis, CUNY, 2017. https://academicworks.cuny.edu/cgi/viewcontent.cgi?article=1000&context=sj_etds.

such measures were taken against a physician who sought only to make known and reform Willowbrook's squalid conditions speaks to the culture in which the abuse of power was intentional.

The Hepatitis Experiments

The hepatitis experiments marked the transformation of Willowbrook from a closed institution into a controlled site of biomedical exploitation. By 1972, Willowbrook's hepatitis infection rate had finally reached 100 percent within six months of admission.⁴⁵ Rather than treating this long standing issue as a public health emergency, researchers used it to justify experimentation. In 1955, Dr. Saul Krugman, a pediatrician and virologist affiliated with NYU and serving as Willowbrook's research director, began controlled hepatitis studies with his team on newly admitted residents.⁴⁶ In Krugman's logic, Willowbrook provided a "natural experiment" environment where hepatitis A and B could be studied under controlled conditions, using a sample size that was vulnerable and immobile.⁴⁷ The justification rested on a simple but highly controversial premise: because children were highly likely to contract hepatitis anyway, exposing them deliberately to known strains was not necessarily adding any additional harm.

The studies, conducted with the backing of the U.S. Army Medical Research Unit and NYU School of Medicine, involved the intentional infection of recently admitted children with various strains of hepatitis via ingestion or injection of fecal material or contaminated serum.⁴⁸ Some children received passive immunization through gamma globulin to test its preventive efficacy. Others did not. Krugman's early publications emphasized the scientific merit of the trials, noting that they advanced understanding of the hepatitis virus's immunological behavior and contributed directly to the development of the first effective vaccines.⁴⁹ The children—most of whom had intellectual or developmental disabilities and could not assent—were enrolled under what Krugman would later call "modified consent procedures", wherein parents were often told that participation in the research guaranteed admission to Willowbrook, which at the time had a long waiting list.⁵⁰ Many residents had no legal guardian to consent on their behalf.⁵¹ The implication was clear: institutionalization itself was conditional on enrollment in a medical trial.

45 "1972. Willowbrook: The Last Great Disgrace." YouTube. <https://www.youtube.com/watch?v=5F7CrMAwCw4>.

46 Krugman, Saul. "The Willowbrook Hepatitis Studies Revisited: Ethical Aspects." *Reviews of Infectious Diseases* 8, no. 1 (1986): 157–62.

47 Ibid.

48 Ibid.; Rothman, David J. "Were Tuskegee & Willowbrook 'Studies in Nature'?" *The Hastings Center Report* 12, no. 2 (1982): 5–7.

49 Krugman, "The Willowbrook Hepatitis Studies Revisited," 158.

50 Ibid., 160.

51 Kristen S. Addessi, "How the Willowbrook Consent Decree Has Influenced Contemporary Advocacy of Individuals with Disabilities" (Master's thesis, City University of New York, 2017), 18.

In a 1986 retrospective published in the Oxford health science journal *Reviews of Infectious Diseases*, Krugman offered a partial defense.⁵² He acknowledged that the ethics of informed consent had shifted since the trials began, but insisted that the research had significantly reduced infection at Willowbrook and posed minimal additional risk to the subjects.⁵³ He framed the studies as a rare case in which public health goals aligned with individual protection. But even in this defense, his language reveals the asymmetry of the relationship. His “subjects” remained unnamed and passive, simply a means to an end to extract data. In one scene of Rivera’s 1972 exposé, the camera pans across an infirmary filled with children who appear visibly ill. Rivera does not identify the hepatitis trials by name, but his narration alludes to “ongoing experimental programs” conducted on-site.⁵⁴ The startling imagery of residents undergoing tremendous suffering contrasts starkly with Krugman’s clinical prose.

David Rothman, writing four years earlier in *The Hastings Center Report*, dismantled Krugman’s rationale by drawing a direct line to the Tuskegee Syphilis Study.⁵⁵ Both studies were justified on the grounds that their target populations were already vulnerable, already infected, and already unlikely to benefit from standard treatment. Rothman termed this logic the “rhetoric of nature”—the belief that when a condition already exists, observing its progression rather than intervening is ethically permissible.⁵⁶ But Willowbrook, like Tuskegee, was not simply an environment where disease happened to spread. The high infection rates were the direct result of overcrowding, poor hygiene, and years of state neglect. Unlike the men at Tuskegee, many Willowbrook residents lacked even basic parental advocacy, leaving them especially exposed to harm within an institution that offered no real protection.⁵⁷ Ethical research cannot be disentangled from context. When subjects are institutionalized, dependent, and cognitively impaired, consent is never neutral, and risk is never fully voluntary.⁵⁸

Despite mounting criticism, Krugman remained a celebrated figure in virology through the 1980s. He received the Lasker Award in 1983 and was inducted into the Institute of Medicine⁵⁹. Krugman’s defenders emphasized the medical breakthroughs his research enabled, framing ethical concerns as

52 Krugman, “The Willowbrook Hepatitis Studies Revisited,” 159.

53 Ibid., 159.

54 “1972. Willowbrook: The Last Great Disgrace.” YouTube. Posted by Geraldo Rivera.

55 Rothman, “Were Tuskegee & Willowbrook ‘Studies in Nature?’” 5–6.

56 Ibid., 6–7.

57 Ibid., 6–7.

58 Elliott, Kevin. “Biomedical Ethics, Public-Health Risk Assessment, and the Naturalistic Fallacy.” *Public Affairs Quarterly* 16, no. 4 (2002): 351–76.

59 Harold M. Schmeck Jr., “FIVE U.S. SCIENTISTS WIN 1983 LASKER AWARD,” *The New York Times*, November 17, 1983, <https://www.nytimes.com/1983/11/17/us/five-us-scientists-win-1983-lasker-award.html>.

secondary to scientific progress. In doing so, they aligned with a broader cultural logic of the period—one that viewed institutionalized, disabled children as both medically valuable and socially expendable.

Exposure, Legal Reckoning, and Disability Rights

The deteriorating conditions of Willowbrook entered public consciousness through a series of dimly lit, unsteady camera shots that aired on WABC in 1972. Geraldo Rivera, then an emerging investigative reporter, entered the institution with covert access granted by Dr. Michael Wilkins. What his *éxposé* broadcasted—children rocking back and forth in boredom, living in their own waste, naked and unattended—would erase the credibility of every prior government assurance that conditions were improving.⁶⁰ Rivera's *exposé* became a sensation for its devastating content and matter-of-factness. His narration was subdued, his tone incredulous but measured. There were no metaphors or editorial phrases. The program aired locally first, then nationally, and the outrage caused by his work became legal momentum.

That same year, the New York State Association for Retarded Children (NYSARC) filed a class-action suit against the state, *NYSARC v. Stanley Brezenoff*, alleging constitutional violations at Willowbrook under the Eighth and Fourteenth Amendments. The litigation focused on systemic neglect, unsafe conditions, and denial of appropriate treatment.⁶¹ The case extended over three years, during which Rivera's footage, survivor testimony, and state documents were entered into the court record. In April 1975, a consent decree was issued: the State of New York would reduce Willowbrook's population to no more than 250 residents, improve medical and psychological services, and begin transitioning residents to community-based residential alternatives.⁶² It became one of the earliest and most significant federal court interventions into state-operated institutions for people with developmental disabilities. Around the same time, a federal court in Pennsylvania ruled in *Halderman v. Pennhurst State School and Hospital* (1977) that institutionalization itself violated residents' constitutional rights,⁶³ demonstrating Willowbrook's role as one part of a growing national legal shift that treated institutional abuse as a constitutional matter.

Compliance proved tenuous. Though the consent decree carried the weight of judicial authority, the Department of Mental Hygiene consistently failed to meet court-mandated benchmarks.⁶⁴ Community placement initiatives stagnated as the state missed deadlines for developing residential

⁶⁰ "1972. Willowbrook: The Last Great Disgrace." YouTube. Posted by Geraldo Rivera.

⁶¹ *New York State Association for Retarded Children, Inc. v. Stanley Brezenoff* (U.S. District Court for the Eastern District of New York, April 30, 1975). <https://archives.library.csi.cuny.edu/~files/ConsentDecree.pdf>

⁶² *Ibid.*

⁶³ Paul J. Castellani, *From Snake Pits to Cash Cows: Politics and Public Institutions in New York* (Albany: State University of New York Press, 2005), 60–64.

⁶⁴ *Ibid.*, 84–87.

alternatives, including group homes and supported apartments. Legislative inertia further impeded progress: appropriations for the Office of Mental Retardation and Developmental Disabilities (OMRDD) were frequently delayed, diluted, or caught in budgetary impasses.⁶⁵ By the early 1990s, many of the decree's mandates remained unfulfilled. In 1993, NYSARC filed a new suit, *NYSARC v. Mario Cuomo*, seeking permanent enforcement of the original agreement. The result was a sweeping federal injunction.⁶⁶ Unlike the 1975 decree, the 1993 order imposed measurable standards: mandated service plans, protection protocols, and external monitoring.⁶⁷

Legal scholars have identified Willowbrook as a pivotal case in the legal governance of disability. John W. Parry argued in the *Mental and Physical Disability Law Reporter* that it marked a shift from medical regulation to constitutional oversight. Tools of civil rights litigation, especially class actions, were now used to impose binding standards on state-run institutions.⁶⁸ Joel B. Grossman, reviewing *The Willowbrook Wars*, highlighted the court's extended role: judges conducted inspections, reviewed compliance logs, and issued orders for years. He called it "the law as stewardship," where the judiciary assumed continuing responsibility for institutional conditions.⁶⁹

Between 1973 and 1990, three major federal statutes restructured the legal landscape of disability. Section 504 of the Rehabilitation Act (1973) prohibited discrimination on the basis of disability by any program receiving federal funds, effectively introducing civil rights protections into education, healthcare, and social services for the first time.⁷⁰ The Education for All Handicapped Children Act (1975), later renamed the Individuals with Disabilities Education Act (IDEA), guaranteed free and appropriate public education in the least restrictive environment, ensuring access to classrooms, individualized learning plans, and procedural safeguards for students with disabilities.⁷¹ The Americans with Disabilities Act (1990) extended these protections beyond federally funded programs, mandating reasonable accommodations in private employment, transportation, public facilities, and

65 Addressi, Kristen S. "How the Willowbrook Consent Decree Has Influenced Contemporary Advocacy of Individuals with Disabilities." Master's thesis, City University of New York, 2017.

https://academicworks.cuny.edu/cgi/viewcontent.cgi?article=1000&context=si_etds

66 *New York State Association for Retarded Children, Inc. v. Mario Cuomo*, 393 F. Supp. (2d Cir. 1993). https://opwdd.ny.gov/system/files/documents/2019/11/willowbrook_permaent_injunction_lori_0.pdf

67 *New York State Association for Retarded Children, Inc. v. Mario Cuomo, et al.*, 393 F. Supp. (2d Cir. 1993). https://opwdd.ny.gov/system/files/documents/2019/11/willowbrook_permaent_injunction_lori_0.pdf

68 Parry, John W. "Mental and Physical Disability Rights: The Formative Years and Future Prospects." *Mental and Physical Disability Law Reporter* 20, no. 5 (1996): 627–33.

69 Grossman, Joel B. Review of *The Willowbrook Wars: Bringing the Mentally Disabled into the Community*, by David J. Rothman and Sheila M. Rothman. *American Bar Foundation Research Journal* 12, no. 1 (1987): 249–59.

70 Parry, John W. "Mental and Physical Disability Rights: The Formative Years and Future Prospects." *Mental and Physical Disability Law Reporter* 20, no. 5 (1996): 627–33.

71 Ibid.

communication.⁷² But these laws did not become fully enforceable overnight. Section 504 remained largely inactive until 1977, when disability rights activists staged a 25-day sit-in at the San Francisco HEW office. Similarly, IDEA's early implementation emphasized paperwork over classroom inclusion, and only gained traction through parent-initiated lawsuits and oversight pressure.⁷³ These laws, though shaped by the public impact of Willowbrook, were enforced through years of advocacy by parents who sued school districts, pressured agencies, and demanded accountability for institutional failures.⁷⁴ Key aspects of the consent decree, such as service planning and community placement, only gained traction after parent groups and legal advocates intervened.⁷⁵

Among those most visible in this new era was Bernard Carabello. After Willowbrook's closure, he emerged as a lead plaintiff, public speaker, and policy advisor. In his interviews with Geraldo Rivera and Dr. Michael Wilkins, he described how years of forced dependence and neglect trained others to dismiss him.⁷⁶ He recalled how the experience of institutionalization continued to shape how others perceived him permanently after his release. His later work included public testimony, survivor advocacy, and policy engagement with the New York State Office for People with Developmental Disabilities. Rivera, too, returned to the subject in later years. His follow-up documentaries departed from the exposé format of 1972, offering instead long-form interviews, archival reflection, and a shift in tone from indictment to introspection.⁷⁷ The public, once shocked into action by the original footage, was now asked to consider not just what had happened, but why it had been allowed to happen—and what forms it continued to take. Even the state's own narrative has evolved. The NYC Mayor's Office for People with Disabilities, an institution once implicated in systems of separation, now frames Willowbrook as a "historic turning point," acknowledging it as both a site of failure and a stimulus for ongoing accountability.⁷⁸

⁷² Ibid.

⁷³ Valerie Leiter, "Parental Activism, Professional Dominance, and Early Childhood Disability," *Disability Studies Quarterly* 24, no. 2 (2004).

⁷⁴ Ibid.

⁷⁵ Addressi, Kristen S. *How the Willowbrook Consent Decree Has Influenced Contemporary Advocacy of Individuals with Disabilities*. CUNY Master's Thesis, 2017.

⁷⁶ Bernard Carabello and Dr. Michael Wilkins, "Remembering Willowbrook," YouTube, August 18, 2022, <https://www.youtube.com/watch?v=CM9fnwUp2iU>.

⁷⁷ "The Path Forward: Remembering Willowbrook." YouTube. NYS Council on Developmental Disabilities, 2024.

⁷⁸ New York City Government. "Our History." NYC Mayor's Office for People with Disabilities. <https://www.nyc.gov/site/mopd/events/our-history.page>

Post-Willowbrook Failures of Reform

The Office for People With Developmental Disabilities (OPWDD) acknowledge Willowbrook as a “catalyst for change,” highlighting community residences and individualized services as the new standard for disability care.⁷⁹ However, records of implementation reveal persistent gaps. Analysis of post-consent-decree compliance (spanning the 1990s and early 2000s) found that many OPWDD-licensed homes lacked essential therapeutic programs, failed to maintain safe resident-to-staff ratios, and struggled to conduct timely service plan reviews.⁸⁰ These issues often mirrored the same oversight failures that had come to define Willowbrook in its final decades.

Investigative reports indicate that abuse and neglect persist in modern group home settings. A 2011 investigation documented multiple fatalities in OPWDD-supervised homes, including a man with epilepsy who died after staff failed to administer required medication, and another resident whose respiratory distress went untreated until he was found dead.⁸¹ Staff responsible for the care of residents with significant medical needs were often inadequately trained. In many cases, incident reports were falsified or never filed. Homes with repeated abuse claims, including scalding injuries, beatings, and medical neglect, remained open with no formal staff discipline. Investigations were often closed internally, and oversight mechanisms failed to prevent recurrence.⁸²

Further evidence emerged in 2020, including the case of a Bronx resident whose death was ruled a homicide but resulted in no criminal charges. That individual was one of more than 2,000 former Willowbrook residents still living in state-operated homes.⁸³ In 2019 alone, there were 97 allegations of physical abuse, 34 of psychological abuse, and 30 of neglect reported against this population.⁸⁴ Some residents were left in soiled clothing for extended periods, others were scalded by hot water, and several were subjected to unnecessary sedation or improper restraints. In many cases, staff accused of abuse remained on the job, protected by civil service and union rules. Despite repeated findings of harm, OPWDD often failed to notify prosecutors, and local district attorneys reported that prosecutions rarely moved forward due to lack of timely evidence or the inability of victims to testify.⁸⁵

79 New York State, “*A Catalyst for Change*,” Office for People With Developmental Disabilities, accessed March 27, 2025. <https://opwdd.ny.gov/willowbrook#:~:text=September 17%2C 1987 marked the,officially and forever closed.>

80 Addressi, Kristen S. *How the Willowbrook Consent Decree Has Influenced Contemporary Advocacy of Individuals with Disabilities*. CUNY Master’s Thesis, 2017.

81 Hakim, Danny. “At State-Run Homes, Abuse and Impunity.” *The New York Times*, March 13, 2011. <https://www.nytimes.com/2011/03/13/nyregion/13homes.html>.

82 Ibid.

83 Benjamin Weiser, “Beatings, Burns and Betrayal: The Willowbrook Scandal’s Legacy,” *The New York Times*, February 21, 2020, <https://www.nytimes.com/2020/02/21/nyregion/willowbrook-state-school-staten-island.html>.

84 Ibid.

85 Ibid.

Labor conditions for direct support professionals (DSPs) exacerbate these issues. Low wages and delayed bonuses contribute to high turnover across OPWDD's provider network.⁸⁶ Many DSPs, whose duties include medication management and crisis intervention, earned near-minimum wage even as legislative funds for pay increases remained unallocated or held up by administrative processes.⁸⁷ In practice, these shortfalls undermined the stable workforce needed to maintain consistent care, recalling Willowbrook's long standing reliance on underpaid and overextended employees. Public commemoration of Willowbrook omits much of this continuity of abuse. The NYC Mayor's Office for People with Disabilities cites the institution's closure as evidence of progress but does not address the ongoing challenges in state-funded homes, including repeated lapses in oversight and training.⁸⁸

While the litigation provided a procedural framework for deinstitutionalization, it left untouched the deeper cultural assumptions that had long sustained institutions like Willowbrook. The original consent decree could mandate services and impose timelines, but it could not alter how society viewed disabled individuals as burdens to be managed, separated, and contained.⁸⁹ The extent of the law is enforcing compliance, as it has not been able to generate the political commitment needed to prioritize inclusion over convenience. In this sense, Rivera's camera may have sparked the collapse of Willowbrook's walls, but the courts were left to slowly and incompletely reconstruct a system of rights and accountability that had never existed before. Meanwhile, the stigma that had justified institutionalization in the first place—the belief that disabled people belonged elsewhere, apart, and under control—remained largely unchallenged in public discourse, policy logic, and everyday practice.⁹⁰

Conclusion

Willowbrook was not the first institution in the United States to subject disabled residents to abuse and neglect, but it was the first whose conditions were aired to a national audience and met with sustained legal, political, and public response. That response would not have taken root without the persistence of families and survivors who refused to stay silent. Many of the most consequential reforms, including school access, residential oversight, and federal protections, were driven not by institutions themselves, but by those who had been excluded from them. Willowbrook closed, but the institutional logic survived. Group homes, special education programs, and

⁸⁶ Lisa, Kate. "Lawmakers Frustrated by Delays in Funding Health Worker Bonuses, Raises." *Spectrum News 1*, September 13, 2022.

⁸⁷ Ibid.

⁸⁸ New York City Government, "Our History," NYC Mayor's Office for People with Disabilities, accessed March 27, 2025, <https://www.nyc.gov/site/mopd/events/our-history.page?slide=10>.

⁸⁹ Addressi, Kristen S. *How the Willowbrook Consent Decree Has Influenced Contemporary Advocacy of Individuals with Disabilities*. CUNY Master's Thesis, 2017.

⁹⁰ Ibid.

residential treatment centers often carried forward the same assumptions and administrative logic that had allowed Willowbrook to function for decades: minimal transparency, low expectations, and bureaucratic distance. The names changed, but the conditions often did not. Abuse still happened, and when it did, families faced the same dismissiveness that had once kept Willowbrook running.

The institution's legacy, then, is not its sensational fall, but the extent to which its model adapted rather than disappeared. To understand that history is to recognize that institutions do not simply end; they reorganize. And unless their assumptions are dismantled with the same force that exposed them, what results is repetition instead of much-needed progress. Why is accountability only triggered by crisis rather than being built into the system by design? What structures remain in place precisely because the public has never been asked to imagine an alternative? And how many systems today are tolerated not because they work, but because the people within them are not expected to matter?

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