

WILLOWBROOK MEMORIAL LECTURE – FINAL

Introduction:

Hello, everyone. Welcome. I hope this talk will be an enlightening and useful experience that stimulates a commitment to assure that we never go back to the neglect and abuse of the developmentally disabled. Forty years ago I witnessed that misery and am happy to say that the following thirty to forty years has seen tremendous growth. More importantly, we have seen a conversion from an institutional system to a system of small community residential homes and services in a single, not dual, system.

I am proud to say that I was part of that conversion as a parent, an advocate, an attorney vindicating the rights of the developmentally disabled, a plaintiff on behalf of my daughter, Lara, in the Willowbrook class action, and a member of the Willowbrook Review Panel - created by the Willowbrook Consent Judgment - and, also, its Vice Chairman.

Today, I no longer practice law and, at 78 years of age, my hope is to encourage, educate and support others to be advocates for the people who cannot advocate for themselves.

The Beginning:

On May 23, 1968, my daughter, my first child, Lara Rebecca Schneps was born at the Brooklyn Jewish Hospital. What was supposed to be a

wonderful and glorious day, instead turned the lives of my former wife and I upside down. The delivery was devastatingly slow and soon after Lara was born she turned blue and never developed beyond infancy.

In a few short months she began developing seizures and a series of tests both in and out of the hospital made it clear that our sweetheart, our darling would be profoundly mentally retarded. That was the characterization in those days. Now the acceptable term is “profoundly developmentally disabled.” Frankly, I always preferred using direct descriptive words that do not camouflage the truth. Nevertheless, some people are offended by the use of the term “mentally retarded” so I do not offend.

It was clear to my former wife and I that it was imperative for Lara to be provided every opportunity to receive services to help her live the best life she could. Our exhaustive research revealed a hard reality. They did not exist. The only place that promised any services was the Willowbrook State School. According to the brochures, it was offering real programs suitable for Lara in its new Children’s Therapy Center. The drawback was that Lara could not participate in any of the promised therapy programs unless she was admitted as a resident and lived there. The Children’s Therapy Center consisted of five building. Each building had four wards holding 50 babies

or young children each – that is 1,000 young children. The five buildings were situated in a large tract of land set out in a circle, resembling the spokes of a wheel. In the center of the circle of five buildings was the new Children’s Therapy Center. Each of the five buildings contained an indoor tunnel into the Therapy Center, eliminating weather as an issue.

In the 50s and 60s it was common for physicians and family members to advise parents of severely and profoundly developmentally disabled babies to “put them away” in institutions and “move on” with their lives. That idea was repugnant to us but our focus was getting services for Lara, so she could have the best life she could. It was all we could think about.

On July 31, 1969, we delivered Lara to Willowbrook. I still remember that dreadful day and act. We sucked up our guts and took what we thought to be the best move we could make for our child.

It’s funny the things that you focus on when you have a disabled baby. We concluded that the direct care staff in Building 14 took good care of our baby because she never suffered a diaper rash while residing at Willowbrook. I suppose that’s a rather narrow view of reality. The truth is that the “Children’s Therapy Center” offered no “therapy” that I was aware of. The baby complex was a cosmetic front for what it really was. It was a place to warehouse babies and young children with disabilities away from

the public eye. In that regard it was no different from the buildings warehousing the other five thousand souls at Willowbrook.

I firmly believe that all life needs to be nurtured to survive. Without human interaction and basic services life dies, bit by bit, day by day. Since Willowbrook never nurtured anyone, I concluded that it was, in fact, merely an institutional killing machine. You don't have to actively take the life of someone who needs help to survive; all you need to do is fail to provide the help. Death is the inevitable outcome and death became a persistent outcome at Willowbrook.

Willowbrook was a huge complex covering 375 acres of parkland. It was the largest institution for the developmentally disabled in the world. In spite of the fact that everyone knows that the least sophisticated people have difficulty dealing with large groups, the severely and profoundly developmentally disabled were forced into large residential facilities of 50 to 80 bunkmates per ward. Instinctively, anyone with common sense would know that plan was disastrous and shocking. An expert is not required to know that.

All of the walls were gray and the Ward was devoid of personal items be it paintings, pictures, toys or clothing. The floors were also gray, made of

hard, cold and filthy Terrazzo stone. The thousands disabled residents were forced to live in a state of deprivation and filth that was shocking to those who saw it first hand. It was a place to hide those folks who didn't measure up.

Geraldo Rivera lamented on his first live broadcast that his camera could only show so much: "This is what it looks like; this is what it sounds like but how can I tell you about the way it smells. It smelled of filth. It smelled of disease. And it smelled of death," he said. Terrazzo is a very hard surface, yet was penetrated by the un-G-dly smells. The smells were absorbed into every floor, wall and ceiling and, even, into your clothing. It is not something you'd ever forget.

Photos can be found in my book, "I See Your Face Before Me," or in your own Internet search of the Willowbrook State School.

It was originally named the Willowbrook State School. However, there were no meaningful educational programs and no one ever graduated from Willowbrook, except in a pine box. What is more important is that the State of New York never fulfilled its promise to the developmentally disabled or their parents, to develop a system of programs and therapies, or even to protect and provide an appropriate life for any of them. Rather, the State herded these poor people into huge institutions, hidden from the public

eye as if the developmentally disabled had communicable diseases, without adequate planning or funding.

Shockingly, the State of New York, in the guise of securing Federal Funds for the benefit of the developmentally disabled, utilized and transferred much of those funds into the general fund for general use and not for the developmentally disabled.

Curiously, the State exclusively selected psychiatrists to be Directors of institutions for the developmentally disabled. Selecting pediatricians to manage a place like Willowbrook made some sense, but no psychiatric services were provided to any of the residents. I concluded that psychiatrists were selected to manipulate and control the parents and direct care staff.

Many of the direct care staff were compassionate people who wanted to provide adequate care. Low pay, lack of training, inept support and crippling budget cuts, caused many to simply quit. Some just never returned to work. High turnover was an endless problem.

Few of the residents were capable of communicating complaints and often parents were afraid to make complaints on their behalf. At one point the budget cuts and resulting staffing shortage sparked a strike by direct care staff and its union. Because of the publicity provided by the daily TV programs, hundreds of volunteers flooded only the buildings of

Willowbrook to help care for the residents. It was an amazing sight seeing that many loving hands can transform and enliven the residents. This public awareness and resultant public response was only possible because Dr. Michael Wilkins, a dedicated and progressive doctor at Willowbrook invited Geraldo Rivera to shine his cameras into Willowbrook and the TV executives supported the daily coverage. This was before our Internet age and cell phone cameras; television coverage was pivotal in raising public awareness and public outrage.

The late 1960s and the early 1970s turned into a perfect storm to effect change. The Willowbrook Class Action lawsuit was designed and initiated by the NYCLU. Almost magically, the right people seemed to appear in one place and gathered to address the issues of Willowbrook. People like Bruce Ennis, Jim Clements, Michael Lottman, Linda Glenn, Vicki Schneps, Willie Mae Goodman, Malachy and Diana McCourt, Charlie and Connie Haney and others had similar views and were committed to making real and significant change in the treatment and care of the developmentally disabled. To them, warehousing and neglecting people in institutions was not acceptable.

The Willowbrook Class Action was filed on March 17, 1972. I was the first named individual as plaintiff on behalf of my daughter, Lara. In

early 1975, the litigation moved to the initial trial of the case. Until that time, the State of New York had dug its heels down deep and was committed to win-- in spite of the fact that the horrible conditions in Willowbrook were indefensible. Finally, in the early days of the trial, the State of New York determined it would lose badly and the embarrassing daily news stories would not diminish.

In June 1975, the State opted not to go to trial and agreed to much of the relief demanded in the Willowbrook Class Action. Both sides signed the Consent Judgment. However, I opposed one provision, which permitted the Legislature to refuse to fund the Willowbrook Review Panel without jeopardy to the Governor, or any State official named as a defendant in the case. I was not successful in getting the attorneys for the plaintiffs to eliminate that language. In 1980, that language was utilized to eliminate the Review Panel.

In spite of the Consent Judgment, the State of New York felt that parents would be quiet and compliant and business as usual would prevail. They did not view us seriously or believe we would be persistent. But they underestimated our commitment and for me, being tenacious was my most dominant attribute. When the State realized we would not simply fade away,

they moved to plan “B”- delay, delay, delay. That scheme was only partially successful; while it slowed progress down it could never halt it.

The State likes to take credit for closing Willowbrook and establishing small residential homes and apartments. The State is not entitled to such credit. Essentially, the State of New York made every effort to stop and delay our goals and the implementation of the steps, standards and procedures mandated by the Willowbrook Consent Judgment.

At the highly advertised Young Adult Institute International Convention, following the entry of the Willowbrook Consent Judgment, Sam Koala, an Associate Commissioner of OMRDD, boldly asserted that the Willowbrook Consent Judgment was an “aspirational document.” I attended that session as part of that panel and spoke immediately following Mr. Sam Koala. I disabused him and all in attendance of such baloney. I can assure you that at that time my words would have been hot. I was furious that a high level OMRDD official would denigrate the Willowbrook Consent Judgment soon after it was signed and ordered by the Federal Court and the ink was still moist.

Appendix “A” of the Willowbrook Consent Judgment consisted of the Steps, Standards and Procedures for implementation of the agreement both

sides had negotiated. It contained 29 single spaced pages and dealt with 23 areas. Every word, provision and page of the agreement was agreed to by all of the parties, executed by responsible and authorized representatives of each and presented to Federal District Judge, Orrin G. Judd, who also agreed to its contents. All the residents on the rolls of Willowbrook on March 17, 1972, the date of the filing of the class action complaint, became class members.

In order to assure that the provisions contained in the consent judgment would be implemented, the parties designed and set forth an independent panel. It became the "Willowbrook Review Panel." Without it, the agreement would have been toothless, and in my opinion, useless. The Review Panel was comprised of seven members - four selected by the plaintiffs' attorneys and three selected by the State. My selection as a Review Panel member was unanimous. With our naming of the other three plaintiffs' members, we were assured that all determinations made by the Review Panel would permit a four to three vote. And that actually occurred- although the defendants' member often voted with us. The other plaintiffs' members were James Clements, M.D., an expert, our Chairman, Linda Glenn and Michael S. Lottman, Esq. I was selected to be the Vice Chairman. The State's selected members of the Review Panel were Dr. William Bitner

of the State Education Department, David Rosen, an expert and Dr. Samuel Ornstein, of OMRDD, soon replaced by James Forde, of OMRDD.

The Review Panel met monthly in its office in the newly opened World Trade Center and I frequently communicated with the office and other members. We had the responsibility to oversee and implement all of the provisions of the Consent Judgment and had the power to prepare and issue to the State informal and formal recommendations guiding and instructing the State actions. Originally, the formal recommendation process required the Review Panel to issue a written formal recommendation. If the State opposed or refused, the Review Panel was required to submit a written application to the Court seeking an order from the Court directing compliance. With the first formal recommendation, the Review Panel and plaintiffs' counsel urged the Court to change the process. The Court agreed that the process needed to be altered and made additional directives: (1) all formal recommendations "made by the Review Panel are entitled to great weight;" (2) based upon the fact that the Review Panel is entitled to great weight, should the defendants' reject a formal recommendation, the State must file an application to the Court seeking an Order overcoming the formal recommendation.

Those directives reversed the burden of proof from being on the Review Panel to being on the State. This was an extraordinary turn of events where the Review Panel could control the implementation, monitoring and evaluating of progress.

The Willowbrook Review Panel understood its expanded power and utilized it for the benefit of all developmentally disabled persons residing in the State of New York. For example, all Class members were placed directly from institutions to community residences, not to other institutions, as we knew it would be more difficult to extricate them.

We were successful in preventing the opening of the newly constructed Bronx Development Center. And we were able to close the Hillcrest Unit within the Wassaic Developmental Center, where 18 young men were “imprisoned” and over medicated because they were deemed to behavior problems. As an aside, all but one of those young men were successfully placed in group homes.

Under the Community Placement, Section V, of the Appendix “A” of the Steps, Standards and Procedures it mandated that within six months the Willowbrook Review Panel would prepare and recommend for implementation a written Community Placement Plan. That Plan was prepared and recommended and approved of by the Court. The Community

Placement Plan converted the institutional system, a dual system between the haves, those who were mildly developmentally disabled living at home with their parents or in group homes (none of which at that time housed any severely or profoundly developmentally disabled people), and the have-nots those who were severely and profoundly retarded and resided in the institutional back wards in our State. That wasteful and destructive competition for funds kept programs and services at a low level.

The elimination of such self-defeating competition assured a long period of positive growth and advancement for the benefit of all developmentally disabled residing in the State of New York, not solely for the benefit of the members of the Willowbrook class members, and even extended to others in other states and nations that followed our lead.

Willowbrook was not the only victory. In 1978, I litigated the last successful class action on behalf of the developmentally disabled. They resided in a better-looking Willowbrook, but equally unsuitable large facility, the Suffolk Developmental Center located in Melville, Long Island. It had newer buildings and newer promises but was merely another large institution that could not deliver adequate care. In my opinion, Suffolk was worse than Willowbrook.

I don't know if you realize that even in 1978 parents were afraid to file a class action suit and even more terrified to testify to the fact that their children were neglected or abused. They were afraid of what would happen to their children. Where would they go? Until his or her own child was placed in a small community residence, a parent could not envision what a difference it could make.

It took a lot of cajoling and some arm-twisting to get parents to testify. But we convinced them that their children deserved their advocacy and they agreed to testify.

One parent testified that her child could speak but staff in the institution was unaware of that fact as the staff never asked him a question that elicited an answer.

Another father testified that after a few weeks in a group home his adult daughter made her own bed and dressed herself for the first time in her life. No one had bothered to teach her. "My daughter had become a woman," he testified. He was so proud of her! When he then testified to the difference the small home made in his daughter's life, I all but burst with pride.

Almost every large institution for the developmentally disabled in the State of New York has been closed and thousands have been appropriately

placed in small community residential homes with appropriate services.

Please keep in mind that institutionalization of the developmentally disabled in places like Willowbrook, actually cost more per person than the per person cost of similar persons residing in group homes or other small community residences. The erroneous belief that there is an economy in size (the bigger the cheaper) is wholly false. There is no economy in size relating to the care of the developmentally disabled.

Today, the State of New York through OPWDD sheds alligator tears imploring parents, family members, advocates and those in the field to participate with the spurious Transformation Panel and tell OPWDD what should be done to provide appropriate services to the developmentally disabled. Are they kidding me? Why are we reinventing the wheel? We need community placements and community services tailored to individual needs.

What Is And What Must Be:

Many people who are 60 years of age and younger may never have experienced a time when New York's developmentally disabled residents lacked appropriate small community residential homes and services. It has been a time of available homes and services and a forward view of continuing growth and development.

However, lately there has been a persistent change regarding the treatment, services and funding for the developmentally disabled. Funding for services has been reduced and funding for the opening of new small community residences has been all but eliminated. OPWDD insists that we does and will have a sufficient number of beds for those who are developmentally disabled. But how can this be if no new residences are being created and funding is being cut?

I believe it is a clear move toward eliminating our system of small community residential homes and services and moving back to the old destructive institutional system. Given the fact that the present number of appropriate small community residential beds is inadequate, and given the fact that each day new handicapped people are born, and given the fact that parents or family members presently providing residential care will themselves get older and incapable of providing care, where will these handicapped people be placed? Without the development of new small community residences the State will move those people into any available bed. That means the use of closed or underutilized hospitals or nursing homes. And that means institutions. **AGAIN! IT IS HAPPENING RIGHT NOW!**

Please understand that any residential facility for the developmentally disabled can be an institution irrespective of size. Of course, any 5,000-bed facility will be an institution, without question. Every such facility will share certain similarities like isolation and idleness. It is also true that a developmentally disabled person residing in a family home or group home can also suffer similar isolation and idleness where NO programs services are provided. It is also an institution. We need BOTH small residences AND services.

The State of New York is again attempting to keep us calm while OPWDD systematically is destroying the system of small community residential homes and services and re-establishing the institutional system -- bringing us back to the horrors of isolation, idleness and the concept of “out of view out of mind.”

Its Transformation Panel invited parents, family members, advocates and those in the field to bring ideas of how to provide residential and programmatic services. The scam is obvious: (1) OPWDD is not waiting for any answers from anyone and has initiated its goal to turn us back into an institutional system without adequate programs; and, (2) the Community Placement Plan worked wonderfully well since 1975 until the State destroyed it.

This is a time of fear and anger in our society and that also means that the developmentally disabled are not favored. In fact the developmentally disabled are viewed as dispensable. Society does not like our children. There, I said it and I am glad I did, because it is true.

When the world goes crazy and fears about things like money and “others” take hold, the developmentally disabled are targets. But do not duck. Stay together and work together. This is a new time and new strategies need to be developed. A recent article written by Thomas Friedman of the New York Times dated March 2, 2016, “Beware: Exploding Politics” wrote of a new approach and new politics being practiced these days. Today we need hybrid approaches and hybrid politics in order to successfully move ahead. Those who have relied upon political resolutions must work with those who relied upon litigation and create a new hybrid approach taking the best features from each and working side by side.

We are in a more conservative period. Clearly, the courts in this country, from the Supreme Court of the United States down through the Federal and State Courts, have become more and more conservative and less willing to vindicate the rights of the handicapped as well as other minorities. Conservatives urge us to let the State’s handle those issues. You may have

noticed that the State of New York and other States handle these matters by cutting funds and eliminating services to those who are the most needy.

What's the answer? Here's my advice:

1. everyone must vote in every election;
2. vote with your brain and heart by voting for your own best interests;
3. the best interests for those who are developmentally disabled

are best served with a liberal Supreme Court of the United States. A conservative majority of the Supreme Court will assure the fact that advocates will be unable to successfully bring new class action litigation on behalf of the developmentally disabled. The death of Justice Antonin Scalia has enlivened this battle.

Today, we are facing a daunting task not that different from what we faced in the late 1960s and early 1970s. However, in the 1960s and early 1970s we were not certain that we were correct, that our goals would ever be achieved and that we could deliver the anticipated high level of service we aspired to. Today we know that we were correct and the deterioration of our victories will feed our disappointments and even, further, to formulate a new hybrid approach with the ultimate goal of new class actions.

In some way this effort may be more difficult because society is not on the side of the handicapped and powerless and because it will be more difficult to demonstrate to the general populace that new institutions, though not looking horrifically like Willowbrook, will be as miserable and destructive as Willowbrook was.

Do not be discouraged, intimidated or dissuaded from your task. The battle is necessary. It can and will be won. We should not be surprised that we must fight and re-fight similar battles from time to time

Beware: “Those who fail to learn the lessons of history are doomed to repeat them.” This is a well-known quote from an unidentified person. While we are at it, I recommend that you read my book, “I See Your Face Before Me,” and visit my website www.murrayschneps.com where my book is available. I forewarn you that some of the pictures of Willowbrook in my book will be disturbing. Some of you will be unable to believe that handicapped people were forced to live in such deprivation. My goal as the aging witness to Willowbrook is to insure that it never happens again. I also invite you to visit my Facebook pages “Murray Schneps” and “I See Your Face Before Me.”

Copies of my book are available at the rear table for the cost of \$15.00, tax included.

Thank you all very much for your attention and time.