## **REMEMBERING WILLOWBROOK**

Super decision Making News YES.

**September 16, 2022** 

Although most of you are too young to remember the infamous 1966 Willowbrook scandal, we want to let you know about an upcoming program about this turning point in the way society "protected" people with I/DD: *Willowbrook State School: How a Lawsuit Closed the Gates to a Notorious Institution and Opened the Doors of Opportunity for Thousands*, sponsored by the Historical Society of the New York Courts, in collaboration with the Willowbrook Legacy Project at the College of Staten Island/CUNY, the New York City Bar Association's Disability Law Committee, and the New York State Bar Association's Disability Rights Committee. It is free and will be both live (at the New York City Bar Association) and livestreamed via Zoom. To register, visit the event page at history.nycourts.gov/events/willowbrook-state-school





When we do information sessions, especially for parents, we often speak about how ideas of "protection" have changed over time, including the growth and prevalence of segregated residential "schools" for people with I/DD that began toward the end of the 19th century. The idea was benevolent at first, educating what were then referred to as "retarded" people so that they could be returned to fully participate in society, but it deteriorated over time into poorly maintained institutions from which residents, once admitted, never left. The largest and ultimately most infamous of these was New York's Willowbrook State School. Located on Staten Island, Willowbrook had more than 3500 residents when investigative journalists exposed the terrible conditions in videos that ultimately led to its closure, and the closure of other institutions like it. (Those videos are still available on Google, but we caution you that they are very disturbing.)

The effort to close Willowbrook marked an important beginning in society's recognition that people with I/DD have rights. The work of advancing and protecting those rights has continued over the last half century, culminating in the new Supported Decision-Making Agreement law signed by Governor Kathy Hochul on July 26. (Good News [7/29/2022]) Celebrating the anniversary of the Americans with Disabilities Act, the Governor noted how, from the shame of Willowbrook, New York has now become a national leader in protecting the rights of people with I/DD.

We're proud that one of the panelists on the program is our friend and Advisory Council member, Beth Haroules, an attorney at the NYCLU who represents the class of Willowbrook survivors. SDMNY has other connections to Willowbrook and the struggle to close it: Advisory Council member and long time self-advocate Bernard Carabello was a Willowbrook resident who worked with journalists on the expose, while Sheila Rothman wrote the definitive book on Willowbrook with her late husband David. Perhaps most important, and most humbling, one of the first Decision-Makers to sign up with SDMNY is himself a Willowbrook survivor. As we remember Willowbrook, SDMNY re-commits to promoting and ensuring the human right of all people to make their own decisions regardless of disability.

## WILLOWBROOK: NEVER AGAIN!

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