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New York Times

Dear Editor:

I found it timely to read Liz Robbins' article entitled For Special-Care Residents, New York State Policy Means Leaving Home it was a sad reminder that considerable gaps remain in the provision of proper services to all developmentally disabled individuals residing in the State of New York.

It was unrefuted at the time of the execution and the Willowbrook Consent Judgment in July 1975 and remains unrefuted today: there is no legitimate basis to imprison developmentally disabled individuals in large institutions. Smaller is better and larger is archaic. As the article points out, small group homes provide great benefits to the disabled. However, that does not mean family members are relieved of their role as advocate.

My heart breaks for John Consentino and his parents as he has been forced to live in the very environment that develops self-abuse. The term "self-abuse" is also known as "self-stimulation." This term explains the nature of the terrible act. Simply explained, people who are forced to live a life without proper stimulation, in idleness and boredom, will choose self-abuse/self-stimulation rather than terminable idleness and

boredom. Occupy the person and keep him/her stimulated with healthful activities with other human beings and such behaviors will be reduced and ultimately eliminated.

In order to protect John from hurting himself he was condemned to reside in a large institution that historically causes and perpetuates destructive behaviors. Why has no one ever explained that to his parents? Why did the State permit John and hundreds others to languish in institutions to their severe detriment? Perhaps utilizing the \$625,000.00 won for John's neglect would be better spent developing and designing a community residence for him and a few others with or without similar problems.

Every parent of a severely disabled child like John is afraid of what happens to their beloved child upon their demise. But perpetuating the large institution that permitted his self-abuse and neglect is not the answer. Of course the Consentino's are afraid for their son. If the authorities are promising that he will have the continued level of care and personnel in a group home then their advocacy would be better spent making sure that that happens rather than trying to keep the institution open. There is no guarantee that his aide will remain employed even at the institution, people change jobs, retire, etc. I applaud their advocacy and that of Mr. Rivera on behalf of his sister. But both John and Theresa deserve to live safely in small homes, which meet their individual needs.

At a time when budgets are tightening we must remember the lessons we learned at Willowbrook. We can never go back to the hellholes of large institutions and must advocate even more strongly to assure that the victories won 40 years ago do not slip through our fingers. In 1975, we won more than the closing of Willowbrook and most other institutions for the developmentally disabled. The punishing institutional system was extensively eradicated and replaced with a system of small community residences.

Supporting that system, at less cost and greater benefit to all, should be a concept we all can recognize and accept.

The Editor

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Very truly yours,

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MURRAY B. SCHNEPS

I am the father of Lara Rebecca Schneps who resided in Willowbrook, was a named plaintiff in the Willowbrook Class Action, an advocate for the developmentally disabled, a litigator, the Vice Chairman of the Willowbrook Review Panel and an attorney for named plaintiffs in the Willowbrook Class action. I am also the author of a memoir published on December 15, 2014, entitled I SEE YOUR FACE BEFORE ME.