

“Lost in the Shadows: Willowbrook and the Era of Institutionalization”

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Willowbrook: Fulfilling the Promise

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George Santayana warned that "Those who cannot remember the past are condemned to repeat it." With this piece of wisdom in mind, I thought it would be worthwhile to visit the recent history that brought us to where we are today and to consider what lessons one might draw from experience that have relevance to the challenges we face now and in the future.

The historian David Rothman who, with his wife Sheila, authored the book *Willowbrook Wars*, had earlier written about the tension between conscience and convenience in the development and implementation of social policy in colonial times. It seems to me, as I look back over not only distant history but the more recent events that have occurred, that struggle between conscience and convenience is very much with us and continues to influence the development and implementation of policy today.

I would like to talk about this tension and the continuing challenge it presents in assuring quality of services through periods of change and upheaval. Along the way, I will digress briefly into international human rights law and the

status of people with mental and intellectual disabilities as a backdrop against which these evolutions were taking place.

One of the lessons that history teaches is that change is hard, even if it is for the better. Today, psychologists tell us that the process of change is so traumatic that people will often cling to the comfort of the status quo even though they don't like it. Change creates uncertainty. A familiar reality must be discarded before a new reality is in place. There is typically a period of confusion and disorder and resistance to change. And experience teaches us that change is not always for the better, so this caution is not misplaced.

(A word about language –I know we have struggled over the years to avoid hurting the sensibilities of people who are wounded by terminology and have gone from using terms like idiot and imbecile, to mentally defective, mentally retarded, developmentally disabled, intellectually disabled and to people first language. In this talk, I may be using old terminology in discussing past events. This is not done with any intention to hurt but simply to describe how these issues were perceived in the past.)

If one goes back into history, it is easy to see the idealism with which the first schools for the people with mental retardation were created in the 1850s. Their articulated purpose was to provide educational facilities to train residents to **participate** in society, to help bring people with mental retardation out of hiding and out of abandonment on the fringes of society—in basements and attics of private homes, or in the poor houses of Colonial America.

The first institutions that were developed in the mid-1800s were intended as an alternative to the almshouses and poor houses of Colonial America, where neglect, exploitation and abuse were rife. They were not intended as places of

confinement but rather were designed to habilitate those people who were able to be trained or educated and to return them into the communities from which they had come. The accounts of these institutions describe them as places in which residents were trained in vocational, social, educational and physical recreational skills and held various jobs at the facility until they were placed back into the community. When initially conceived, the institution was a great reform from the prevailing practices in the poor houses and alms houses. But the conscience – driven idea of a pastoral safe haven and a temporary refuge was strangled in its crib by the demands of convenience, which led to overcrowding, understaffing and the eventual abandonment of the inmates by society at large.

This conscience-driven reform soon ran into a host of practical problems. The reformers miscalculated how hard the task would be. They misunderstood the diverse nature of the population they had undertaken to serve. They misread the patience of the constituency groups whom they had sold on their reforms. And they soon became overwhelmed with the magnitude of the task, the paucity of resources and the scarcity of allies, especially in serving the large percentage of the institutional residents who were recent immigrants and the working poor. They learned firsthand the truth of the statement made by the Queen in Lewis Carroll's *Through the Looking Glass*: "It takes all the running you can do to keep in the same place... If you want to get someplace else, you must run at least twice as fast." But they couldn't, and the institutions born in such great promise soon became custodial warehouses. For many, one could truthfully have posted the caution from Dante's *Inferno* --"Abandon hope, all ye who enter here."

The advent of the eugenics era towards the end of the 19th and the beginning of the 20th centuries began to change the initial reform. The idea that people with

mental deficiencies would be temporarily housed in an institution, rehabilitated and then returned to the community was abandoned. Instead, a medical model was adopted in which the institution, under the direction of physicians, assumed total control over the lives of the residents. Aggressive efforts were made to identify and confine large numbers of people living at the margins of society, and to prevent them from reproducing. During this era we saw the advent of laws that permitted the incarceration of youth who were “morally depraved or in danger of becoming morally depraved.” Again, clinicians held vast discretion to identify those who would be locked up and sterilized. Not surprisingly, these laws were usually applied to the poor, the undereducated, and people with mental disabilities and it led to the practice of sterilization of large numbers of people to stamp out what were believed to be the seeds of deviance. Institutions became larger and more custodial and the population also changed, especially as they became dependent upon the labor of the residents to maintain the facilities and the farms which supported them. Once again, the demands of convenience, coupled with vast discretion conferred upon clinicians, shaped public policy and the lives of untold thousands who could not be released because the institution had grown dependent upon their unpaid labor.

For most of the next 100 years, even the professionals charged with providing services essentially abandoned any hope, especially when it came to the more severely and profoundly disabled residents. So completely was this group written off that even when, at the dawn of the New Deal, the Social Security Act of 1935 was enacted, it made no provisions for persons with mental handicaps. In many states, children with mental retardation were specifically excluded by law or

regulation from the benefits of the crippled children's provisions of the Social Security Act.

The stigma of disability and relegating people with disabilities to a lesser status as human beings was not a uniquely American experience but reflected a more universal attitude.

A theme that runs through history is that people with mental disabilities are among the most ignored groups when it comes to protection through law. It is my broad perspective that institutional systems, especially for mental illness and developmental disabilities, historically have existed or have regarded themselves as existing outside the rules of law, custom and practice that applies to most of the rest of medical practice and clinical care, and indeed that applies to most of the rest of society. In significant respects, the institutionalized populations in particular have lived outside the protection of the laws that protect everyone else-- and there is a long tradition of regarding them in this fashion. For example, enforcement of the penal laws rarely has extended into institutions where thefts, assaults, and rapes have routinely occurred, gone unreported, uninvestigated, unprosecuted and unpunished. The right that prisoners of war and convicted criminals have had to at least an hour a day of outdoor fresh air and exercise was not recognized and routinely denied in many institutions for people with mental disabilities across America. They are so ignored that even mainstream Human Rights organizations like HRW and Amnesty International have paid scant interest to what goes on in mental institutions all over the world. No prisoners of conscience there, although there are thousands, if not hundreds of thousands of people who are locked up, sometimes for life without any legal process whatsoever.

In preparing for this talk, I did some research and found that in the last century alone, there were 24 International Human Rights Conventions adopted by the international community.

A consistent theme in these Conventions is their concern with slavery, forced labor, exploitation of persons and the rights of disadvantaged and confined people like prisoners of war, women, children and racial minorities. What is interesting is that *none* of these Conventions adopted in the 20<sup>th</sup> century mentioned disability although people with disabilities have been subject to peonage and forced labor in institutions for most of the 20<sup>th</sup> century; they have had fewer rights than prisoners of war (fresh air); they've been subject to physical abuse and sexual exploitation; and to torture, and cruel and inhuman and degrading treatment such as ECT without anesthesia, the use of painful and noxious aversives, the misuse of restraints and seclusion for weeks and months at a time, including placement in cages, which have caused serious injuries and death. But none of these conditions which have existed in institutions all over the world caused them to be a subject of a human rights convention until 2006.

Perhaps the most important development in the area of human rights in the 20<sup>th</sup> century was the passage in 1948 of the Universal Declaration of Human Rights by the General Assembly of the United Nations. What is significant about this document is the word *Universal* –going to the core of the protection and respect that everyone is entitled to by virtue of their status as a human being. The UDHR contains sweeping language applicable to All and Everyone, with no explicit exceptions.

## Article 2.

*Everyone* is entitled to all the rights and freedoms set forth in this Declaration, without distinction of any kind, such as race, color, sex, language, religion, political or other opinion, national or social origin, property, birth or other status. \* \* \*

Despite the very progressive ideas embodied in the Universal Declaration of Human Rights, one must remember that it was a product of its time. One of the problems with the Universal Declaration of Human Rights was that, like other generic documents, many people and governments thought it could not possibly have been meant to apply to *everyone*, including people with disabilities.

As one example of the assumed exclusion of people with disabilities from generic protections, it is useful to recall other significant developments in the immediate aftermath of the Second World War. Among the many revelations that horrified the world were the stories that emerged about the experiments done by the Nazis and the Japanese on human beings, many of whom were POWs or other captives. As a reaction to these revelations, the Nuremberg Code of 1947 was adopted.

The first Principle in the Nuremberg Code reads:

“The *voluntary* consent of the human subject is absolutely essential. This means that the person involved should have legal *capacity to give consent*; should be so situated as to be able to exercise *free power of choice*, without the intervention of any element of force, fraud, deceit, duress, overreaching, or other alternative form of constraint or coercion; and should have

*sufficient knowledge and comprehension* of the elements of the subject matter involved as to enable him to make an understanding and enlightened decision.”

This, by the way, is the foundation of modern law of informed consent.

This essential human rights protection was ultimately incorporated into the International Covenant on Civil and Political Rights (1966), which is binding international law for the 152 states which have ratified it. Article 7 states: “No one shall be subjected to torture or cruel, inhuman or degrading treatment or punishment. In particular, *no one* shall be subjected without his free consent to medical or scientific experimentation.”

Notwithstanding this plain language, in the context of research protection, the widespread view in the research community apparently was that the Nuremberg Code of 1947 could not have meant to include people with mental disabilities. Thus, respected researchers in respected institutions continued to perform experiments at high levels of risk upon persons with mental impairments, without any consent at all, and to publish their findings and methods in respected journals with impunity.

The research conducted during the Second World War into malaria, dysentery and influenza frequently used residents of state institutions for the mentally ill and mentally retarded as their human subjects without any consent at all. But these are

not problems that occurred in distant places only. In Massachusetts, radiation experiments were conducted on institutionalized mentally retarded adolescents whose parents were misinformed about the nature of the experiments. They were fed radioactive iodine in their cereal, while their parents were told they were getting vitamins. In New York, residents of the Willowbrook State School were deliberately infected with live hepatitis virus while researchers misinformed their parents that they were receiving vaccines. The inducement for participation was transfer to the research wards which had better conditions than the general wards at Willowbrook.

Even during the recent surge of interest in the protection of vulnerable populations in human subject research, people with mental disabilities in institutions have been left out in the cold to fend for themselves. Thus, at present, the federal regulations governing human subject research have followed recommendations to implement special safeguards for children, pregnant women, and prisoners. However, despite repeated recommendations of three Presidential Commissions, at present convicted criminals have better recognition in law of their special vulnerability in human subject research due to institutionalization than do people institutionalized due to mental disability.

My point is that generic recognition of human rights for *all* people was insufficient to bring people with disabilities under the same umbrella because there

had been a long history in society of regarding them as a separate class, with separate and lesser human rights. *All did not mean All*. Separate but equal was not a good education policy; separate and unequal was disastrous to people with mental disabilities. So in succeeding years, as greater consciousness developed about the special problems being experienced by people with mental and physical disabilities, the United Nations adopted several new international declarations on their rights.

### *Rights of persons with Disabilities under International Law*

- 1971--UN Declaration of the Rights of Mentally Retarded Persons
- 1975--UN Declaration of the Rights of Disabled Persons
- 1991--UN Principles for the Protection of Persons with Mental Illness & the Improvement of Mental Health Care

Each of these added more specific provisions to the international recognition of the rights and vulnerabilities of people with disabilities. However, while the Conventions to which I referred earlier are binding international law and enforceable in several ways, and the Universal Declaration of Human Rights is also considered binding law, these Declarations that deal more specifically with people with disabilities are neither binding law nor enforceable. That's not the only problem with them.

While, for example, the Declaration of the Rights of Mentally Retarded Persons was a very progressive document for its time in recognizing that people with mental retardation had any rights at all (recall that this was the time when states like New York, Pennsylvania and Alabama were busy defending the conditions at institutions like Willowbrook, Pennhurst and Partlow), it is nevertheless a limited recognition. After enumerating that people with mental retardation have many of the same rights as spelled out in the Universal Declaration of Human Rights, *this* Declaration says in its final paragraph:

“Whenever mentally retarded persons are unable, because of the severity of their handicap, to exercise all their rights in a meaningful way or *it should become necessary to restrict or deny some or all of these rights*, the procedure used for that restriction or denial of rights must contain proper legal safeguards against every form of abuse. This procedure must be based on an evaluation of the social capability of the mentally retarded person *by qualified experts* and must be subject to periodic review and to the right of appeal to higher authorities.”

This final paragraph focused not on the *substance* of the individual rights that were being recognized, but on the *procedures* by which they could be denied. So, in essence, these rights, unenforceable as they were, could still be limited based

on vague standards applied by unspecified experts –no doubt experts of the kind who worked in institutions like Willowbrook and Pennhurst, and helped defend their conditions against legal challenges. And the appeal to higher authorities was likely to the people who hired them in the first place.

The history of Willowbrook fairly well captures much of the modern struggle of conscience and convenience in providing for the care of persons with mental retardation. The planning for this facility began in the mid-1940s. It was not an auspicious start. As soon as the facility was ready, the intended beneficiaries were displaced by returning war veterans. It was not until 1951 that it became the Willowbrook State School for the Mentally Retarded. Its original capacity was 2,950 but by 1963 it had over 6,000 residents.

Many think that Geraldo Rivera's TV exposé in the early 1970s blew the whistle on the shocking conditions of human abandonment in Willowbrook. The harsher truth is that these conditions were well know and well documented for years, but conscience could not overcome the convenience that permitted them to endure.

In 1964, prodded by complaints from parents, Senator William Conklin -- who would later champion the cause of a separate Department of Mental

Retardation -- toured Willowbrook and publicly reported on the vile stench and the crude way of life of the residents.

In 1965, there were several violent deaths and a grand jury investigation. Senator Robert Kennedy made an unannounced visit and reported that "the wards were less comfortable and cheerful than the cages in which we put animals in a zoo."

NY was not unique. Willowbrook was typical of other large institutions like Pennhurst in PA, Partlow in AL, Forest Haven in DC, Pineland in ME and other similar facilities in other states that also became targets for institution reform lawsuits.

Yet, the state policy throughout the 60s continued to neglect the needs of the residents. One must remember that for much of this time, the State was on a spending binge -- building the Albany Plaza, several SUNY campuses, new state institutions for the mentally ill and mentally retarded. In fact, there was so much construction going on that people joked that Governor Rockefeller had an Edifice Complex! If one looks only at dollars and cents, millions were spent on mental health and mentally retardation, mostly on the construction of institutions. The construction trades unions were delighted. But there was little provided to operate these institutions or to care for their residents. The political force -- the drive of

convenience -- was behind the construction of institutions, not the care of the residents. One illustration -- in 1965, Willowbrook had 59 nurses for 6,000 residents, and 114 vacancies for nurses! The parents' calls of conscience -- continually complaining about injuries, malnutrition and even death --were lonely voices in the wilderness.

The political support for these institutions was weak, with the result that they did not fare well in the competition for allocation of fiscal resources by the executive and legislative branches of government. In part, as an attempt to improve these conditions, professional organizations began to develop standards to create expectations for the quality of services in these institutions. In 1964, the American Association on Mental Deficiency (AAMD) published *Standards for State Residential Facilities for the Mentally Retarded*. The AAMD was the major organization of persons working in the field of mental retardation and many, if not most superintendents of institutions belonged to the organization. In its Preface to the standards, the AAMD stated that the institutions could “not offer much more than the barest level of existence,” that they had a “tradition of neglect,” and that “conditions, even at the best of state institutions, were far too low.” The standards articulated by the AAMD were its attempt to formalize uniform guidelines for the operation of state residential institutions, which had never been done before in the United States. The standards – developed over a

several year period based on the experience and consensual judgments of panels of experts and practitioners in the field – were intended to be attainable by all state institutions within a 5 – 10 year period. The standards were aspirational and served as an advocacy tool for the state superintendents to help them in their annual budget battles to obtain more resources for their overcrowded, understaffed and under-resourced institutions.

In 1971, NY like many other states, had a budget problem. There was a hiring freeze and DMH facilities lost 5,000 positions in one year. Willowbrook lost 22% of its staff, leaving it with 912 staff for 6,000 residents. With pervasive neglect at the highest levels of government, it is possible to understand why life on the wards would be portraits of abandonment -- children in strait jackets or naked, rolling on the floors in feces, entire wards without furniture. On some wards, only the staff were clothed. The institution, which had been the reform, was what residents now had to be protected from. The few professional staff who tried to advocate for more resources faced ostracism, retaliation and dismissal. Their only allies were parents.

**(Show Video “The Last Great Disgrace”)**

And the parents and NYSARC decided that, having failed to move the legislative and executive branches, they would seek the intervention of the

judiciary. The Willowbrook lawsuit was filed. And the rest, as they say, is history which you will hear in more detail about from the panels which follow.

The deinstitutionalization movement which began in the 1970s with a series of class-action lawsuits across the country prompted by the wretched conditions into which institutions had fallen, eventually lead to the erosion of the medical model and its replacement with a rehabilitative model, but clinical professionals were still very much in charge of the lives of people in institutions and in the fledgling community programs being created. The values espoused were *freedom and normalization*. But convenience raised its ugly head and soon the normalized group homes created by parent and family organizations like NYSARC, were converted into Medicaid reimbursable ICF/MRs, often subjecting them to regulations which were anything but normalizing and greatly inflated their operating costs.

The most recent development, beginning in the late 1980s and 90s, with the passage of the Americans with Disabilities act, the Fair Housing Amendments, the HCBW, the Supreme Court decision in Olmstead and the subsequent implementing policies of the federal government, all emphasize *equal rights and full participation*.

In this broad sweep of time, it has only been relatively recently that self-advocacy, self-determination, consumer empowerment and choice have been values that have been recognized in public policy, but again, there has not been much explicit discussion of these values or how they are operationalized in daily practice or balanced against other competing interests. And it is here that the familiar tug between conscience and convenience, continues to play itself out.

There are many challenges that the panels will address later today. One that I would like to touch on briefly is protection from harm, the constitutional underpinning of the Willowbrook lawsuit.

Over the past four decades, we invested massive resources in developing quality standards for institutional programs and later for ICF's and other types of licensed community residences. But there has been a growing trend to placing people into unlicensed and uncertified settings, especially in efforts to comply with the ADA, *Olmstead* and the Medicaid waiver. The intention is good and motivated by a desire to allow people to live in the community in normal settings – in their own homes, apartments, or shared living. But this good intention also creates a new challenge and is also subject to the demands of convenience.

Traditionally, responsibility for safety, incident reporting, investigations and corrective action were placed with the custodian institutions. In the first wave of

deinstitutionalization, these responsibilities migrated to the community and obligations were often transferred to licensed community programs. Now as we move away from licensed settings to independent living, we are dealing with a very different world.

In the community, provider agencies may be part of a different human service system with different standards and expectations –board and care homes, foster care, assisted living or housing.

Moreover, many of the community provider agencies have been undergoing consolidations to achieve economies and are increasingly serving multiple and different population groups and often have funding and regulatory mandates from different government agencies –which are often inconsistent with one another. For some, there is no longer any clear locus of responsibility for assuring safety of people living in these unlicensed settings.

- i. No clear obligation for reporting, no clarity about where to report;
- ii. No clear responsibility for investigation, no clear authority to investigate, and inadequate tools to respond.
- iii. Misunderstanding of the balance between autonomy and protection, no clear guidance on when to intervene and offer protection --case managers and other staff need to be trained far more than they are to exercise good judgment and need a universal

code of ethics and training on how to live it. (CQC highlighted this issue almost 20 years ago at a conference on Choice & Responsibility)

- iv. Often, harm results not from staff actions but decisions of the individual himself --from uninformed choices, exposure to financial or sexual exploitation by roommates, community "friends" and others they encounter.
- v. The generic safety net outside licensed and certified facilities is Adult Protective Services --but this is an area where APS admittedly is unprepared to respond --it is often weak and ineffective, with little or no federal standards or financial support (compare child abuse). APS has no crisis resources of its own and the service systems that do, generally do not have effective working relationships with APS.

This situation presents a huge challenge to all of us who support the policy of community living. The highly visible failures that are being experienced in some places around the country are being used to push back against efforts to close unnecessary institutional beds, as if the solution for the public policy failures is to continue to confine the victims. It is therefore incumbent upon us to become

engaged in honestly examining and correcting the defects in public policy that permit such failures to occur.

In my experience, the shift from acting on conscience to acquiescing in the demands of convenience is rarely marked by a precipice from which one chooses to jump into the abyss. It is more often measured in small and seemingly insignificant steps down a slope when no one but you is aware you are taking the steps. There, alone with your conscience, in that small place, you must decide where you stand in protecting human rights of people with disabilities.

The real lesson that one draws from history is that the job of advocacy is never done. The same persistence and the same vigilance that many demonstrated through the dark days of Willowbrook are still needed. In some ways, the job of advocacy is more difficult. Usually, there is no stark horror like Willowbrook that could easily galvanize even the most stone-hearted person. The evil is more likely the unstated acceptance of a lesser status of citizenship, a lesser scope of human rights and ultimately, a lesser standing as a human being before the law and in society for people with disabilities. In my report to Governor Cuomo, I wrote about the four pillars of the safety net. But there is no safety net that can bear the weight of human indifference.

In closing, I will leave you with the words of Eleanor Roosevelt, who spent many years here in NY, and then played a critical role in the process leading up to the United Nations' adoption of the Universal Declaration of Human Rights. She said:

"Where, after all, do universal human rights begin? In small places, close to home - so close and so small that they cannot be seen on any maps of the world. Yet they are the world of the individual person; the neighborhood he lives in; the school or college he attends; the factory, farm, or office where he works. Such are the places where every man, woman, and child seeks equal justice, equal opportunity, equal dignity without discrimination. Unless these rights have meaning there, they have little meaning anywhere. Without concerted citizen action to uphold them close to home, we shall look in vain for progress in the larger world."

Thank you.