

The Last Great Disgrace

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Growing up, I wouldn't smile at strangers, could sit and read a book for hours, and not speak at all unless spoken too. Although I hit all of my benchmarks, my mom sensed that something was *off*, so she consulted with a behavioral therapist who promptly diagnosed me with poor hand-eye coordination, a limited vocabulary, and a high probability of having "high functioning autism." Fortunately, I was young enough that I could be put into an early intervention preschool for children who exhibited similar traits. Still, I cannot help but think about how just 50 years earlier, instead of being supported due to my differences, I would have been shuttled away to a care home. A care home like the now notorious Willowbrook State School, which was disbanded in 1987 due to the collective efforts of citizens, senators, and journalists, like my father, Geraldo Rivera.

The Willowbrook State School in Staten Island, New York was a government sponsored care home for children with special needs. During the forty years it was open, it was the largest public institution for those with developmental disabilities, hosting over 6,000 patients at a time (despite capacity being just 4,000), including adults.¹ Resources surrounding the care of kids with special needs were scarce, according to Ellen Wiseman, author of *The Lost Girls of Willowbrook*, "the majority of parents sent their children to Willowbrook after being encouraged by doctors to relinquish their disabled children for the sake of the family."² The doctors entrusted to take care of their dependents were not the kind hearted professionals the families believed them to be. Instead, they all were beholden to one simple rule: silence the patients at all costs.

¹ "About | Willowbrook Mile | College of Staten Island Website." n.d. [www.csi.cuny.edu](https://www.csi.cuny.edu/about-csi/president-leadership/administration/office-vp-economic-development-and-community-partnerships/reporting-units-and-initiatives/willowbrook-mile/about).
<https://www.csi.cuny.edu/about-csi/president-leadership/administration/office-vp-economic-development-and-community-partnerships/reporting-units-and-initiatives/willowbrook-mile/about>.

² Wiseman, Ellen. 2022. "The Dark History of Willowbrook State School." CrimeReads. September 16, 2022.
<https://crimereads.com/the-dark-history-of-willowbrook-state-school/#:~:text=Many%20sent%20their%20children%20to>.

However, this was not the case for all staff. Those who rebelled against the status quo were quickly fired, and many stayed for fear that if they left, someone more willing to assimilate to Willowbrook's rules would take their place. The institution was overcrowded, and underfunded with 100 patients being assigned to one nurse at a time. This was an open secret; in 1965 senator Robert F. Kennedy visited and called the place a "snake pit."³ Additionally, mental health activist Donna J. Stone (having been a patient of Willowbrook herself) gave first hand accounts of the mistreatment to members of the local press.⁴ Eventually, the state's ignorance became too much for one staff doctor, Michael Wilkins, MD, to handle.⁵ Fired due to his advocating for the patients, he contacted my dad, then an investigative reporter for WABC-TV in New York. He told him to bring his camera crew unannounced to one of the large buildings that housed the patients on campus. What my dad saw was appalling, but it was the brave patients interviewed who really showed him, and the rest of the world, the horrendousness they had allowed to prosper underneath their noses.

One of these patients was Bernard Carabello, a resident of Willowbrook who had been there since birth. When my dad asked what it was like living in Willowbrook, he said it was a "disgrace," that the "conditions were getting worse."⁶ It wouldn't take long until *Willowbrook: The Last Disgrace* aired for others to see for themselves. New York State officials knew this, and threatened lawsuits to prevent the expose from airing, saying that the privacy of the residents was

³ "Archives & Special Collections - Guide to Willowbrook Resources." 2023. Archive.org. 2023. <https://web.archive.org/web/20120414093059/http://www.library.csi.cuny.edu/archives/WillowbrookRG.htm>.

⁴ Ryan Elainska. "Radical Woman of the Day: Donna J. Stone." 2019. Ryan Elainska. 2019. <https://www.ryanelainska.com/jesus-and-venus/2013/2/23/radical-woman-of-the-day-donna-j-stone>.

⁵ Disability Justice. 2014. "The Closing of Willowbrook." Disability Justice. 2014. <https://disabilityjustice.org/the-closing-of-willowbrook/>.

⁶ "Willowbrook: The Last Disgrace." 1972. Wwww.youtube.com. February 2, 1972. <https://www.youtube.com/watch?v=IRK0LO-9ZYk>.

violated.⁷ When Bernard was interviewed about this, 50 years later, he put it succinctly: "their privacy was violated anyways."⁸ The director of ABC news, Al Primo, listened and agreed to put the doc on hold until he saw the reel. When he did, he knew that there was no other choice but to air it, no matter what legal backlash the network could face as a result. And there was, but not against the network.

When Willowbrook parent Vicki Schneps watched the documentary, she was horrified.⁹ Her infant daughter was one of the thousands of patients being mistreated, and she wasn't going to let the government get away with the treatment. Gathering a group of other parents who felt similarly enraged by what their children had suffered, they filed a class action lawsuit against the state of New York, arguing that the facility had violated the patients' constitutional rights. While the judge, one Orrin G. Judd, ended up disagreeing with the constitutional ramification, he agreed that "the conditions in Willowbrook violated the constitutional right of persons living in state custodial institutions to be protected from harm."¹⁰ To remedy this, the judge laid out the Willowbrook Consent Judgement in 1975¹¹, which established new governmental guidelines for the baseline level of care required for those with special needs. Now, due to the efforts of the

⁷ Tyree, Jesse. 2022. "50th Anniversary Showing of 'Willowbrook: The Last Great Disgrace' - Cerebral Palsy Associations of New York State." Cerebral Palsy Associations of New York State. February 16, 2022. <https://cpstate.org/50th-anniversary-showing-of-willowbrook-the-last-great-disgrace-on-feb-16/>.

⁸ "Remembering Willowbrook: A Conversation with Bernard Carabello and Geraldo Rivera." n.d. [www.youtube.com](https://www.youtube.com/watch?v=9_4nYMu1IE0). Accessed December 14, 2022. https://www.youtube.com/watch?v=9_4nYMu1IE0.

⁹ Keller, Kaitlynn, and Cheryl Wills. 2022. "'Life's Wor' Founder and Activist Vicki Schneps Discusses Her Daughter's Experience inside Willowbrook." [Ny1.com](https://ny1.com/nyc/all-boroughs/in-focus-shows/2022/07/09/-life-s-wor--founder-and-activist-vicki-schneps-discusses-her-daughter-s-experience-inside-willowbrook). Spectrum News NY1. July 10, 2022. <https://ny1.com/nyc/all-boroughs/in-focus-shows/2022/07/09/-life-s-wor--founder-and-activist-vicki-schneps-discusses-her-daughter-s-experience-inside-willowbrook>.

¹⁰ Disability Justice. 2014. "The Closing of Willowbrook."

¹¹ "APA Dictionary of Psychology." n.d. [Dictionary.apa.org](https://dictionary.apa.org/willowbrook-consent-judgment). <https://dictionary.apa.org/willowbrook-consent-judgment>.

press, the parents, and the petitioners, there was now recourse for those who had been ignored for far too long. From being the last great disgrace, came a way to move forward.

At first, the government of New York was willing to ignore the residents of Willowbrook who were suffering, because they saw their lives as unimportant, and there was little an individual could do to create change. Michael Wilkins, MD was fired from Willowbrook for voicing his concerns about how the patients were treated. Bernard Carabello, was relegated to the depths of Willowbrook. My father, Geraldo Rivera had no clue of what was going on in his backyard, and Vicki Schneps had been trying to mount a lawsuit for years to no success. Willowbrook could have remained open to this day, yet because these to each other decided to give all they could to one cause, they were able to create massive reforms. As a girl who could have been sent to Willowbrook herself, this story had taught me about the importance of the group; that an individual can be an underdog on their own, but as a collective they can be as strong as any institution.

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