Willowbrook case brought needed national reform

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The recent sanctions in an ongoing federal court case focused on the former Minnesota Extended Treatment Options facility bring to mind how other abuse cases brought changes in laws and practices.

One of the nation’s most scandalous incidents was exposed in the 1960s at the Willowbrook State School on Staten Island in New York City. Willowbrook shaped state and federal laws and policies including the 1980 Civil Rights of Disabled Persons Act and the 1990 Americans with Disabilities Act or ADA, but it took decades of pain and struggles.

Willowbrook was planned in the late 1930s as a home for children with intellectual disabilities, but instead it opened in 1942 as a U.S. Army hospital. In late 1947 the New York State Department of Mental Hygiene opened Willowbrook State School there as planned.

Conditions were deplorable, with frequent outbreaks of hepatitis and controversial medical studies during its first decade. Willowbrook was designed to house up to 4,000 children with developmental disabilities. By 1965, it had a population of more than 6,000 children. Willowbrook was the world’s largest state-run institution of its kind. It had a reputation for housing children that families and the care systems had abandoned.

When New York Sen. Robert Kennedy toured Willowbrook in 1965, he was shocked. In an interview, Kennedy compared the residents’ living conditions to a “snake pit.” Kennedy declared that residents were “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.”

Others also drew attention to Willowbrook. A series of articles in local newspapers described the horrible conditions and treatment of residents. Residents suffered physical and in some cases sexual abuse.

Public shock and outcry regarding abuse and neglect of residents exploded as organized parent protests and media exposés ignited mass awareness. In early 1972, Geraldo Rivera, an investigative reporter for WABC-TV in New York, was contacted by an activist physician recently fired for speaking out about the abysmal conditions. Rivera’s resulting exposé, Willowbrook: The Last Great Disgrace, garnered national attention. It was a stinging indictment of institutionalization and treatment of persons with developmental disabilities. Rivera won a Peabody Award and used the report to shine a spotlight on Willowbrook. He appeared on the Dick Cavett Show and showed part of the exposé.

A class-action lawsuit was filed in federal court on March 17, 1972. It resulted in a settlement with New York’s State Department of Mental Hygiene on May 5, 1975. It took years to
implement and didn’t win final approval until February 1987. The settlement called for Willowbrook to close and residents placed in the community. The last residents left in September 1987. Many in the “Willowbrook Class” are adults living in community facilities throughout New York State. Some were featured in the 1997 documentary Unforgotten: 25 Years After Willowbrook.

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