

TESTIMONY TO OPWDD - TRANSFORMATION PANEL FORUMS

My name is Murray B. Schneps. My first child, LARA REBECCA SCHNEPS, was born on May 23, 1968, and was diagnosed as suffering from profound mental retardation with severe cerebral palsy. LARA was blind and totally dependent upon the assistance of others. When it appeared that no community services were available for LARA, our desperate search for services to provide her with the opportunity to be the most she could be, led us to the Willowbrook State School. Although Willowbrook had a miserable history, highlighted with the visit made there by Sen. Robert Kennedy in 1965, it was the only place that offered such services. A new Children's Therapy Center was available and my former wife and I jumped at the opportunity, although we knew that our darling could only access such services if she resided at Willowbrook. Willowbrook was the largest residential institution for the mentally retarded in the world.

Not only did we surrender our daughter to the horror house of Willowbrook but the promised services did not exist. It was a fraud. Appropriate services were never provided. The State breached its agreement to us, to wit: give us your child and we will provide appropriate services and care for her.

During the time LARA resided in Willowbrook I became more and more educated and came to the conclusion that Willowbrook, and all such institutions, must be closed, that a system of small community residential homes and services must be established and that LARA and others should reside in small units with no more than three beds. I concluded that I could only protect LARA by making certain that she, and all of the developmentally disabled, would be safe within the State of New York. Only in that way could I die peacefully.

My activities were thought by some to be radical but I knew I was simply a father who was fulfilling his promise to his child. I kept pushing as the Chairman of Action Committee of the parent organization at Willowbrook (Benevolent Society for Retarded Children – BSRC). This was a life and death battle that we could not afford to lose.

I joined that movement to file a class action and became the first named individual plaintiff on LARA'S behalf, handled several law suits vindicating the rights of the developmentally disabled and other handicapped people, became the Vice Chairman of the Willowbrook Review Panel and more recently wrote a unique and compelling book about my experiences as parent, advocate and lawyer.

The Willowbrook Consent Judgment, in 1975, and its Willowbrook Review Panel brought an almost 40-year period of time that saw the establishment of a new system for delivering humane and appropriate services to the developmentally disabled in small community residential homes and services. What began as an experiment has become a wonderful conversion, from an archaic horrific system of warehousing human beings in large institutions, into the warmth and peacefulness

of a real home with all appropriate and necessary services. Such changes did not only elevate those whose rights we were seeking to vindicate but they also elevated their parents and family members and providers in the field.

For whatever reason, the government that originally brought us places like Willowbrook is now making major efforts to bring us back to the misery of institutions. It seems to me that the eminent New York Times, a newspaper that never seemed to fully support the developmentally disabled, is supporting this effort. Over the past year or so the NYT has published several articles praising and urging and supporting the opening of institutions. I refer you to the following articles and Op Eds that the NYT elected to publish: Joe Nocera Op Ed published January 24, 2014, entitled, **“For the Mentally Ill, It’s Worse”** seeking for “a humane hospital” because the State is not providing funding in the community; Liz Robbins’ article published January 29, 2015, entitled, **“For Special Care Residents, New York State Policy Means Leaving Home”** where a father extensively bemoans the closing of the Brooklyn Developmental Center where his son has suffered extensive abuse and became self-abusive/self-stimulating. The father’s sad ignorance is not addressed; Christine Montross, M.D. Op Ed published February 18, 2015, entitled, **“The Modern Asylum”** urges for the establishing of “modern asylums” modeled on residential facilities due to the fact that group homes have “undergone devastating budget cuts.”

The State of New York has recently failed and refused to develop and open new and additional small community residential homes and provide services. At the same time, every day additional handicapped babies are born who will continue the need for community residential homes and services. Every day additional parents having developmentally disabled children who are residing at home with them will get older. Many will reach the point where the parents are no longer able to provide such services to their children and some will die. Without new and additional small community residential homes and services where will the children (young and adult) be cared for? The answer is simple. If placements in small community residential homes are not available, the State of New York will house them “wherever.” “Wherever” will mean the use of underutilized or empty hospitals and nursing homes. That means, **“INSTITUTIONS.”** And they exist!

It is time to scream and demand that this insanity stops, now!!

Neither government agencies nor our politicians are listening or care about the pleas for fairness and decency. This is not a game. It is life and death and they are moving us to institutionalization for our developmentally disabled children, family members, friends and citizens.

With very good reason, I have never trusted the State of New York and its agencies allegedly established to oversee and protect the rights and interests of the developmentally disabled. From the time when my former wife and I were assured that, if we admitted our daughter into Willowbrook, services would be provided to

her; or to the threats to my child's welfare and safety because I was a vigorous advocate and leader of the parents organization; or to the State's vigorous defense mounted against the Willowbrook Class Action; or to the State's attitude that it could disregard the terms of the Willowbrook Consent Judgment it signed before the Federal Court and merely do business "as usual." Even after the Federal Court mandated that the State comply, it persisted in delaying tactics by objecting to almost all the recommendations made by the Willowbrook Review Panel and dragging its feet on implementation and, finally, did away with any Panel oversight by refusing to finance it. The current budget cuttings and the State's failure and refusal to fund and support the opening of new small community residential homes is **nothing new**. It is merely an old reaction to current budget concerns **DESPITE** empirical data that **institutions don't save the state any money**.

You can label these "Transformation Panel Forums" anything you want but they are designed to distract and redirect our energy. It is time to put pressure upon the State of New York, Governor Cuomo, the Department of Health, the Department of Social Services and the Office of People with Developmental Disabilities demanding that they strengthen the current system of small community residential homes and services. The goal must be to assure an appropriate residential placement for every developmentally disabled individual with the required and appropriate services. Beware of the fact that OPWDD has been stripped of its power and authority. Despite the fact that OPWDD has advanced these Transformation Panel Forums in truth, Governor Cuomo and his Department of Health will make all determinations. OPWDD is powerless and without any meaningful input

After almost 40 years of real advancement and benefits for the developmentally disabled where they are able to live good lives in the sweetness of a real home, I am unwilling to give up and see them returned to the hell of institutionalization.

It is time to unify and take real action and move toward another class action. Remember that the battle for the rights of the developmentally disabled and others in similar situations is a lifelong endless fight. We must be prepared to be realistic and truthful. We are thankful for the almost 40 years of peace and sanity but we will not quietly let it be taken away.

I urge you all to read my book, "I SEE YOUR FACE BEFORE ME" available on my website (www.murrayschneps.com) and visit my website and Facebook page. History is our greatest teacher.

It has been said that those who fail to learn the lessons of history are doomed to repeat them. We have lived and learned the lessons and must take immediate appropriate action.

Dated: September 29, 2015

s/ Murray B. Schneps
MURRAY B. SCHNEPS