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Ann Nehrbaauer, 95, looks at photos of her son Stephen at home in Hastings-on-Hudson. Nehrbaauer was honored by Arc Westchester Foundation with its Lifetime Advocate Award. SETH HARRISON/THE JOURNAL NEWS

Disability rights activist honored by Arc Westchester

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Disability rights activist Ann Nehrbaauer received the Lifetime Advocate Award last Wednesday from The Arc Westchester Foundation at the organization's 18th annual "Matter of Taste" gala.

At age 95, Nehrbaauer – known for her role in fighting to get the infamous Willowbrook State School for disabled children and adults shut down – received the award amid a large celebration com-

memorating The Arc Westchester's 75th year. The event was both a celebration and a call-to-action: The Arc Westchester Foundation invited community members to purchase tickets to fundraise for its programs, which assist with the needs of disabled people and their families in the area.

"It's hardly enough," said Barry Clark, executive director of The Arc Westchester Foundation. "Lifetime advocate is the perfect name for this award – it's tireless advocacy efforts on the part of Ann, and other people like her, that has made this the world we live in instead of

the world that we were in 75 years ago."

At the time that Arc Westchester began its work, the organization made a huge difference for people like Nehrbaauer, who utilized Arc's services to move her son, Stephen, away from the abhorrent conditions at Willowbrook into an Arc Westchester house in Scarsdale. Stephen, who was developmentally disabled, received the care he needed from the time he left Willowbrook in 1979 until he passed away last year at the age of 67.

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Nehrbaauer

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"Getting this award sort of makes me appreciate the fact that this book that has been written about Stephen, and all of his friends," Nehrbaauer said of receiving the Lifetime Advocate Award. "All those developmentally, intellectually (disabled) people that are living today are being better served, are being treated as brothers and sisters of the general population."

"I'm grateful for that," Nehrbaauer continued. "Very grateful. It's a joy."

About Willowbrook State School

In 1964, Nehrbaauer and her husband, George, moved Stephen into Willowbrook State School in Staten Island. With five other children (which later became six), and the full-time attention Stephen required, his needs outgrew what the Nehrbauers could provide at home. The family was advised to institutionalize Stephen.

The day Nehrbaauer left Stephen at Willowbrook, she knew she had to fight to get him and the other residents out.

"My husband had him in his arms ... and Stephen had his hand around George's neck," Nehrbaauer said, "and when we had to put him down and leave him there, he clawed the back of George's neck so he wouldn't have to let go."

"That was the moment," Nehrbaauer continued, "I had thought, 'He can't stay here. He can't.'"

By then, Nehrbaauer had already joined Arc Westchester as a member. While Stephen lived at Willowbrook, Nehrbaauer continued going to Arc meetings, getting involved to "bring these people back."

The fight to be treated 'as a fellow human being should be treated'

Willowbrook, though located in Staten Island, was "controlled by Albany," according to Nehrbaauer. It had more than 5,500 residents across numerous buildings during the time Stephen was a resident. Each ward had 80-90 residents, with beds lined up just inches away from one another. Children often did not have enough to eat, and during mealtimes, snuck bread into their shirts and hid it under their pillows.

Although Willowbrook was called a school, there was little education taking place.

"They tried," Nehrbaauer said. "But it wasn't enough."

The conditions were so horrendous that journalist Geraldo Rivera recorded the 1972 expose "Willowbrook: The Last Great Disgrace" documenting the institution's mistreatment of its residents.

Nehrbaauer and the parents of 5,000 Willowbrook residents worked with the Civil Liberties Union to sue the state of New York in federal court in the 1972 landmark lawsuit *New York ARC v. Rockefeller*. The case led to the placement of what became known as the "Willowbrook Class" into homes throughout the community. It also led to the eventual closure of the institution in the 1980s.

Stephen was able to move back into the community



A photograph of Stephen Nehrbaauer, left, with family members. Stephen, who was developmentally disabled, was a resident at Willowbrook State School in the 1970s. His mother Ann Nehrbaauer was among those who brought a civil rights lawsuit against the institution. PHOTO PROVIDED BY ANN NEHRBAUER

in 1979. He moved into his home at the Arc Westchester house in Scarsdale where, according to Nehrbaauer, he "went into that community every single day."

"It was an awakening to him," Nehrbaauer said, "and a joy to him to think that he was able to go on a public bus...and see other people and go to a restaurant. He was treated as a fellow human being should be treated."

A true lifetime advocate

In addition to her involvement in Arc Westchester and the fight to close Willowbrook, Nehrbaauer became a member, and then the chair, of the Consumer Advisory Board for the Willowbrook Class. She and the Board acted "in loco parentis," meaning "in the place of a parent," for more than 2,500 former Willowbrook residents.

"We placed people all over the state of New York into homes," Nehrbaauer said, "made sure that (the homes) were adequate and that there were services there to support them."

At 95 years old, Nehrbaauer still advocates tirelessly. She continues her work with the Consumer Advisory Board doing life and death decisions. She shares information about Westchester area care workers' (also known as "Direct Support Professionals" or "DSPs") fight for a cost-of-living adjustment, workers who help make it possible for people like Stephen to live in their community. She remains involved with Arc Westchester, advocating to keep its services going, like its houses for disabled community members and its guardianship program.

"We seem to be on a downturn," Nehrbaauer said. "But I still have hope. There's a lot of good people out there who really care, and who are going to work ... to make things better."

"They're going to turn it around," she continued. "A little bit at a time, one day at a time. So that services will not only be maintained, but they'll grow – even if it's a little growth – that they will grow."