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HOW THE WILLOWBROOK CONSENT DECREE HAS INFLUENCED CONTEMPORARY ADVOCACY OF INDIVIDUALS WITH DISABILITIES

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WILLOWBROOK INFLUENCE ON CONTEMPORARY ADVOCACY

**HOW THE WILLOWBROOK CONSENT DECREE HAS INFLUENCED
CONTEMPORARY ADVOCACY OF INDIVIDUALS WITH DISABILITIES**

by

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B.A., Psychology City University New York, College of Staten Island, 2007

**A master's thesis submitted to the Graduate Faculty in Liberal Studies in
satisfaction of the requirements for the degree of Master of Arts, The City
University of New York, College of Staten Island**

2017

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Individuals with Disabilities**

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**This thesis has been read and accepted for the Graduate Faculty in Liberal Studies
in satisfaction of the thesis requirement for the degree of Master of Arts.**

Date

**Professor Edward F. Meehan, PhD
Thesis Advisor**

Date

**Professor Ismael Garcia-Colon, PhD
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Thesis Abstract**How the Willowbrook Consent Decree Has Influenced Contemporary Advocacy of
Individuals with Disabilities**

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Advisor: Edward F. Meehan

The existence of the Willowbrook State School was a culmination, of over a one-hundred-year history of Western society's attempts to provide adequate care, and treatment for individuals with disabilities. The residents housed there, suffered violations of their human and civil rights in various forms of severe abuse, neglect, and violence. Following a three-year legal battle in 1975, as a result of the travesties that occurred, the legal doctrine known as the Willowbrook Consent Decree was written. The Consent Decree was implemented to ensure that the residents' human and civil rights are met and protected. The Willowbrook State School and the Willowbrook Consent Decree have both positively influenced contemporary advocacy for individuals with disabilities, as models of failure and mistreatment and correction of these grave errors.

Keywords: Willowbrook State School, disabilities, institutions, advocacy, human rights

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The Willowbrook State School and the Willowbrook Consent Decree

In conjunction with constitutional rights and several federal laws, the Willowbrook Consent Decree has had a significant impact on the lives of individuals with Intellectual disabilities. Since its inception, the Willowbrook Consent Decree has provided the patients who resided at the Willowbrook State School the previously unattainable opportunity to live and thrive in their communities. It is an unfortunate truth that it took society to recognize this as a societal problem that needed to be addressed by community inclusion and not to be hidden away.

The Willowbrook Consent Decree was a court -mandated order that was signed on April 30th, 1975, by Judge Orinn G. Judd. It enforced the constitutional rights of the residents of the Willowbrook State School, to live in the least restrictive environment possible and to receive free appropriate education. It had mandated that all but approximately 250 out of its 5,400 residents to be integrated into their communities by its expiration date in 1981. A consent decree was chosen, as it was thought to be the most expeditious legal route to resolve the atrocities that been scandalously addressed, to the public by Senator Kennedy in 1965 and investigative reporter Geraldo Rivera's televised expose in 1972.

A review of the history of the 20th century shows the effect that numerous civil rights movements had in transforming and molding our society to meet everyone's needs; naturally including individuals with disabilities. However, despite presidential efforts to enforce equal opportunity and rights to individuals with intellectual disabilities, the Willowbrook State School seemed to remain immune to these changes.

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As they say, truth is stranger than fiction, and the events and circumstances that perpetuated the existence, and finally the ultimate closure, of the Willowbrook State School, confirms the idiom. The Willowbrook State School was located in what is referred to as “The Forgotten Borough” of New York City, Staten Island. Staten Island would remain a rural and relatively isolated locale, until the Verrazano Bridge was completed in 1964. Staten Island was similar to other islands that surround the perimeter of Manhattan Island, as they also housed institutions. Willowbrook was one of the most notorious institutions that housed a spectrum of patients. It is unfortunate that the institutions throughout New York City were not the only places where patients were treated horrifically. However, the Willowbrook State School was highly instrumental in the deinstitutionalization revolution and in the care of individuals with disabilities. It most importantly spurred a fight for their rights as human beings and the passing of the Willowbrook Consent Decree and eventually the Americans with Disabilities Act.

When studying the history of places and events it is easy to place judgment by using our “contemporary standards” as a justification that we are progressing and moving forward. However, it is in the act of looking back and seeing where we’ve come from to know how effectively we have adjusted and continue to improve our future. This brings to mind a vital question: how was the Willowbrook State School instrumental in the normalization, centralization and deinstitutionalization of individuals with intellectual disabilities? Also, how does the Willowbrook Consent Decree continue to impact individuals with intellectual disabilities today?

Throughout this paper I will review the history of the institutions and define the criteria for residency, as well as the standards of living and treatment of the patients. I

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will discuss the following questions: What was the process that dictated that these individuals reside at these institutions? Were these processes governmentally mandated? In addition, I will briefly discuss the academic and medical standards of care that were in place for the residents in these institutions as well the standards set for effective community living. I will address the role that the Willowbrook State School had in the implementation of the Federal and State legislations as a case in point of the unavoidable gravity of the processes of the centralization of institutions and eventual deinstitutionalization.

What can we learn from the Willowbrook Consent Decree is that all individuals with intellectual disabilities have the same rights as all members of society. What can the inescapable truth of learning from the past and advocating for change in the future teach us about the impact of centralization within institutions? How did these events and their subsequent consequences influence the public's awareness and ultimately affect those who were directly involved? Finally, this paper will investigate if the efforts to reach normalization have been effective.

Methodology

I will be conducting my research by implementing scholarly journals and books that discuss historical, sociological and political facets of the events that resulted in the Willowbrook Consent Decree and the significant role of advocacy. In addition, I will review primary sources including video documentaries of Geraldo Rivera's "Expose of the Willowbrook School" as well as contemporaneous newspaper articles. I will further utilize my academic, voluntary and employment experience as a Student Intern through the College of Staten Island while working with consumers of the Multiple Disabilities Unit (MDU) of the Staten Island Developmental Disabilities Service Office (SIDDSO): The Office of People with Developmental Disabilities (OPWDD), as well as my employment experience as a Medicaid Service Coordinator.

My aim will be to analyze the history of the impact upon communal living and self-advocacy that the Willowbrook Consent Decree has had on people with intellectual disabilities. I will address this by discussing the events that triggered the bureaucratic avalanche of the centralization movement and the countless closures of institutions throughout the nation. An examination of the societal repercussions that triggered these events will be evidenced by the significant role the media and politics had played in facilitating the revolution in the care for individuals with intellectual disabilities.

These questions are to address the process of acknowledging that change was necessary, ultimately noting how this civil rights movement was unique. What was the significance of this period of time that results in the unfolding of these events, which resulted in the apex of deinstitutionalization? What were the repercussions of Geraldo Rivera's "Expose of Willowbrook State School"? Last but most significantly, I will

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explore how this movement has impacted contemporary advocacy and how the past forty years since the Willowbrook Consent Decree was implemented, and had impacted people with intellectual disabilities. Has there been effective change in manifesting equality for people with intellectual disabilities; or does social inclusion continue to act as a veil that masks the perpetuation of discrimination?

My investigation will be to analyze how the events that led to the execution of the Willowbrook Consent Decree and laws such as the Rehabilitation Act of 1973 have impacted the entire nation, and furthermore how these laws continue to influence advocacy and what improvements still need be addressed.

Annotated Bibliography:

Bly, N. (1887). *Ten Days in the Madhouse* (Kindle DX version). Retrieved from Amazon.com

Braddock, D.L. & Parrish, S. L. (2001) "An Institutional History of Disability." *Handbook of Disability Studies*. Ed. Albrecht, Gary, L., Katherine D. Seelman, and Michael Bury. London, England, Sage. Web. 2001 11-68

This chapter discusses the history of the identification of disabled persons and how ancient to modern societies addressed people with mental or physical impairments. As well as further discussion of the Theory of Evolution which led to Social Darwinism which resulted in the study of Eugenics and what was deemed to be worthy hereditary factors to pass on to offspring.

Buechler, S.M. (2011) *Understanding Social Movements: Theories from the Classical Era to the Present*. Boulder, CO Paradigm Publishers. Print.

This book presents how social movements create change by propelling paradigm shifts in collective consciousness. Examples from the turn of the century through the 1990's are analyzed.

Carabello, B., Wilkins, M., Rivera, G, & College of Staten Island. Library Media Services. (2006). *Willowbrook the last disgrace - twenty-five years later*.

Nationally broadcasted expose on WABC in 1972 by Geraldo Rivera that was edited into a documentary demonstrating the conditions at the Willowbrook State School before and after political intervention.

D'Antonio, M. (2004) *The State Boys Rebellion*. New York: Simon and Schuster.

This source speaks about the medical mistreatment and mismanagement of the students and residences at the Willowbrook State School and how it tragically led to the death of many residents.

Data Research, INC. (1994) *Rehabilitation Act. Statutes, Regulations and Case Law Protecting Individuals with Disabilities*.

This book is a reference to the Rehabilitation Act of 1973. It provides the details as written in the law protecting the rights of disabled Americans.

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Gelb, J. & Palley, M.L. (1971) *The Politics of Social Change: A Reader for the Seventies*. New York, NY, Holt, Rinehart and Winston, Inc,

This book shows what the political climate was like before the travesties that were occurring at Willowbrook were exposed in 1972. This source indicates the political motivations of the time and what had been deemed as important for social change.

Goffman, E. (1961) *Asylums. Essays on the Social Situation of Mental Patients and Other Inmates*. United States, Anchor Books. Print

Goffman explains the sociological theory of the Total Institution. Explaining the environment and how people functioned within these systems.

Gould, S.J. (1981) *The Mismeasure of Man*. New York: W.W. Norton and Company. Print.

This book deals with testing of the students that were mandated in to the state schools. This was to measure their mental function and attached specific vices to this functionality.

Goode, D., Hill, D. & Reiss, J. (2013) *History and Sociology of the Willowbrook State School*. United States of America: American Association on Intellectual and Developmental Disabilities

This book contains countless interviews of Willowbrook State School residents and their families. These are primary sources in the words of those who were directly and indirectly affected by the institution.

Milza, J. (2012, February 12). Recipe for Success. *Staten Island Advance (NY)*. Retrieved from

<http://infoweb.newsbank.com/resources/doc/nb/news/13CE60CE87024408?p=NewsBank>

This article discusses On Your Mark's Choice's Café: a voluntary agency's community service that provides employment and community inclusion opportunities to people with Intellectual disabilities.

Myers, J.E., Sweeney, T.J., & White, V.E. (2002). Advocacy for Counseling and Counselors: A Professional Imperative. *Ebsco Journal of Counseling & Development (Fall 2002)*: 397-402. Web.

This article discusses the necessity of advocating as a major facet of a counselor's occupation as well as for specific clients. It emphasizes the need for counselors to be ambassadors for social change.

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Penny, D. & Statney, P. (2008) *The Lives They Left Behind: Suitcases From the State Hospital Attic*. New York, Bellevue Literary Press. Web.

This book addresses the deplorable conditions at the Willowbrook State School that resulted in severe illnesses and death. It shows how the Willowbrook State School served as an example of the necessity for immediate change to occur in the operations of the institutions.

Roberts, S.V. (1986, January 2) The Art of Public-Interest Lobbying *The New York Times* *Ebsco*. Web. 29 Aug. 2015.

This article discusses how the Advocacy Institute organizes and trains people and groups to effectively advocate for important issues.

Rothman, D. J. & Rothman, S.M. (2005) *The Willowbrook Wars: Bringing the Mentally Disabled into the Community*. New York, Transaction Publishers. Print

This book is about the legal battle faced when attempting to return the residents of the closing Willowbrook State School to the community. As well as developing a new bureaucratic process to address the needs of this population.

Trent, J.W. (1994) *Inventing the Feeble Mind: A History of Mental Retardation of the United States*. Los Angeles: University of California Press. Print.

This book addresses the state mandate of those who were considered “feeble minded” or “mad”, into state schools. It speaks about how those who were cared about at home were taken out of their homes and placed into state school.

Wolfenberger, W. (1972) *The Principle of Normalization in Human Services in Human Services*. Toronto, Canada: National Institute of Mental Retardation. Print

This source discusses the archaic and religious ways people viewed the mentally disabled. It speaks volumes of why specific populations were mistreated for such a long period of time.

Literature Review

The literature regarding the Willowbrook State School, states the horrific environment that its residents who lived there were subjected to. It had been among numerous institutions throughout the United States and Europe that housed those who were deemed a “social problem”. These places, which were first constructed to help the sick and mentally ill, soon became a catchall place for a spectrum of people, including those who were deemed burdens or troublesome to society. In Nellie Bly’s “Ten Days in the Madhouse”, she goes undercover as an investigative reporter to demonstrate how minimal the official protocol and insufficient was the scientific/medical evidence required for admission into the asylum. She wrote the story as an expose of the tribulations and pitfalls that anyone could potentially fall victim to.

A similar message can be heard in Geraldo Rivera’s expose, the purpose of which was to show the public how those who were being hidden away in Willowbrook were being neglected. The Willowbrook Consent Decree culminated from the conclusive evidence that was provided as testimony as well as the subsequent first- hand observation by Judge Judd of the United States Eastern District Court of New York, which detailed the horrific environment. The Consent Decree was implemented to close Willowbrook as well as to provide and grant the residents their constitutional rights.

It has been noted in “A History and Sociology of the Willowbrook State School” (Goode, Hill, Reiss & Bronston) that it and “The Willowbrook Wars” (Rothman & Rothman) are the only two academic books written on the subject of Willowbrook State School. There are however several newspaper articles, scholarly articles and a couple of documentaries. These authors are puzzled by this fact and urge the academic community

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and the public to conduct more research and to be aware of The Willowbrook State School's history and impact on American society. These books are written to ensure that The Willowbrook State School's story is not forgotten. Many academic books have been written about institutionalization and life in an asylum, Irving Goffman explains "Total Institution" in *Asylums*. "Asylums: Essays on the Social Situation of Mental Patients and other Inmates"

Scholarly articles in the fields of Social Work and Sociology attest that Willowbrook has been integral in the history of Disabilities Studies and advocacy, including self-advocacy for those with disabilities. The timeline of The Willowbrook State School's impact is not explicitly detailed; but there is evidence for said impact as a result of the scandals that occurred and by virtue of the Willowbrook Consent Decree that facilitated New York State's community-based living as a model for other states across the nation.

Importance

As the adage goes those who do not learn from history are doomed to repeat it and it is equally important to understand all aspects of our society, as our history is overshadowed and forgotten if we ignore the past. It is vital and necessary for all of us to actively practice our civil duty. It could be assumed that typically the events that surround the learned histories are abstract and far removed from our “possible realities”. This history and many others should and need to be heeded as these travesties can happen again at any time if we are not diligent in ensuring that civil rights for all continue to be observed.

Understanding the asylum culture and the events that led to world-wide deinstitutionalization is imperative as we are all connected to the unfortunate souls who lived and experienced the horrors of the institutions. We are forever indebted to them for their bravery and survival. They unwillingly participated in horrific experiments that exposed them to terrible diseases and deadly living conditions which “fortunately” resulted in saving lives. It is vital to remember all of the patients who had inhabited the asylums during their existence. For those who were fortunate enough to be released to their families, as well as those who unfortunately had no family to go to after its closure, they must all be remembered for they have impacted our global society more than we realize.

While the closing of the Willowbrook State School politically resulted in the Willowbrook Consent Decree, in the late 1980's the campus was closed and was eventually renovated and converted in 1993 to the present day College of Staten Island (CSI) of the City University of New York (CUNY). It must never be forgotten

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Willowbrook was a place of unimaginable despair and horrors that unlike the truths that exist in most horror movies and urban legends the events that occurred there were quite within the bounds of reality. It then begs the question of how aware our society is today of these events. Grade school students learn about the recent past of distant World Wars and the Holocaust and touch on the civil rights movements, but do they know how these events impact their lives today? These simple truths that are vital to our everyday lives that we take for granted? Given that there are multiple academic disciplines that have stakes in Willowbrook, I will explore how well known is its true history.

Treatment of the “disabled” from the 18th Century through 1940

The American Civil and Human Rights movements have been arduous, segregated journeys, of an elusive history that is ever evolving. This history has frequently changed things sometimes for the better and other times for the worse. As a result of various reforms, both the well-meaning and tragic methods that people have implemented, have led to specific individuals being confined within institutions, as well as horrifically, by genocides. It is a history that has been facilitated by many catalysts within American society, and their attempts to care for and meet the needs of people with all cognitive and physical abilities and needs. It is an awful truth that our collective understanding and assumptions morph in the realm of addressing the grave errors in the specificities and sometimes administration of our Constitutional Rights. One specific example of addressing the needs of the people, is the infamous the Willowbrook State School and the resulting Willowbrook Consent Decree.

The historical parallels of these legal landmarks and the advocates for those with varying abilities, with perceived limitations categorized as disabilities, will be the focus of this chapter. This will be an effort to provide a foundation to understanding the legal battle that led to the existence and demise of the Willowbrook State School (WSS) and the initiation of the Willowbrook Consent Decree. The Willowbrook Consent Decree has had a significant effect on the advocacy for individuals with intellectual disabilities, formerly known as developmental disabilities and their lives. This Decree was a legal triumph that facilitated the close of the Willowbrook State School. (Goode, 2013, p. 16). The chain reaction over the past forty years will be discussed in the subsequent chapters.

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The social sciences use formal classifications to identify various stages or identities depending, on our own life stage as: children, adolescents, students, parents, employees, employers, etc. However, these labels, identifiers and names, are themselves irrelevant in reference to their existence of how rights are granted to people in our societies (Foucault, 1961, p. 18). As one of the most famous poetic lines from *Romeo and Juliet* teaches, "What's in a name? That which we call a rose by any other name would smell as sweet" (Shakespeare, p. 26). This statement about the rose is more than a romantic analogy. It is a lesson in learning how foolishness, selfishness and ignorance lead to tragedy.

The play can be an analogy for what a person is identified as, could mean life or death and/or having rights or being institutionalized. For Romeo and Juliet, their names meant life or death in the world of their feuding families. In the same way for the disabled, they are victims of their feuding governing authorities. As a result, the innocent has no recourse when they are at the mercy of an ignorant authority. It raises an integral moral question and bursts a necessary bubble demonstrating that a person is not merely what they are labeled.

A review of this history will most assuredly provide evidence of both the tragic truths of the varying degrees of abuse and neglect of those whom society has deemed "undesirable". The truly horrific fact is that throughout this history, these basic human needs have been overlooked, and at times blatantly denied or simply ignored. The only fact that is true is that we are all human and we all require basic human needs such as food, compassion, and shelter. These facts and histories go hand in hand with the advocates and crusaders of justice who strive for such public awareness.

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The contemporary vague “umbrella term” of “Intellectual Disabilities”, as its own discipline and subsequently having its own encyclopedia of terminology, like all areas of study, is ever evolving (Goode, 2013, p 16). Both successful advocating for those who do not fit the “normal” intellectual functioning, and require an environment that is fluid and can adjust to their needs, will be discussed, as well as when advocating had been unsuccessful. Michael Foucault (1988) explains various theories and histories in his book, *Madness and Civilization: A History of Insanity in the Age of Reason* of modern European societies and their attempt to address people who have specific or perceived characteristics that are “not normal”. Throughout our society’s history, finding the most effective practices to care for all people with dignity and respect has proven to be a great challenge. Regardless of all this information, the collective consensus is that no one has the right answer (Chesterton, 1927, p. 39).

There is significant historical evidence throughout American history, that the classifications “unwanted” and “unfit” (Sanger, 1922, p. 81 & p. 279), have been used to demonstrate how our collective society has been shunning or hiding away their citizens, known contemporaneously as the disabled (Goode, 2013, p. 48). Additionally, many people in our history with various capacities have had the dismay of possessing and/or being imprisoned by copious identifiers that, only until very recently have displayed a hint of humanity. It is deeply saddening that those individuals with intellectual disabilities, only until recently were labeled as idiots, imbeciles, feebleminded, lunatics, morons, mentally deficient, mentally retarded, inmates, patients, consumers, clients, and residents (Goffman, 1961, xi; Goode, 2013, p.14-15; Scheinfeld, 1961, p. 236). They are

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only recently beginning to be viewed and addressed as who they and have always been; people and individuals, just like all of us.

What was the social and political climate of Willowbrook?

The Willowbrook State School was an institution that was located in the center of Staten Island, New York. It was envisioned, or at least sold to the public, as a place of respite for the families of children and adolescents with disabilities (Goode, 2013 p. 53, 59); or who were in 1939 referred to as “mentally deficient” (Scheinfeld, 1961, p. 236) and/or “mentally handicapped” individuals (Goode, 2013, p. 15). During its existence it became one of the most infamous institutions in New York State.

In order to understand the impact of this institution, there must be a discussion of the societal and historical climate. Its vision and conception came toward the end of period of time when total institutions were constructed of “post eugenics” (Goode, 2013, 48). A total institution is a concept that was developed by Erving Goffman:

“A total institution may be defined as a place of residence and work where a large number of like-situated individuals, cut off from the wider society for an appreciable period of time, together lead an enclosed, formally administered round of life” (1961, p. xiii).

A total institution should or would be capable of providing all necessary basic needs, such as food, clothing and shelter. In theory, the Willowbrook State School was capable of providing such necessities, but at the most basic and minimal capacity that it could parcel out. Throughout its history, the top justification for the insufficient distribution was blamed on lack of funding and insufficient staffing. However, a deeper, more long standing explanation is that the individuals housed in these facilities, were

viewed as less than worthy members of the general population (Goode, 2013, p. 103).

This fact is evident by the ways the residents lived.

Rights working for and against advocacy

As The Declaration of Independence of the United States of America states, “We hold these Truths to be self-evident, that all Men are created equal, that they are endowed by their Creator with certain unalienable Rights, that among these are Life, Liberty, and the Pursuit of Happiness”, however, as many social movements unfortunately need to continually prove, this is not an ambiguous statement (Amar, 1998, p. xi). There are many instances where those who are classified as disabled have had to call upon many laws and ratifications of the amendments to ensure that their rights are observed. The battle for civil and human rights as with most has been fought on a constantly changing topography. It appears that the laws continue to constantly require revisions and only regress instead of progress, from the time of the Renaissance (Foucault, 1961, p. 36).

From this time of new beginnings and rebirths, there has been a split and separation from the human experience to obtain perfection; be that within both the arts and sciences. What should be learned from this bell curve of sorts is that perfection will or can only be reached by fully embracing the reality in which we exist, and not a matter of molding it to fit what we have idealized.

It goes without saying that the amendments to the Constitution have been instrumental in facilitating effective changes with regards to civil and human rights. One case in point that directly impacted the closure of the Willowbrook State School was, the 8th Amendment. This will be discussed in chapter two. Clemente writes that the 8th Amendment expressly proscribes that “cruel and unusual punishment” is prohibited,

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however, the 8th Amendment which was ratified in 1791, prohibits governing bodies from inflicting “cruel and unusual punishment”, if it violates the “evolving standards of decency that mark the progress of a maturing society” (Clemente, 2015, p. 2748).

Michael Clemente wrote in, “A Reassessment for Common Law for ‘Idiots’” (2015, p. 2755) that in 1791, people described as idiots or lunatics were collectively referred to as persons “non-compos mentis”; a legal term from Latin meaning, a person who is not of sound mind (Clemente, 2015, p. 2756). For instance, in 1791, “English common law considered it “cruel” to execute idiots, lunatics and the insane...a survey described the execution as savage and inhumane...a miserable spectacle... of extreme inhumanity and cruelty” (Clemente, 2015, p. 2748). Clemente cites the English common law, as execution “denies the condemned an opportunity to find peace with God; and ‘madness is its own punishment’ (Clemente, 2015, p. 2757). This would have meant that in 1791, people with mental retardation were protected from being executed, in contrast to inmates with disabilities who are on death row today (Clemente 2015, p. 2748). English Law found it unethical and immoral to accuse a defendant of a crime when he or she was deemed to have the “incapacity to function at an adult level cognitively and morally despite (their) chronological age” (Clemente, 2015, p. 2794-2795).

It shows that English society, had viewed those who were labeled as idiots, lunatics, and/or insane, as non-threatening to their authority. It appears that they were viewed as less problematic and/or treated with slightly more sympathy (Foucault, 1961, p. 154). “The classification system born from the scientific method has provided history with a prism of terminology; by broadly defining mental ages of their subjects. Both the

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judicial system and medical community have fully implemented this classification system.

In 1784 a Supreme Court Case *Ezra Penniman v Caleb French*, ruled that if a person was labeled as an “idiot”, and was willed property, it would immediately become the property of the “idiot’s” guardian. Further noted that guardian has power of attorney and may possess any property of the “idiot”. The Supreme Court Case Document of 1806 of *Penniman v French* in Braintree, Massachusetts, was an appeal of the Supreme Court statute of 1784, which stated that property willed to a person by court decree deemed whom is “non-compos,” all belongings are property of his/her guardian, including any inheritance, i.e. goods or property. The Supreme Court case in 1806 was an attempt to appeal the restrictive nature of a court appointed guardian. Caleb French had presented himself as the uncle of Ezra Penniman, an “idiot” to act on his behalf. The case was dismissed because the uncle could not justify the necessity of his appeal. The Judge denied the appeal and upheld that only legal guardians who are court appointed to the “non-compos”, creditors or other legal bodies “lawful right or claims could advocate on the person’s behalf; “in the same manner as is by law prohibited in case of concealment or embezzlement of the effects of the persons deceased” (LEXIS 35; 2 Tyng 140).

Historic Styles of Treatment

While contemporaneously the Supreme Court cases were establishing guardianship laws, the medical field and religious sects were addressing the concrete matters of day-to-day matters of caring for and treating people with psychological and cognitive deficiencies. Among the first to establish centers of care were the Religious Society of Friends. Debbie M Price (1998) wrote in a New York Times article, “For 175
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years: *Treating Mentally Ill with Dignity*” explains how the Pennsylvania Quakers established the first private psychiatric hospital in the United States called: “Friends Asylum for the Relief of Persons Deprived of the Use of Their Reason”. It continues to operate with the principle of Moral Treatment for all; believing in providing dignity to all affected persons. Their treatment plans were designed to last a maximum of one year, and then for the patients to be returned to society. Readmission was to only occur if necessary. The Quaker’s practices have greatly impacted the development of effective treatments, including but not limited to the field of Psychoanalysis. For the Quakers discussing their views on the “disabled” is a moot point as they believe in equality for all people (Waldman, 2001, p. 49). Price writes that the Quakers, “unlike their contemporaries who saw insanity as a form of demonic possession, believed that the mentally ill could be cured if treated with kindness and respect in a salubrious atmosphere.” (Price, 1988) It is an amazing fact that over the past 200 hundred years this principle has existed but continues to elude most contemporary practices.

In response to the Quaker Institution, Social Reformer, Dorothea Dix agreed with their humane and moral treatment doctrine of the “insane” and “idiots”. In 1837, believing that religion should be removed from the equation; she petitioned the government that there was a need to create brick and mortar institutions to establish custodial care and the state would manage the treatment (Michel, 1994, p.50). Sonya Michel writes, that their “illnesses were due to extravagant, religious and intellectual excitements and the unregulated competition for wealth and fame that categorized modern society” (Michel, 1994, p. 50). As a result, in 1850 the State Lunatic Hospital in Harrisburg, PA, opened in October 1851 based on the Quaker model. Michel states that

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1854 President Franklin Pierce vetoed a bill that congress had passed for federal funding for a hospital for the insane. Michel sites that a Mental Health Reform Historian, Gerald Grobb claimed that “Dix was responsible for initiating ‘the thrust toward broadening the role of government in providing institutional care and treatment of the mentally ill’ (Michel, 1994, p. 108). There is bittersweet appreciation for social reformation that Dorothea Dix spearheaded, as it laid the groundwork for the official state run institution, that later sprung up throughout the country. While there had been facilities such as poorhouses, almshouses, and jails already in existence, Dix’s counterpoint to the place of true respite and compassion propelled the downward spiral of the horrific conditions that existed in all institutions that came after.

Paul Castellani, in *Snake Pits to Cash Cows: Politics and Public Institutions in New York* explains the economic incentives that drove the process of the boom of institutions throughout the country. In 1878, the New York Custodial Asylum at Newark was an “experimental program”. He cites Lerner, who wrote that it was for “custodial care’, and sequestration of idiotic and feeble minded girls and women, for their protection and the protection of the State from hereditary increase of their class of dependents on public charity.” It was the second institution in the United States of its kind (Sparer, 2006, p. 322). The experiment was evidently effective enough for more institutions to become the popular “effective” way of managing the “unwanted” people of society (Sanger, 1922).

In 1887, Journalist Nellie Bly (1887, p.1) reports in her book “Ten Days in the Madhouse”, that she went undercover to Blackwell Island Asylum which is now known as Randall’s’ Island, New York. Blackwell Asylum was the first institution in New York

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City of its kind for lunatics, and the first municipal mental hospital in the United States.

In order for her to do her research, incognito, she faked being “insane”. Bly writes that, “I shudder to think how completely the insane were in the power of their keepers and how one could weep and plead for release, and all of no avail, if the keepers were so minded. Eagerly I accepted the mission to learn the inside workings of the Blackwell Island Insane Asylum”.

Bly (1887, p.15) continues to write, “It was only after one is in trouble that one realizes how little sympathy and kindness there are in the world.” Bly (1887 p. 15) explains the steps it took for her to be admitted, as proclaiming it as a success and horror, that it did not take much evidence to convince the physicians and judges of her incapacities. She started off by going to a halfway house for the poor, where she was fed stale bread.

She began to not eat, stared at the wall, and pretended to have hallucinations. The police were who then took her straight to the Blackwell Island ward. When taken before a judge, she answered all the questions intelligently and honestly, and because of her previous behavior, they deemed her insane due to being inconsistency. She was accused of lying and being incoherent. She had been sent to the ward for the severe, because she would refuse to eat the food. She observed the fellow patients and reported that 90% of those who were on the ward were poor, depressed and no one she had encountered seemed to have psychiatric issues (Bly, 1887 p. 35). Bly’s work prompted a Grand Jury investigation to ensure that the admission criteria to asylums are only for the severely ill. This resulted in change to the regulations and increased funding for charities and correction facilities (“Unknown Nellie Brown”, 1887, p. 12:1).

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The Pursuits of Scientific Evidence

There have been several pivotal milestones in multidisciplinary understanding and cataloging of people with several means of classification. In 1908 Alfred Binet, developed the first practical intelligence test now known as the Binet-Simon scale, following collaboration with Theodore Simon. Edmond B. Huey, Ph.D. writes in the article “The Binet Scale for Measuring Intelligence and Retardation” that, “it seems to be generally conceded and I think correctly, that we have in this scale the most practical and promising means yet made available for determining the fact and for measuring the amount of mental retardation” (Huey, 1910, p. 435). According to Amram Scheinfeld (1961 p. 236) in *The New You and Heredity*, had cited the American Association for Mental Deficiency, “a person with a mind so retarded as to make him incapable of competing on equal terms with his normal fellows, or of managing himself or his affairs with ordinary prudence”. He further explains the degrees of I.Q. classifications (Scheinfeld, 1961, p. 237). The Binet scale was the foundation for the Stanford-Binet Intelligence Scale is used today and is used to measure a person’s intelligence quotient or I.Q. (Scheinfeld, 1961, p. 236).

“90-80: dull;
 80-70: on the borderline between dullness and sub-normalcy;
 Below 70: feeble-minded;
 69-62: High-grade moron;
 62-55: Mid-grade moron;
 55-50: Low-grade moron;
 50-20: Imbecile; 20-0: Idiot”.

Parallel to the constructions of state facilities was the development of formal educational models to teach the new populations that were being corralled into the new institutions. In “*Sequine’s Principles of Education as Related to the Montessori Method*”

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by Katrina Myers (2002) critique of Edouard Sequin's book "Moral Treatment, Education and Hygiene of Idiots" is explained, in conjunction to the Montessori Method, as the ideal pedagogy of education. The principles state that the children should be intellectually stimulated by multiple mediums, such as school gardens, classes outdoors when possible and that "gayety and mirth should be provoked several times a day; for happiness is the object as much as progress and children will not be sick when they laugh" (Myers, 2002, p. 551).

The Impact of Eugenics

Henry Goddard's "The Kallikak Family: A Study in Heredity of Feeble-mindedness" was a case study that unintentionally provoked and promoted the American Eugenics Movement. Goddard noted that there appeared to be specific features that were passing through each of the family's generations. He documented his finds by using the contemporary "new" technology of the photograph as his "scientific proof" (Chaloupka, 2015, p. 269). Evan Chaloupka (2015, p. 270) writes that, Goddard actively engages and guides the reader through his eugenic project through his "scientific truth" through his photographs and "hereditary charts" (Chaloupka, 2015, p. 269). Goddard's writings, among countless other academic, scholarly and philosophical influences, fueled what began the American Eugenics Society.

Fredrick Osborne stated in "Development of a Eugenic Philosophy" it is firstly a philosophy it is and should be ever changing, secondly it should be a move toward increasing "the freedom of parents in their choice of size of family would have various social advantages in addition to the eugenic improvement which would be their primary aim" (Osborn, 1937, p. 394). Secondly "intelligence' as measured by psychological tests

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certainly has a part in determining social value” (Osborn, 1937, 1936). (Osborn, 1937, p. 396) Through public lectures the organization promoted racial betterment, eugenic health and eugenic education.

The American Eugenics Society began in 1921, and sprung from the British Eugenics Education Society that began in 1907. Eugenics is defined by Montague Crackanthorpe “almost soon as man acquired by his higher intelligence mastery over the lower animals, he discovered that he could increase their usefulness by what is called “breeding for points” (Crackanthorpe, 1909, p. 20). It is then broken down into positive eugenics and negative eugenics as “it is important that the right people should be born as that the wrong people should not be born” (Crackantrope, 1909, p 20); as this is a culmination of a divergence of Social Darwinism of “the survival of the fittest” (Crackantrope, 1909, p. 20).

This course propelled the 1927 Supreme Court Case *Buck v Bell* (Hall, 2005, p. 115). This case established the national rationale for involuntary sterilizations of persons who were judged to be mentally defective. The case was about a teenage girl named Carrie Buck who was deemed “feeble-minded”. She had been raped and then had been “committed to the State Colony for Epileptics and Feeble-minded in Lynchburg, Virginia” (Ricks & Dziegielewski, 2000). Carrie’s character and moral state was questioned openly. The judge ruled that she should be sterilized, to stop the progression of “her kind” (Hall, 2005, 115)

This case facilitated a “forty-nine-year period of involuntary sterilization of thousands of developmentally disabled individuals”, (Ricks, & Dziegielewski, 2000) whose defense was appointed by the plaintiff. As stated in the Supreme Court Case
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Record, *Buck v Bell* ruled that the “sterilization of those deemed to be feeble-minded satisfied due process of the Fourteenth Amendment, and the procedure was limited to people housed in state institutions” (Ricks & Dziegielewski, 2000). The Supreme Court Document stated that, “the court affirmed the state Supreme Court’s judgment, the hearing procedure provided before sterilization of those deemed to be feeble minded, satisfied due process under the 14th amendment and the fact that the procedure was limited to people housed in State Institutions did not deny the inmate's equal protection.” The document further states that, “the public welfare may call upon the best citizens for their lives. It would be strange if it could not call upon those who already sap the strength of the state for those lesser sacrifices, often not to be felt by those concerned in order to prevent our being swamped with incompetence. It is better for the world, if instead of waiting to execute degenerate offspring for crime or let them starve for their imbecility, society can prevent those who are manifestly unfit from continuing their kind. The principle that sustains compulsory vaccination is broad enough to cover cutting the fallopian tubes.” Justice Oliver Wendell Holmes Jr. ’s closing words were “Three generations of imbeciles are enough.” (Hall, 2005, p. 116). Additionally, in 1931, the Supreme Court passed a forced Sterilization Law in Oklahoma (Daniel, 2007).

In 1942, Supreme Court Case *Skinner vs. Oklahoma* (Hill, 2005 p. 222) attempted to override *Buck vs. Bell*; but failed with the ruling that “none of Carrie Buck’s rights had been violated as her choice was null given that she was “feebleminded” and was “protected” under the guardianship law. Individuals with disabilities would not have rights independent and/or in conjunction of their guardianship until 1963 (Martakis, 2013, p. 1).

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In this era of institutions popping up; rankings were naturally common practice. One institution in an article in the *British Medical Journal* by C.K. Clarke (1923, p. 128), “Psychiatric Lessons from America”, explains how people with disabilities were treated in state hospitals and schools; specifically speaking about Letchworth Village as an “ideal” model. The article mentions that the eugenics movement was hotly debated in the U.S. consensus but was not unanimous in reference to practicality and effectiveness. In addition, the journal states that, “well organized state social services were being developed in New York and New England, the larger unit provided by a state allowed a coordination of activities that was not possible in smaller units.” “The chronic patients in large state hospitals in America were not any better dealt with...in America overcrowding occurred in many places. According to Clarke (1923, p. 127) much difference in opinion existed as to what was the best size of a mental hospital.” It further discusses psychiatry could revert back to a closed system.

This brief timeline demonstrates how the Federal and State government along with the scientific community has responded to and influenced reforms that led to and permitted the idea of Willowbrook State School. While this is a very limited review of the history of institutionalizations, guardianship, and the establishment of civil rights; there is a wealth of information that collectively culminates in a tug of war, of how to care for members of our society who need more support. The next chapter will detail a brief history of the Willowbrook School’s existence, the environment, the population, and the political response of its construction and subsequent demise.

The Beginning and End of the Willowbrook State School: 1940's through 2000

It is evident that from the 18th to the 21st century there has been a gradual shift regarding medical and custodial care of those society has deemed disabled. This has ranged from the construction of asylums, almshouses and mental health institutions to the horrors of the Eugenics movement and the Holocaust. This chapter will continue a review of the history from 1946-2000, and how it resulted in the formation of and the implementation of the Willowbrook Consent Decree.

World Wars and Eugenics

At this point in time, psychiatric institutions were a longstanding mainstay, and the care had been both militaristic and chaotic (Goode, 2013, p. 39). The effects of the eugenics movement, Holocaust, and how they influenced the atrocities and horrors that occurred at The Willowbrook State School and institutions similar to it; are in the process of being discovered and fully discussed. The Eugenics movement had been fully underway and had its intended effects on the “unwanted” of our society. Goode gives examples of a propaganda film and other materials used from approximately World War I. Goode writes, “The film was made as a part of an American physician’s attempt to influence the public to accept mercy killing of children who were disabled” (Goode, 2013, p. 39). Goode explains that Americans' understanding of the eugenics movement and the undisclosed partnership with Britain and Nazi Germany is only beginning to be fully realized (Goode, 2013, p. 39).

Following the end of World War II, the need for improved mental health care was apparent and was understood to be a national problem (Shalit, 1950, p. 94). In 1950,

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Pearl R. Shalit, R.N, who was the Mental Health Nursing Consultant for the National Institute of Mental Health expressed that, “Training programs and research are improving the quality and quantity of psychiatric and mental health nursing services, and showing us how they can be utilized more effectively” (Shalit, 1950, p. 94). The efforts to address these issues came in 1946, when President Harry Truman passed the National Mental Health Act. Its creation was to ensure there are sufficient avenues of treatment and support for all Americans, who suffer from mental illness as a differentiation from physical illness (Felix, 1947, p.94).

This was in response to the increase of Federal funding for research to comprehensively understand mental illness and mental and psychiatric disabilities (Shalit, 1950, p. 94). Additionally, Robert Felix, the founding Medical Director, Mental Hygiene Division, of the U.S. Public Health Service in 1947 stated, “Institutionalizing that unfortunate person whose abnormal behavior cannot be ignored is hardly a solution to the problem of mental illness” (Felix, 1947, p. 9). This begs the question of how the Willowbrook State School was envisioned to be an institution to resolve the overcrowding from the other state institutions throughout New York City and New York State (Goode, 2013, p. 65). Overcrowding in the institutions is detrimental to care in its own right, as it stymies proper facilitation of care. It occurs as result of underestimation of need and failure to effectively anticipate cost of care.

The “virtual small city” (Goode, 2013, p. 61) campus that would become Willowbrook was Halloran General Hospital. It was first built as a hospital for “feeble-minded” children, and then was taken over as a military hospital from 1942- 1951 (Hamburger, 1947). According to Goode, there is little written about the culture and

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history of Halloran General Hospital's daily existence (2013, p. 61). The transition of the campus from Halloran General Hospital as a debarkation hospital to the Willowbrook State School, was how the previously mentioned overcrowding was relieved (Hamburger, 1947).

Ethics and Research

In 1951 the patients were dispersed to other hospitals across the neighboring North Eastern states. Simultaneously, the number of patients at the Willowbrook State School had reached 2,480 as a result of the attempt to relieve overcrowding at other institutions. There was a period of mixed population of the disabled children along with the veterans. After active requests for this to be rectified and later would become part of what the Willowbrook Decree enforced, a clear distinction and separation of populations was implemented. The conclusion of World War II in many ways influenced the development of Bioethics Medical Field and the lives of those deemed "non-compos" (Clemente, 2015, p. 2756). In 1947 the Nuremberg Code set the standard for international regulations that mandated that, voluntary consent of human subjects was absolutely essential (history.NIH.gov). Conversely, the federal guardianship laws continued to stifle those who were deemed non compos.

There are a few aspects that can be distilled from the admissions criteria that are apparent. The families were told that the admission of their children would provide them relief from the burden of caring for their complex needs. As residents they would receive support and treatment designed to give habilitation and would relieve the overcrowding of other institutions that inhibit these goals. The families were promised that the school would provide a proposed centralized place for children of like needs, such as

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developmentally or physically disabled. While it did fulfill these promises, it however, had not disclosed that there were no clear habilitation programs to implement (Goode, 2013; Hill, 2016).

What is known about the standards of living of the residents of The Willowbrook State School has been presented to the public by newspaper articles, admissions paperwork and sporadic interviews with residents and staff. The Willowbrook State School was described with lovely winding roads lined by beautiful trees that dwarfed the buildings; with evidence that children resided on the grounds (Goode, 2013, 136). William Bronston (Goode, 2013, p. 138) stated in his recollections as physician at The Willowbrook State School as “Short of Dachau, or a concentration camp in Germany where they were actually burning people every day, they didn’t have to burn people here. They needed to keep them alive because they needed to make money off them”. Goode (2013, p. 138) discusses a 1950’s newspaper article titled “The Living Dead at the State School”, decaying with no hope of resurrection and they were completely unaware of their fates. They would be given among other medications, Thorazine; a heavy tranquilizer that was only given to ease the staff burdens of caring for the residents. In a time of strong paranoia of communist influence and wake of the atrocities of biological warfare of the holocaust; the residents of Willowbrook were unknowingly experiencing it as a reality.

Throughout the 1950’s “Willowbrook opened its doors to numerous visitors”, (n.d. p 16; Goode, 2013, p. 69) from various political leaders to university educators and students (Goode, 2013, p. 69). The visits by the medical schools to facilities like The Willowbrook State School, was the implementation of the need for research for mental

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health and medical professionals to have training environments that provided opportunities for optimal learning environments so they could learn to best treat their patients. Some notable visitors were State Commissioner of Mental Hygiene Nelson Bigelow in 1950 and 1951, Governor Nelson Rockefeller in 1959 as well as academic professionals, university administrators, medical students and nursing students who also visited as part of their degree curriculum (Goode, 2013, p. 69). Irving Goffman and Michel Foucault explain that these forced environments isolate symptoms by creating them, not by reducing interfering stimuli (Goffman, 1961; Foucault, 1961).

In an indirect and manipulated manner of compliance with the Nuremberg Code, Dr. Saul Krugman, the Medical Director of the Willowbrook State School, in 1955, began the “Hepatitis Studies”. As an effort to understand how the disease functions, he utilized the residents of Willowbrook where he explains there were numerous disease endemics (Krugman, 1986, p. 157). After receiving “informed consent” from the resident’s parents and/or guardians, via letter correspondence; and admissions applications were geared toward recruitment for pursuit of research “that could potentially benefit their children” was received with their full support. Krugman had administered the Hepatitis Virus to uninfected residents to observe the progression of the disease. His research ultimately resulted in the medical breakthrough of classifying the two strains as Hepatitis A and Hepatitis B (Krugman, 1986, 159). This ultimately culminated in the development of vaccinations for both strains. Krugman was honored as a medical hero for his efforts. All this had unfortunately and serendipitously occurred in a time in our social and civic history prior to civil rights for all people; especially including those who are “disabled” (Goode, 2013).

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As a result of Krugman's studies the Willowbrook Decree explicitly states that the residents are protected under the 8th and 14th amendments to be free from unethical experimentation and exposure to harmful environments without full informed consent. However, the glaring issue continues to exist under the guise of guardianship, as minor's rights are often not accounted or fully realized. It is a false assumption that information cannot be effectively disseminated and/or understood; first there must be the chance for there to be a failure.

Advocates and Politics

Both *A History and Sociology of the Willowbrook State School* (David Goode et al.), and *The Willowbrook Wars: Bringing the Mentally Disabled into the Community* (David J. Rothman and Sheila M. Rothman) provides a brief description of the culture of The Willowbrook State School, with the preface that is it not a complete account as a result of the claim of poor record keeping and limited accounts by staff and residents. However, truth takes its time to be exposed. A case in point is the archival analysis that Darryl B. Hill (2016) provides that discusses the previously discussed admissions criteria of the residents' sexuality in conjunction with race and their presumed and documented I.Q. (Hill, 2016, 103).

Among the many theories that have both been discussed, and have yet to be, Wolf Wolfenberger and Stephan Tullman (1982, p.131) explain the normalization theory as it became prominent in the 1960's. "Normalization is concerned with the identification of the unconscious, and usually negative, dynamics of certain groups of people in a society, and with providing conscious strategies for remediating the devalued social status of such people" (Wolfenberger & Tullman, 1982, p. 138). The theory explains that due to the

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extent of the depravity within a large social setting, people, on an unconscious level begin to view these processes as normal in their conscious mind; he explains that this is naturally prominent in human services.

The era of the 1960's was full of reform and civil rights. These efforts most certainly include, when President John F. Kennedy's family was personally faced with the decision of addressing their sister Rosemary's own special needs (Castellani, 2005). They did comprehend the magnitude of the horrendous world that The Willowbrook State School existed and among their "offerings" was that real political action is needed to take to correct these humanitarian errors and finally grant rights to those who have been silenced. Initially, control was asserted over the poor, "paupers", without differentiation in terms of specific mental handicap (Allman, 2013).

In 1963, President John F. Kennedy announced his intentions to establish a national committee to address a plan of action for people with mental retardation. In 1963 in "Special Message to the Congress on Mental Illness and Mental Retardation" he announced his plan to move away from institutions to community-based living and support systems. Despite these great ambitions, progress to effectively aid all people with disabilities had and continues to be slow. In 1965, Senator Robert Kennedy toured the Willowbrook State School and labeled it a "snake pit". However, many facilities including Willowbrook continued to be overlooked until 1972. An investigative reporter, Geraldo Rivera was given a lead by his friend and a physician at Willowbrook of the abuse, neglect and deplorable conditions that had and continued to occur there.

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New York policymaker, Paul Castellani's focus on the developmentally disabled, provides a unique perspective on the legislative and political history (Sparer, 2006, p. 322). In his book, "Snake Pit to Cash Cows", Castellani argues that the 1965 Medicaid program fueled the community-based residences because of the increase the federal reimbursement, broadening the possibilities to provide care to those of low or no income (Sparer, 2006, p. 322). It seems more happenstance that because of the Medicare/Medicaid system they became cash cows. They pay salaries to those who are caring for them. The "virtue" of the capitalist system is if something is not making money than it is perceived as useless to society. The system is dependent on the suppression of others, as Karl Marx notes in the Communist Manifesto, "It has resolved personal wealth into exchange value, and in place of the numberless indefeasible chartered freedoms, has set up that single unconscionable freedom - free trade." (Marx, 1998, p. 38). How many others have to be suppressed so that more money can be made?

In 1972 the Supreme Court Case *Wyatt vs. Stickney of Alabama* (344 F. Supp. 373; 1972 U.S. Dist. LEXIS 14201), a state institution determined a patient who had been involuntarily committed, wanted better treatment as required by the Constitution. The professionals were allowed six months to increase the level of care to an acceptable standard. The court would not allow any additional admissions until the standard of care was increased to an acceptable level. This case provided a Federal mandate for the Willowbrook Consent Decree to be facilitated.

During a visit to the institution in 1972 by reporter Geraldo Rivera, an expose on the grounds of The Willowbrook State School was conducted, and brought to light the deplorable conditions in which the patients lived. Then shortly after the broadcast, the Addressi

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public demanded that something be done. Simultaneously the Federal Law of Rehabilitation Act of 1973 was enacted to ensure that all Americans were protected from mistreatment, and in 1975, New York State produced the legislation known as The Willowbrook Consent Decree (Lexis Nexis; 29 USCS & 701). This dictated that all residents of the Willowbrook State School would have the same rights as all other New York State citizens; and to later be applicable to residents of all institutions like it.

On April 10, 1973, the three- year legal battle demanded by the public for the conditions at the Willowbrook State School to improve was begun. The decree states that the patients of Willowbrook are under congressional right by the 8th and 14th Amendments to be protected from harm and receive “free appropriate education”. Rivera had been invited by Dr. Michael Wilkins a physician and advocate who had been working in Willowbrook’s Building six at the time. He had done all that he could from the inside to raise awareness of the terrible conditions the patients and staff were experiencing to no avail. Having no recourse, he contacted Geraldo Rivera to see if he would be interested in organizing an investigation (Rothman, 2005, p. 16). Rivera had felt he was up for the challenge, as he previously was a war correspondent and spent time investigating other urban matters (Rivera, 1972).

The horrors that were experienced by the patients of The Willowbrook State School were completely inhumane and unacceptable. Under the Constitution, all persons have the right to protection from harm; which was most evidently violated for all patients at Willowbrook.

The trials that resulted in the Willowbrook decree focused on reviewing violations of any Constitutional rights of the patients. Judge Judd’s main focus was on differentiating

“Right to Protection” and “Right to Treatment”; he focused on the semantics of how many or whether or not any or all toilets were in working order (Rothman, 2005, p. 2).

Did the patients continue to suffer malnutrition, self-harm and more often physical abuse from other patients or neglect from staff? Only following a visit to the facility itself did the distinction between “rights to treatment” and “right to protection” began to blur.

The Willowbrook Consent Decree

The Willowbrook Consent Decree was signed in April 30th 1975 by Judge Judd. It was written as a means to resolve the conflict between the mistreatment of the patients at Willowbrook without fault or charges brought to the people involved and/or responsible for their mistreatment. A three-year trial commenced after Geraldo Rivera’s expose aired on WABC on January 6th, 1972. The Willowbrook Consent Decree states that a consent judgment was selected as the most effective legal measure; blame would not be set forth onto any party but it was to be a means of to efficiently facilitate correction of the atrocities (Rothman, 2005, p. 3 & Willowbrook Consent Decree).

The decree mandated that within 45 days a Review Panel consisting of a total of seven members (two selected by the defendant and three from the plaintiffs, to be approved by the court, in addition to two recognized experts in the field of mental retardation (the Willowbrook Decree p. 5). The Review Panel would be responsible for monitoring and ensuring that the contents of the decree are and continue to be upheld. It details the current hierarchal order of reporting from direct care staff to medical directors and state representatives.

The “Appendix ‘A’: Steps, Standards, and Procedures” of the decree provides the details in multiple categories the entitlements and rights of the “Willowbrook class”. It

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begins with details how the residents should be living, “residents shall be provided with the least restrictive and most normal living conditions possible. Residents shall be taught skills that help them learn how to manipulate their environment and how to make choices necessary for daily living”. The Director of the Willowbrook Developmental Center must provide documentation of all legal and civil rights to each resident.

Specific of environment that are reflections of the Quaker model of quality of life and honorable living, “defendants shall provide living facilities which afford residents privacy, dignity, comfort and sanitation”. Additionally, educational programming specific to each individual’s needs must be designed and provided to all patients. At the time in legal education history, the Rehabilitation Act of 1973 was reached. Education and habilitation goals were mandated to be organized and implemented. Furthermore, specific guidelines regarding research in which a “Willowbrook class member” was a subject could not be of an aversive nature unless approved by a physician or verified as a known proven safe treatment. The research that had been conducted at Willowbrook was coercive and clandestine (Goode, 2013, p.137). Going forward, residents must be fully informed and consented.

The Willowbrook Consent Decree, once finally completed, dictated that all patients be relocated and integrated into the community and into the least restrictive environment as soon as possible, leaving only a maximum of 250 patients at The Willowbrook State School by 1981 (Rothman, 2005). How this was to be executed remained to be seen. Over the course of the past forty years’ various group homes had been established through state and federal funding; managed and maintained by both government and voluntary agencies.

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Rothman (2005) discusses throughout “Willowbrook Wars” three phases or wars; the first as Geraldo Rivera’s expose; the war on the public, the second as the war on the legal system and the third as a war within the community. Following the decision of the decree; and the deadline of 1981, the challenges of bringing the residents both into and reintegrating them into the community proved to be a nearly impossible task. It had been met on all three counts with great opposition. When it was time for the residents to be integrated into the community, most group homes or families were not fully prepared to accept the resident or accommodate all of their needs. Proper training for these new locations had not been accounted for in the protocol and effectively delayed numerous transfers.

It was only when deinstitutionalization began in the 1960’s and 1970’s had there been a realization that a societal shift in identifying these individuals was overdue and necessary. However, new categorizations for “people” continue to confound the efforts of seeing them as everyone else.

In contrast, individual people with Developmental Disabilities until recently were glommed together and historically labeled as “idiots, imbeciles, morons, mentally retarded, patients, consumers, clients, residents” to only now are they viewed and addressed as who they have always been; “people or individuals” just like all of us.

Moving Forward to Freedom for All: 2000 to Present

While there have been civil rights laws that have positively changed the lives of those with developmental disabilities, there continues to be the guardianship laws and sterilization laws established in 1929 that impede progress. The Willowbrook Consent Decree is an evocative reminder of the progressive history of both the nature of institutional living and essential civil rights that we are all are entitled to exercise. Goode explains that it is necessary to study Willowbrook State School and the Willowbrook Consent Decree as a living history that continues to directly and indirectly impact many lives (Goode p.305).

Multidisciplinary Interactions

Contemporaneously there is very limited scholarly documented literature on both the history and analysis of the full impact of both the Willowbrook State School and subsequently the Willowbrook Consent Decree. As a result of this history, many academic disciplines such as History, Social Work, Disabilities Studies, Anthropology, Sociology, Psychology, Neurology, Medicine, Philosophy, Political Science, and Economics have a wealth of information at their fingertips to be analyzed. While there has been progress in accessibility to services for all peoples' needs and rights to be met; there continues to be violations of civil rights both as subtle and blatant discrimination. This is unfortunately equally true for both those whose are and are not outwardly seen as disabled (Goode p. 305).

Over the past decade there has been a shift in focus from a person's limitations to their assets; from the term "disability" to "accessibility". This means that the focus becomes what one can do versus what cannot be done. This model is evident in most

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professional and academic disciplines of Business, Economics, Physics and Engineering, by recognizing the circumstances and utilizing the materials that are on hand to propel the individual as opposed to hindering of what might or had been thought of as lacking.

This is evidenced in the New York Times Magazine Article by Genevieve Field, “Should Parents of Children with Severe Disabilities Be Allowed to Stop Their Growth?” that discusses the ethics of “Ashley X Treatment”. This is a procedure where a child’s growth is attenuated, in effort to aid in the long term care of the severely disabled. Disability advocates argue that this procedure is unethical and violates the child’s “rights to privacy and freedom from unnecessary bodily manipulation, which are the sorts of things the Americans with Disabilities Act, the Rehabilitation Act and the even the 14th Amendment were supposed to protect people from.” (Field, New York Times, 2016). Following an investigation, the advocacy group found that this procedure does not “break state law by sterilizing a disabled minor without a court order” (Field, New York Times, 2016) as the state sterilization laws written in 1929 continue to permit the perpetuation of procedures of this nature.

“At its core, the battle over growth attenuation is a battle between old and new ways of thinking about disability: the old “medical model,” which regards disabilities as a problem to be fixed, and the new, ‘social model’, which frames disability as a natural facet of the human experience. The social model promotes self-determination for those who have even the most complex disabilities; society should adapt to them, not the other way around” (Field, New York Times, 2016).

As previously stated, the Willowbrook State School’s existence was a direct result of the progression of the institutions for the disabled; the Willowbrook Consent Decree is what has significantly improved the lives of those who were at the Willowbrook State School and those who were saved from it. The social scientific observational nature, of

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the residents of the Willowbrook State School continued to be facilitated in the community after its closure. As a direct result of the Willowbrook Consent Decree the residents were relocated into group homes. These are residential options for people to be integrated into to the community and live as independently as possible. Residents attend to vocational, recreational activities and services at day programs, where they also learn essential life and job skills, to eventually be granted the opportunity to obtain meaningful employment in either sheltered workshops or in the community.

The Willowbrook Internship

My final semester as an undergraduate in Psychology, while operating under the assumption that I was firmly grounded in the Freudian thought; I was delightfully challenged while completing my final class -Learning and Behavior lab. During the course I had developed an appreciation for behaviorism and was reluctantly shedding ill-held conflicting beliefs and thoughts that would be the end of the challenges, until I faced Graduate School. I was wrong. The professor had asked me, as he had all the students of their plans following the conclusion of the class. I explained my desire to become a Psychoanalytic Psychotherapist, and in return, the professor proposed that I postpone my planned January graduation to take the Applied Behavior Analysis Internship that he was organizing the following semester. After careful contemplation, to not pass up the opportunity, I agreed. The internship would change my life, my perspective and teach me more than I had ever imagined.

The internship was held bi-campus, on the College of Staten Island and the Staten Island Developmental Disability (SIDDSO) Service Office a sector of the then, named Office of Mental Retardation and Developmental Disabilities (OMRDD); now called the Addressi

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Office of People with Disabilities (OPWDD). Our assignments were to observe the consumers of the SIDDSO of the Multiple Disabilities Unit (MDU). The residents whom were also referred to as consumers; had both psychiatric and developmental disabilities, resided on the MDU unit at South Beach Psychiatric Hospital and their day program at Learn and Earn. We were instructed to simply observe and not participate in any intervention.

The consumers were immediately friendly and sociable; on the other hand, the staff viewed us as “spies”. The mixed air of innocent trust and paranoia resulted in a curious experience. The staff, once they acknowledged that was in fact simply students, there for the sake of observing the consumers; they began to relax and then there was a dichotomist shift. The staff assumed that we would then treat the consumers the same “other” way as they had, but when we continued to treat them as people we were stuck in a unique situation.

Prior to our first day on-site, we were all debriefed about the history of the grounds that we were going to be working on. Most of us were completely shocked to learn that the very campus we had spent our entire college life on had been the main grounds of the Willowbrook State School. The site the internship was held was the remaining grounds that are now owned by New York State, to provide community resources for the surviving members of the Willowbrook class. In those moments I had an embarrassing recollection of when I was in one of the basement classrooms on campus. I turned to my friend, and said “it’s so creepy down here, to which I naively joked “if you’re quiet you can hear the chanting”. She not finding it amusing turned and reprimanded me, promptly informing me, that before it was the College of Staten Island it

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was Willowbrook. I then forgave myself for the insensitive thought as I simply didn't know. The debriefing continued as a holistic approach to the campus' history.

As part the preparation for the internship, we were instructed to watch Geraldo Rivera's 1972 Expose, "Willowbrook, the Last Disgrace" for perspective. We were instructed that the patients could be potentially dangerous at times, given their psychiatric histories but not to be concerned and to conduct ourselves as naturally and calmly as possible; with the keystone notion that they are people just like ourselves. For me this perspective was only truly challenged by the mentality of the staff. Although I admit that at times the conflict was infuriating and confusing, I did my best to treat everyone; consumer and staff with equal respect.

Throughout the semester we studied principles of behavior and mindfulness for what at first seemed a matter of routine for theory and practical application. But when it came to the practical application, the principles of mindfulness almost seamlessly facilitated the principles of behavior without judgment in a most poetic manner. As the semester neared its end, I was mentally preparing myself to move forward to finally graduate. Much to my surprise and giddiness, I was given the honorable choice to continue on with the internship over the summer, to perpetuate the internship's operation. I was thrilled and humbly grateful for the opportunity.

Over the summer, a highly selected enclave of students including myself continued to develop the internship and prepare for the fall semester. During this time, our titles changed to Student Assistants and we became official interns of New York State, OPWDD. As our roles changed, the temporary relationships we developed with the consumers and staff had shifted. We became more respected by the administration, and

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the consumers became more comfortable with socializing with us however, the staff became more apprehensive to speak with us.

Distinguished Professor of Law and Ethics of the University of Chicago, Martha C. Nussbaum, argues in The Supreme Court 2006 term, that the most effective way to communicate a point is to state it simply. Not to have the cause of a problem, attempt to be the solution to the problem. She uses the example “the way to stop discrimination on the basis of race is to stop discriminating on the basis of race”; the best way to stop the segregation of people who need supports that are alternative to “normal” is not by continue to create and maintain separate worlds for them to exist. Nussbaum goes on to explain how “lofty formalism” (Lexis Nexis, 121 Harv. L. Rev. 4) causes more problems than it solves by clouding the details of the issue by placing people in boxes; this only further supports discrimination. It is time for the vocabulary to evolve to a more collaborative and equal existence.

Executing the Willowbrook Consent Decree

As a direct result of the Willowbrook Consent Decree, these services were made to be and continue to be monitored and arranged by Service Coordinators. These roles are made available through the Federal and State Medicaid systems and are managed by a hierarchy of Social Workers known as Medicaid Service Coordinators. The role of a Medicaid Service Coordinator is to ensure that all the basic and social needs of the participant are being met.

As a medical service coordinator (MSC) I served children, adolescents and adults through two voluntary agencies under OPWDD of two separate populations: autism and traumatic brain injury. They were both established and operate to serve the community of

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Willowbrook class residents and all other individuals with disabilities. As detailed in the decree, my role as an MSC was to write the service plans for each patient. By assessing their psychosocial needs, I would coordinate the habilitation, education, and/if when necessary residential services that state and/or the community had established as available to them.

As with the training under my internship, there was a light review of participants' psychosocial and medical history. The experience on the Willowbrook grounds served as the most immersive education that only a few articles or text books could never compare.

In this age of "Individual Service Plans" and advocating for those who qualify for Medicaid due to "a permanent disability". Reports were constantly necessary and more often than not directly interfered with the individual receiving the very services that were detailed in the plan. That was the most stressful part of the job; the drudgery and bureaucracy of the paperwork. As a direct result of the supposed "poor record keeping" at Willowbrook, the decree made it explicitly clear that everything must be documented.

At most I must argue it is necessary to ensure safety protocols are always met and civil and human rights are always honored. However, it is when the course of documenting, all minute details continues to separate the needs from the person, is when paperwork is no longer effective. This ironically occurred because of the very bureaucracy that created the need for endless reports in the first place.

To ensure that the decree and all these protocols were followed, monthly contact was mandatory but only within a specific range of contact. Too much or too little must mean that new or changed services are needed. The simply normal acts of social bonding

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between people was frowned upon, because the role of an MSC is simultaneously an advocate for the patient and the state, a duality that is a most difficult balance.

For all my time there, it was always the smiling faces of the children and the warm welcomes of the parents that made all the madness of bureaucracy and Medicaid reimbursement tolerable. It was my need to be human and my empathy for helping people that had and will always be my driving force for understanding and advocacy.

Social integration is an essential facet of the justification of people with disabilities residing in the community, however, even though they may live in a group home in the middle of an active community, active participation continues to be stymied until there is global acceptance. David Goode notes that the Willowbrook State School's history is significant because tragically "Global Willowbrooks" (Winerip- Times) continue to operate. However, recognition of the history "has become a motivating factor for a global movement to help these countries close such places and recognize the rights of people with intellectual disabilities" (Goode p.305). The social hierarchy of authority continues as a both a constructive and destructive force in how all people should be cared for.

How far have we actually progressed from Dorothea Dix?

New York Times article "Global Willowbrook" written by Michael Winerip, describes how Virginia Gonzalez "Mexico's Dorothea Dix" a woman from a wealthy family that has dedicated her life to helping the mentally disabled exercise their universal civil rights. The article explains how Gonzalez and Eric Rosenthal, who founded the Disabilities Rights International partnered to survey the psychiatric hospitals in Mexico,

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and around the world. The team had snuck into several psychiatric hospitals to investigate the operations and the state of the patients who reside there.

The team lead by Gonzalez and Rosenthal found the same circumstances in Hidalgo, Mexico in 2000, as Geraldo Rivera had when he explored the Willowbrook State School in 1972. Gonzalez had utilized personal assets to establish the first group home in Mexico. In contrast to Rivera's investigation, which propelled deinstitutionalization across America, then government funded group homes, following an epidemic of homelessness. The team's investigation found there was no such support in Mexico, however, according to Mexican government officials, up to "80 percent of patients could live in the community if there were supervised housing programs" (Winerip, New York Times, 2000). Rosenthal hopes that the unfortunately high likelihood of homelessness could be avoided and be prevented at critical times.

Further inquiry found that the Mexican government had discussed plans of replicating deinstitutionalization and the group home model; however, the main dilemma lies in the proper eventual and personal funding to be secured. After a year, the team found that to facilitate civil rights for the mentally disabled in Mexico, "in much the way that an activist American lawyer tries to squeeze a civil rights or labor precedent from the Supreme Court, Mental Disability Rights is trying to squeeze human rights precedents from existing international law. For this they have relied on a mix of U.N. resolutions, including the International Covenant on Civil and Political Rights. That treaty provides in Article 7, that "no one shall be subjected to torture or cruel, inhuman or degrading treatment" Rosenthal writes that witnessing, women who are patients of the psychiatric

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hospitals in Hidalgo, naked and shivering, is a violation of Article 7 of I.C.C.P.R.: “cruel, inhuman or degrading treatment.” (Winerip, New York Times, 2000).

Rosenthal writes that this is a violation of the 1991 U.N. General Assembly Resolution 119, Principles for Protection of People with Mental Illness: “Every person with mental illness shall have the right to live and work, as far as possible, in the community.” (Winerip, New York Times, 2000). Anchoring these efforts in international law is vital as Rosenthal writes, “we are sending a message...that this is not about comparing Mexico to Western standards: this is about the violation of universal law” (Winerip, New York Times, 2000). Unfortunately, a million violations mean nothing without world opinion on your side that is that second, more important---and far more difficult change that must take place to establish a new human right. Rosenthal proclaims, “You have to shame the world”.

Where do we go from here?

In conclusion, the Willowbrook Consent Decree has positively impacted advocacy for people with disabilities. As previously stated, this consent decree was the most expeditious legal path chosen to close the Willowbrook State School. It was an effective tool for change, by proving that the Willowbrook State School and institutions like it were in grave violation of constitutional rights, specifically the 8th and 14th Amendments. These amendments protect all American Citizens from harm, cruel and unusual punishment and reinforce their right to appropriate treatment. The right to treatment includes appropriate education, vocational, medical and psychiatric (when applicable) care, that the resident or individual, requires at any given point in their lifetime.

This closure not only promoted the residents return to the community, where they belong, it also propelled the deinstitutionalization process throughout New York State and the United States. The Willowbrook Consent Decree further ensured that the residents would now, be not only permitted to exercise their rights, but ensured that the individuals responsible for their care would be held accountable and responsible for reinforcing their rights. Following the closure as well as contemporaneously, the individual is evaluated and assessed for their baseline level of independence, akin to what can be best described as a home economics course. The results of these evaluations, determine the level of professional assistance the resident would require and is designed to teach life skills, which build independence. Following the completion of the assessment, the individual is given the choice of where they would prefer to live,

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naturally depending on availability within the community. It is a true triumph for these individuals, that this is now the same process as any citizen, within the perimeters of preference and income.

However, due to changes in the United States Department of Education's curriculum, home economics courses are now known as Family and Consumer Science, and are sporadically available in primary schools for the general population. This in turn means that the general population now has their own limited access to necessary life skills. Additionally, the Willowbrook Consent Decree ensured that individuals have socialization opportunities that are organized similarly to the socialization within the general population, of like demographic pairings. According to Dan Allman in "The Sociology of Social Inclusion", social integration is essential to our daily lives, as it facilitates how we interact within our community and navigate our society (Allman, 2013, p. 1).

The Willowbrook Consent Decree declared that specific professionals known as Service Coordinators are to be the responsible parties, to be the individual's personal advocate. The Service Coordinator monitors all activity of the individual's life to ensure that all their basic life and personal needs are met. However, as an additional result of the Willowbrook Consent Decree, advocacy is not limited to the Service Coordinators; it is the individual, the individual's family, their Social Workers, Psychologists, Nurses, Case Managers, and personal staff all are present to be positive influences and ensure that the individual's maintains a quality of life and receives all they need as it should be in any community. All the caregivers are additionally present to promote and support the

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individual to be a self-advocate. This is for the individual to express their specific wants and needs, as well as be permitted to take all action necessary to complete achieve these goals. It goes without saying that we all need help from each other at any given point in time, Self-Advocacy is simply granting those who were previously denied this very same opportunity, of independence and freedom.

As per our Constitutional Rights we have the right to choose or decline, educational, vocational and medical services. When necessary, individuals are provided all these whenever they are applicable. The Willowbrook Consent Decree and later the Rehabilitation Act of 1973, secures that the individual has informed choice and their right to treatment is obliged. Informed choice, which is the same as informed consent, is that all options are explained in detail at a level that is comprehensible to the person receiving the information, this again, is a victory as it is the same for a typical well visit at your primary care physician's office or when signing a lease agreement for an apartment. The flip side of these documents is that, any additional training that an individual may need, should be offered and provided, when or if accepted, as a part of society. Although it is still not equal to everyone and their needs, due to availability regardless of general population or disability, but for some things those with disabilities have an advantage over the general population and vice versa. The access to specific resources, such as socialization or vocational programs are more readily available for someone with a disability, because of the Consent Decree, this is more readily available. Those in the general population need to seek this out.

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As it has been shown, Civil and Human Rights have greatly impacted and improved everyone's lives, especially those members of society who have been marginalized. For the individuals with disabilities, all the advocates that have been discussed, all have led to the changes that were propelled by the Willowbrook Consent Decree and continue to maintain and push for further necessary change. An example of these continuing strides is the Americans with Disabilities act of 1990, which has since been amended to be more inclusive than segregating. This act coupled with the Rehabilitation Act of 1973 ensures that people with medical, physical, or developmental needs, now referred to as Intellectual Disabilities receive education and employment equality and opportunity to be able to function to the best of their ability without restrictions. These acts further protect individuals from discrimination based on their disabilities.

On the one hand there has been great progress forward, yet there are still further legal and societal changes that continue to be necessary. For instance, there is great need for the sterilization laws adopted in 1924, to be amended to either include, the informed choice of the person the sterilization is to be inflicted upon, or abolished the law entirely. Additionally, sex education, should be included but is not limited to sexual health, sexual practices and orientation counseling, for individuals and caregivers, when applicable, is necessary to ensure that all the individual's basic human needs are addressed and met. Additionally, the antiquated guardianship laws and regulations are in much need of revision. They continue to impact both children and adults, and above all others facets, cause the most restriction, and need to be changed to reflect and support an individual's right to informed choice.

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Further legal changes include, streamlining of bureaucratic monitoring of individuals with disabilities, be granted and receive fuller independence and autonomy over their lives. As is currently due to the multitude of overseeing governing entities that monitor an individual with disabilities life, this can be more suffocating than advocating. This is again, where full adoption of the Quaker model is imperative, as it provides not only a foundation of full support for the individual, it provides structure for independence and autonomy; due to the assumptions of equality and compassion facilitates and promotes effective learning.

While the general public has been made more cognizant of individuals who were considered at one time known as “disabilities”, should be now seen as capabilities and abilities. This is a necessary shift in perspective, one that is in fact taught to all of us in elementary school, to be open to each of our own unique qualities. Serendipitously, the Disney/Pixar films “Finding Nemo” and Finding Dory” are mirror reflections of these very notions of reassurance that we are different and all have various strengths and weaknesses and that when we all work together anything can be accomplished (Scott, New York Times, 2016). Awareness of these differences will only help individuals be fully integrated into the general public, while facilitating awareness through advocacy as well as reducing segregation. This is an effort to fulfill the adage, “do unto others, as you would want done unto you”.

It is an unfortunate fact that institutions like the Willowbrook State School are still in existence around the world. It is through the tireless efforts by such advocates as the Disability International that effective deinstitutionalization continues to occur.

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However, there is still a long way for our global society to go before we achieve full equality through compassion and humane treatment. While the task of changing the global society's perspective on how we all should be treated is a huge undertaking, it is an entirely plausible and achievable task. As we all are affected and impacted by limitations that are results from medical, psychiatric and developmental complications, it is through community and awareness that we can only progress as a global society.

Reference List

- Agnew, H. (Eds.). (1933). Mental institutions in Canada. [Editorial] *The Canadian Medical Association Journal*, 29(1), 73-74.
- Allman, D. (2013). The sociology of social inclusion. *Sage Open*. January-March, 1-16.
- Amar, A.R. (1998). *The Bill of Rights: Creation and Reconstruction*. New Haven: Yale University Press.
- Auden, G. A. (1947) Mongol and Cretin. *British Medical Journal*, 2(4534) 871
- Bassett, D. S. & Smith, T. E.S. (1996). Transition in an era of reform. *Journal of Learning Disabilities*, 29(2), 161-166.
- Bassett, D., Dunn, C, & Cheney, D. (2012). Transition tips for educators working with students with emotional and behavioral disabilities. *Intervention in School and Clinic*, 48(1), 22-29.
- Blalock, G. (1996). Community transition teams. *Journal of Learning Disabilities*, 29(2) 148-159.
- Bly, N. (1887). *Ten Days in The Madhouse* (Kindle DX Version).
Retrieved from <http://www.Amazon.com>
- Boleyn, T. & Legge, D. (1997). Abandoned to their fate: Social policy and practice towards severely retarded people in America, 1820–1920: By Philip M. Ferguson. Temple University Press, Philadelphia, PA, 1994. 212 pp., U.S. \$34.95 (cloth). *Social Science & Medicine*, 44(4), 549-550.
- Bowman, M. (1996). Open debate over closed doors: The effect of the new developmental disabilities regulations on protection and advocacy programs. *Kentucky Law Journal*, 85, 955.

WILLOWBROOK INFLUENCE ON CONTEMPORARY ADVOCACY

- Breslin, E. R. (1980). Backlash against the disabled: In the areas of mass transit, housing and education, disabled people face new challenges to their hard-won rights. *Mental Disability Law Reporter*, 345–355.
- Brinkerhoff, L. C. (1996). Making the transition higher education: opportunity for student empowerment. *Journal of Learning Disabilities*, 29(2) 118-136.
- Buck V. Bell, Superintendent, (1927). (No. 292) Supreme Court of The United States.
- Carabello, B., Wilkins, Mike, Rivera, Geraldo, & College of Staten Island. Library Media Services. (2006). *Willowbrook the last disgrace - twenty-five years later*. 2006, 1997.
- Castellani, P. (2005). *Snake Pits to Cash Cows*. State University New York: New York
- Carreira, H. (2001). Protecting the “class of one”. *Real Property, Probate and Trust Journal*, 36(2), 331-363.
- Chaloupka, E. (2015). Imagining cognitive disability: Recursive reading and viewing processes in Henry H. Goddard’s the Kallikak family: A study in the heredity of feeblemindedness. *CEA Critic*, 77(3), 269–277.
- Chesterton, G.K. (1927). *Eugenics and Other Evils*. New York: Dodd, Mead & Company.
- Clarke, C. K. (1923). Letchworth village, a model institution for the care of defectives. *Canadian Medical Association Journal*, 13(2), 127.
- Clarke, R., Camilleri, K., & Goding, L. (2015). What’s in it for me? The meaning of involvement in a self-advocacy group for six people with intellectual disabilities. *Journal of Intellectual Disabilities*, 19(3), 230–250.

WILLOWBROOK INFLUENCE ON CONTEMPORARY ADVOCACY

- Clemente, M. A. (2015). A reassessment of common law protections for 'idiots'. *Yale law journal*, 124(8), 2680-3203.
- Crackanthorpe, M. (1909). The eugenic field. *The Eugenics Review* 1(1), 11-25.
- Cuthbertson, D. P. (1947). Mongols and Cretin. [Book Review] *British Medical Journal*, 2(4534), 871.
- D'Antonio, M. (2004) *The State Boys Rebellion*. New York: Simon and Schuster.
- Daniel, M. (2007). Should the protection and advocacy of individuals with mental illness preempt peer review-an analysis of center for legal advocacy v. Hammons. *Oklahoma. City University Law Review*, 32, 333-505.
- Data Research, INC. (1994) *Rehabilitation Act. Statutes, Regulations and Case Law Protecting Individuals with Disabilities*.
- Deinstitutionalization standards detailed in consent decree. (1983). *Mental Disability Law Reporter*, 7(3), 221-224.
- Deweaver, K. L. (1983). Deinstitutionalization of the developmentally disabled. *Social Work* 28(6), 435-439.
- Dixon, L. B., & Goldman, H. H. (2004). Forty years of progress in community mental health: the role of evidence-based practices. *Australian and New Zealand Journal of Psychiatry*, 37(6), 668-673.
- Dow, J. F. (1930). Psychiatric lessons from America. *The British Medical Journal*, 1132-1132.
- Dowdy, C. (1996). Vocational rehabilitation and special education: partners in transition for individuals with learning disabilities. *Journal of Learning Disabilities*. 29(2) 137-147.

WILLOWBROOK INFLUENCE ON CONTEMPORARY ADVOCACY

Eleventh circuit rules on rights of child committed by parents. (1983). *Mental Disability Law Reporter*, 7(3), 220-221.

Felix, R. H. (1947). Operation of the national mental health act. *The Compass*. 28(2), 9-12.

Flynn, E. (2013). Making human rights meaningful for people with disabilities: advocacy, access to justice and equality before the Law. *The International Journal of Human Rights*, 17(4), 491–510.

Friedman, P. R. (1977). Human and legal rights of mentally retarded persons. *International Journal of Mental Health*, 6(1), 50–72.

Gelb, J. & Palley, M.L. (1971) *The Politics of Social Change: A Reader for The Seventies*. New York, NY, Holt, Rinehart and Winston, Inc,

Goffman, E. (1961) *Asylums. Essays On The Social Situation of Mental Patients And Other Inmates*. United States, Anchor Books.

Goode, D., Hill, D. & Reiss, J. (2013) *History and Sociology of the Willowbrook State School*. United States of America: American Association On Intellectual and Developmental Disabilities.

Gottlieb, J. (2010, June 7). *Name change at agency to remove 'retardation'*. The New York Times. Retrieved from <http://www.nytimes.com>

Hamburger, P. (1947, September 25). "The Boys in Maroon". Retrieved from www.newyorker.com

Hall, K., Ely, J.W. & Grossman, J.B. (2005). *The Oxford companion to the Supreme Court of the United States* (2nd Ed.) New York: oxford University Press.

WILLOWBROOK INFLUENCE ON CONTEMPORARY ADVOCACY

- Hardcastle, L. A., & Zirkel, P. A. (2012). The “new” section 504 student issues in the wake of the ADA. *Journal of Cases in Educational Leadership*, 15(4), 32–39.
- Hayden, E. A. (1909). The social will. *The Psychological Review: Monograph Supplements*, 10(2), I.
- Heilman, K. M. (2008). The rights of others: protection and advocacy organizations’ associational standing to sue. *University of Pennsylvania Law Review*, 157(1), 237–278.
- Hill, D. B. (2016). Sexual Admissions: An Intersectional Analysis of Certifications and Residency at Willowbrook State School (1950-1985). *Sexuality and Disability* 34(2) 103-129
- Hollander, R. (1986). Mental retardation and American society: The Era of Hope. *The Social Service Review*, 395–420.
- Huey, E. B. (1910). The Binet scale for measuring intelligence and retardation. *Journal of Educational Psychology*, 1(8), 435.
- Ignatieff, M. (1981). State, civil society, and total institutions: A critique of recent social histories of punishment. *Crime and Justice*, 153–192.
- Isaacs, D. (2015). Advocacy. *Journal of Paediatrics and Child Health*, 51(8), 747–748.
- Jocher, K. (1939). Philadelphia Folks, Ways and Institutions in and About the Quaker City. [Book Review]. *Social Forces*, 18(1), 141–142.
- Johnson, A. (1899). Concerning a form of degeneracy. II. The education and care of the feeble-minded. *The American Journal of Sociology*, 4(4), 463–473.
- Keeble, K. (1984). Second Circuit Review-1982-1983 Term: Federal Court: Judicial Modification of Consent Judgments in Institutional Reform Litigation. New York Addressi

WILLOWBROOK INFLUENCE ON CONTEMPORARY ADVOCACY

State Association for Retarded Children, Inc. V. Carey. *Brooklyn Law Review*, 50, 657-1103

Kleinfield, N.R. (1997, June 22). Patient's quest for normal life, at a price. *The New York Times*. Retrieved from <http://www.nytimes.com>

Krugman, S. (1986). The Willowbrook Hepatitis Studies revisited: Ethical Aspects. *Reviews of Infectious Diseases*, 8(1), 157-162.

Landesman, S., & Butterfield, E. C. (1987). Normalization and deinstitutionalization of mentally retarded individuals: controversy and facts. *American Psychologist*, 42(8), 809.

Loh, W. D. (1984). *Social Research in the Judicial Process: Cases, Readings, and Text*. Russell Sage Foundation: New York.

Lombardo, P. A. (1996). Medicine, eugenics, and the Supreme Court: From coercive sterilization to reproductive freedom. *The Journal of Contemporary Health Law and Policy*, 13(1), 1-25.

Lowry, J. V. (1949). How the national mental health act works. *Public Health Reports (1896-1970)*, 64(10), 303-312.

Marx, K. & Engles, F. (1998) *The Communist Manifesto: A Modern Edition*. Verso: New York

Mental defectives and epileptics in institutions in the United States, 1936. (1938). *Public Health Reports (1896-1970)*, 53(21), 864-869.

Michel, S. (1994-1995). Dorthea Dix; or, the voice of the maniac. *Discourse: Insubordinate Bodies: Feminism, Spectacle, History*. 17(2) pp. 48-66.

WILLOWBROOK INFLUENCE ON CONTEMPORARY ADVOCACY

- Myers, J.E., Sweeney, T.J., & White, V.E. (2002). Advocacy for counseling and counselors: a professional imperative. *Ebsco Journal of Counseling & Development*: 397-402.
- Myers, K. (1930) Seguin's principles of education as related to the Montessori method. *The Journal of Education (1913)*. 77(20). Pp 538-541, 550-551.
- Mylza, J. (2012, 12 February). Recipe for success. *Staten Island Advance (NY)*, Retrieved from:
<http://Infoweb.Newsbank.Com/Resources/Doc/Nb/News/13CE60CE87024408?P=Newsbank>
- Nussbaum, M.C. (2006). Constitutions and capabilities: "perception" against lofty formalism. *Harvard Law Review*, 121, 4-2262
- Penniman v. French (1806) 2 Mass. 140; 1806 Mass. LEXIS 35; 2 Tyng 140
- Penny, D. & Statney, P. (2008) *The Lives They Left Behind: Suitcases from The State Hospital Attic*. New York, Bellevue Literary Press. (Kindle DX Version). Retrieved from <http://www.Amazon.com>.
- Price, D. M. (1998, 17 April). For 175 years: treating mentally ill with dignity. *The New York Times*. Retrieved from <http://www.nytimes.com>.
- Rebell, M. A. (1986). Structural discrimination and the rights of the disabled. *The Georgetown Law Journal*. 74 1435-1791.
- Ricks, J. L., & Dziegielewski, S. F. (2000). Involuntary sterilization and the mentally retarded, Revisited. *Human Rights Review*, 2(1), 125–133.
- Roberts, S.V. (1986, 2 January). The art of public-interest lobbying. *The New York Times*. Retrieved from <http://www.nytimes.com>.

WILLOWBROOK INFLUENCE ON CONTEMPORARY ADVOCACY

- Rothman, D. J. & Rothman, S.M. (2005) *The Willowbrook Wars: Bringing The Mentally Disabled into The Community*. New York, Transaction Publishers.
- Rubin, P. N. & McCampbell, S. W. (1995). The Americans with disabilities act and criminal justice: mental disabilities and corrections. *National Institute of Justice*. July, 1-7.
- Ryerson, E. S. (1933). The qualification of specialists in Canada. *Canadian Medical Association Journal*, 29(1), 72.
- Ryndak, D. L., Jackson, L. & Billingsley, F. (2000). Defining school inclusion for students with moderate to severe disabilities: what do experts say? *Exceptionally*, 8(2), 101-116.
- Sanger, M. (1922). *The Pivot of Civilization*. (Kindle DX Version). Retrieved from <http://www.gutenberg.org>
- Scheinfeld, A. (1961). *The New You and Heredity*. Philadelphia: Lippincott
- Schmelkin, A. (2015). Making space for a spectrum of community residences: building sustainable and inclusive communities through New York's Padavan Law. *Vermont Law Review*, 39(4) 1025-1055
- Scott, A. O. (2016, 15 June). Review: In 'Finding Dory', a Forgetful Fish and a Warm Celebration of Differences. *The New York Times*. Retrieved from <http://www.nytimes.com>.
- Seguin, E. (1866). *Idiocy: and Its Treatment by The Physiological Method*. W. Wood & Company. Retrieved From <Http://Books.Google.Com/Books?hl=En&lr=&id=T085AQAAMAAJ&oi=fnd&pg=PR7&dq=%22Society+expects+in+return+for+the+foundation+of+the>

[%22+%22present+Time+Seems+Therefore+Particularly%22+%22our+Share+In+The+Treatment+of+Idiots+In+This%22+%22of+Pecuniary+Advantage%3B+And+Dr.+E.+C.+Seguin+Revised%22+&Ots=f0vwsxd9uo&Sig=r3ompurqwwxgbe i6bdrjk8bd6qa](#)

Shakespeare, W. *Romeo and Juliet*. (Kindle DX Version Waxkeep Publishing).

Retrieved from <http://www.Amazon.com>

Shalit, P.R. (1950). The nurse and the national mental health act. *The American Journal of Nursing*. 50(2). 94-96.

Sparer, M. (2006). From Snake Pits to Cash Cows: Politics and Public Institutions in New York, By P. Castellani. Albany, NY: State University of New York Press, 2005, 302 [Book Review] *Publius: The Journal of Federalism*, 36(2), 322–323.

Spaulding, L.S. & Pratt, S. M. (2015). Article 7: A review and analysis of the history of special education and disability advocacy in the Unites States. *American Educational History Journal*. 42(1). 91-109.

Staiculescu, C. & Ungureanu, M. (2012). The social inclusion of the children and young people with social disabilities-between desideratum and reality. *Revista de Asistena Sociala*. XI 191-206.

The modification of consent decrees in institutional reform litigation. (1986). *Harvard Law Review*, 99, 1020-2001.

Tolman, R. (1985). The Practice of Clinical Research: The Single Case Method. [Book Review]. *Social Service Review*, 59(4), 665-666.

WILLOWBROOK INFLUENCE ON CONTEMPORARY ADVOCACY

- Tran, C. (2012). Facts and evidence in litigation under the charter of human rights and responsibilities act 2006 (Vic) and the Human Rights Act 2004 (Act). *Melbourne University Law Review*, 36, 287-1037.
- Tuntiya, N. (2007). Free-air treatment for mental patients: the deinstitutionalization debate of the nineteenth century. *Sociological Perspectives*, 50(3), 469–488.
- Uerling, F. (2007). Federal legal protections for educators with disabilities. *Educational Considerations* 34(2) 4-8.
- Waldman, B., Cannella, D., & Perlman, S. P. (2011) Quaker views of people with disabilities. *American Academy of Developmental Medicine and Dentistry* 41(3) 48-49
- Winerip, M. (2000, January 16) *The Global Willowbrook*. The New York Times.
Retrieved from <http://www.nytimes.com>
- Wolfenberger, W. (1972) *The Principle of Normalization in Human Services in Human Services*. Toronto, Canada: National Institute of Mental Retardation.
- Wolfensberger, W., & Tullman, S. (1982). A brief outline of the principle of normalization. *Rehabilitation Psychology*, 27(3), 131.
- Wright, A. C., & Taylor, S. (2014). Advocacy by parents of young children with special needs: activities, processes, and perceived effectiveness. *Journal of Social Service Research*, 40(5), 591–605.
- Wyatt v Stickney, (1972) 344 F. Supp. 373; 1972 U.S. Dist. LEXIS 14201.
Retrieved from www.lexisnexis.com/hotttopics/Inacademic

WILLOWBROOK INFLUENCE ON CONTEMPORARY ADVOCACY

Yanos, P., Stefanic, A. & Tsemberis, S. (2011). Psychological community integration among people with psychiatric disabilities and nondisabled community members. *Journal of Community Psychology*, 39(4), 390-401.