DEINSTITUTIONALIZING DIFFERENCE: ASYLUMS FOR THE SEVERELY OR PROFOUNDLY MENTALLY RETARDED BETWEEN 1960 - 2000

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BETWEEN 1960 - 2000

by

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This is a history between 1960 and 2000 of asylums operated in the United States for children labeled as "severely or profoundly mentally retarded," and "emotionally and behaviorally disturbed." I use one primary case study of the Willowbrook State School in Staten Island, New York. Willowbrook has already received some focus in the works of David and Shelia Rothman as well as Drs. David Goode, Darryl Hill, and William Bronston, and Geraldo Rivera's newscast in 1972. Primary focus has been given to it because it is both unique and indicative of asylums across the U.S. during the mid 20th Century. It was unique in some of the severity of treatment, which its residents experienced, but overall mirrors national trends in brutal and neglectful living conditions. It also signals larger national trends in the mid to late 70s, which carry over into the 80s and early 90s as part of the deinstitutionalization movement. I find that this movement was largely a response to the conditions for which Willowbrook became a national symbol. Furthermore, even in the wake of the deinstitutionalization movement, there are many problems with federal and state policy that disproportionately disaffect people of color as well as poor people. Finally, I argue that the historical canon must expand somewhat to take into account Deleuze and Guattari's ideas about Societies of Control. Many scholars, such as the Rothman, Tonya Titchkosky, Kim E. Nielsen, and others base their work on the Foucault's notion of a 'disciplinary' society. But Deleuze (sometimes with Guattari) offers a sympathetic

critique of Foucault’s understanding of discipline that adds a great deal of depth to the study of asylums and deinstitutionalization in the mid to late 20th Century.

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"Pay no attention to the man behind the curtain."

- The Wizard of Oz.

"From *Madness and Civilization* on, Foucault analysed the discourse of the 'philanthropist' who freed madmen from their chains, without concealing the more effective set of chains to which he destined them. That everything is always said in every age is perhaps Foucault's greatest historical principle: behind the curtain there is nothing to see, but it was all the more important each time to describe the curtain, or the base, since there was nothing either behind or beneath it. By objecting that there are statements which are hidden, we are merely stating that there are locutors and addressees who vary depending on the systems or conditions. But locutors and addressees are only some of the variables of the statement, and depend greatly on the conditions which define the statement itself as a function."

- Gilles Deleuze, *Foucault*, 54.

The Eastern coast of the United States is jagged, due to millennia of waves crashing against the coastline to produce rigid rock formations, narrow waterways, and on the Eastern front of New York, a series of islands. Below the island of Manhattan is New York City's fifth borough, Staten Island. It is a small island, about 100 miles in area, where it rains one third of the year. The pace and temperament are different than the other four boroughs. It is not a fast paced bustling market or a neighborhood of artisanal eateries and record shops. It is more residential, with slow traffic, and thick accents. In the center of the island stands the City University of New York Staten Island located on Victory Boulevard. Trees line the walkways like they do at so many Eastern schools. Students move around, trying to get to class or meet up with friends. Few recognize just how old the campus really is. Most have no idea that prior to serving as a college, the red brick buildings housed thousands of children diagnosed as 'severely or profoundly mentally retarded.' Almost no one questions why there are so many more buildings made inaccessible by a chain link fence surrounding most of the campus. CUNY CSI sits on the former campus of the Willowbrook State School, the launching point for the deinstitutionalization movement. It was here that a "revolution in care and training" was sought so that children marginalized from broader society might finally enter it, no longer having to "wait around until they die(d)."[1] Despite the efforts of the city, the project has yet to come to fruition, and the events surrounding, and lives of the children at, the Willowbrook State School are still forgotten.

The State of New York took an active role in the lives of people labeled as 'severely and profoundly mentally retarded' very early compared to other states nationwide. In 1890, the New York State Legislature passed the State Care Act, placing all individuals determined to have "mental disorders" under the care of the state.[2] The Willowbrook State School was erected in 1938. It was initially named the Willowbrook Home for the Retarded, but was not immediately used as a school for children understood to be retarded. Rather, during the Second World War, it was utilized as a hospital for returning veterans diagnosed with a variety of injuries. In 1951, it was finally converted to serve its original purpose, housing approximately one thousand adolescents. It operated under the title of Willowbrook State School. Despite the fact that children "attended classes, the institution (was) not really a state school."[3] It was more a repository for society's abject youth than it was an institution of learning, given that by 1973, approximately half of the residents at Willowbrook had been there for more than twenty years, many with IQs lower than thirty-five.[4] With thousands of children, it is safe to assume that a great deal of workers were needed, however due to "high rate(s) of absenteeism at

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[1] Eric Sandahl, "Warehousing at Willowbrook," Letters to the Editor, New York Times, January 21, 1972 and Geoffrey D. Garen, "For a Friend in the Snakepit," *Harvard Crimson*, October 5, 1973, http://www.thecrimson.com/article/1973/10/5/for-a-friend-in-the-snakepit/.

[2] Bonita Weddle, "Mental Health in New York State: 1945 - 1998," New York State Archives 70, 1998, 2.

[3] New York State Association for Retarded Children et al. and Patricia Parisi, by her Mother Lena Steuernagel, et al. v Nelson A Rockefeller, individually and as Governor of the State of New York, and Alan D Miller, MD, individually and as Commissioner of the New York State Department of Mental Hygiene, and Miodrug Ristic, MD, individually and as Director of Willowbrook state School, et al, 72C – 356 and 72C – 357, (Eastern District Court, 1973), 6.

[4] Ibid.

(Willowbrook) there (were) rarely enough individuals on any one ward, on any shift, to properly care for the patients," a problem that only grew worse over time.[5]

Students residing at Willowbrook were provided care through public tax dollars. This is important given that many were from families that could not afford treatment in private institutions or asylums, and could not afford, or did not want, to keep those children at home. The school was not the best care facility in the country, or even in New York State for that matter. However, the offer for free or cheap medical care for children enticed many parents who could not, or would not, look after their children. Very early, thousands of children were housed at Willowbrook. While the school was located on a sprawling campus with dozens of buildings to look after the young students, the infrastructure did not exist to care for their needs effectively. Almost immediately, the school had problems with overcrowding. This issue was compounded by severe understaffing due to the low level of nurses, doctors, and other professionals who wanted to work with children labeled as disabled. A few years after the school opened, it housed six thousand students, despite having been built to house only four thousand. Furthermore, despite having two thousand more students than they could handle, the administration was only able to fill half of its open positions.[6]

As one might expect, this meant that the majority of children received very little care. Many were not able to see physical therapists or speech pathologists that would have been able to help them advance their physical and vocal capabilities. Many children, due to the disabling nature of Willowbrook's gardens, were not taken outside. Several were not able to use the restroom, and many restrooms were out of order. As a result, they were required to sit in their own urine and feces until wardens could clean them. Frustrated, and often unable to

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[5] Ibid., 7.

[6] Michael Ely, "Disinterestedness at Willowbrook," UTSA COLFA Conference, 2014, http://colfa.utsa.edu/colfa/docs/conference/2014/Conference-Work-Ely.pdf.

communicate, several students lashed out, getting into fights with other residents, or even administrative officials themselves. Many, unable to navigate Willowbrook's debilitating architecture, often fell and injured themselves as a result.[7] Due to the high level of physical incidents, and the low number of staff, several children who were injured did not receive treatment for quite some time, if at all. Lack of treatment was so bad, in fact, that one boy who was injured in a fight with another resident received no treatment and lost an eye. When asked about the incident by the boy's parents, doctors responded by stating "it's one of those things that happen." Later, it was found that the same boy had several teeth that were inexplicably broken, and "two unexplained holes in his head."[8] While it is difficult to say specifically why this child did not receive treatment, it is likely that it was a combination of factors. Among them: small staff numbers meant that care givers would not have noticed increasing complications, and treatment would have been even less likely if the incidents occurred at night, given that that is when much of the staff was not working; inexperienced staff, given that much of the staff did not have the proper training, and did not receive updates to training they received previously; and a possibility that the boy was attacked rather than the attacker. In the Willowbrook system, many of the students who got the most attention were those that acted out. This incentivized negative behavior, but also meant that students who were not violent would not receive the appropriate care or treatment even after a violent episode.[9]

This was not an uncommon problem nationwide, but Willowbrook stood out from many other schools. The factor that separated Willowbrook from other state schools across New York

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[7] New York State Association for Retarded Children Inc. et al and Patricia Parisi by her mother Lena Steurenagel, et al., v Nelson A Rockefeller individual and as Governor of the State of New York, Alan D. Miller, MD, individually and as Commissioner of the New York State Department of Mental Hygiene, Miodruy Ristic, MD, individually and as the Director of Willowbrook State School et al, 72C-356 and 72C-357, (Eastern District of New York, (1973).

[8] Ibid.

[9] Ibid.

at the time was that it accepted students under five years old, and had the highest population of black and latin@ students state wide.[10] This unique factor separated it from many asylums at the time, given that the Supreme Court had not yet mandated desegregation. Here, it is necessary to understand disability, not as a unique category itself. Rather, it is wrapped up in the matrix of other classifications such as race, class, and gender. These four groupings reinforce one another, and cannot be thought of separately. This is especially important as institutionalization rates rose throughout the 20th Century. By the mid century, approximately 156,000 people labeled as mentally or intellectually retarded were institutionalized across the United States.[11] Analyzing the lives of people labeled as profoundly or severely mentally retarded is key to understanding the modern age of deinstitutionalization. Without analyzing the lives of people at Willowbrook though, we get an incomplete understanding of the past. This is important as it provides us the ability to comprehend the treatment of hundreds of thousands of people, as well as some of the prevailing ideas that dominate fields of education and mental health following the 1980s.

Focus on disability services, and disability as a concept, has grown over the last two decades within academic settings. This is not a curious phenomenon given that currently, twenty percent of adults in the United States are labeled as having some form of disability, making them the largest statistical minority group in the United States.[12] Frequently, and especially over the second half of the twentieth century, disability has been understood according to a medical

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[10] New York State Education Department, "Historical Records Sources on Latinos in New York State," New York State Archives, (2000), http://www.archives.nysed.gov/a/records/mr_pub66.pdf, 39.

[11] Dennis Felty, "A Brief History as Remembered by Dennis Felty," Keystone Human Services, http://www.keystonehumanservices.org/about-us/history/history-8.php.

[12] Center for Disease Control, "How Many People have Disabilities," http://www.cdc.gov/ncbddd/documents/Disability%20tip%20sheet%20_PHPa_1.pdf, and US Census Bureau, "US Census," http://quickfacts.census.gov/qfd/states/00000.html, last updated June 11, 2014. Of course, when it comes to women, they account for approximately half of the population of the United States. The question of women as a minority group largely comes from symbolic and representational power within local, state, and federal governments, rather than their status as a numerical minority.

model based on physical or mental deficiency, utilizing some notion of "normal" as a basis for understanding other people in daily life and in the law. This is highlighted in the Americans with Disabilities Act of 1990, where disability is defined as "(A) a physical or mental impairment that substantially limits one or more major life activities of such individual; (B) a record of such an impairment; or (C) being regarded as having such an impairment."[13] Here, "major life activities," generally refer to the ability to function daily without assistance, but instead "for oneself," and to appropriately control the "operation of any major bodily function."[14] Furthermore, a person with such disabilities will still be considered disabled even if there are "mitigating effects" of medication, or other forms of assistance.[15] Here too, the rubric of what defines normal is not questioned, nor are the assumptions that any person is capable of living fully autonomously, without the need for assistance, and certainly not whether any human is even capable of controlling major bodily functions, such as their immune system.[16] While this portion of the law was written to echo concerns brought up in the 1990s, it carries on a legacy from the 1930s, in which a person was considered disabled if they could not work, procreate, or live on their own.[17] It should be noted that this is not a statement that simply because one cannot completely control all aspects of their biology that normative descriptions fall by the wayside, but rather that normative classifications themselves create categories which are often inappropriate for large portions of the population because they are too general and wide sweeping.

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[13] Americans with Disabilities Act of 1990, Pub. L 110-325, 110 Congress, (July, 2009), http://www.ada.gov/pubs/adastatute08.pdf, 7.
[14] Ibid.
[15] Ibid., 7 – 8.
[16] This may seem to be an arbitrary distinction to make, however, it is an important one. People understood to have Multiple Sclerosis, AIDS, or Addison's Disease, are considered to be disabled, while people who do not fall under any category of immune disorder are considered to be healthy and "normal." Certainly, no person in either group has control over their immune system, thus the category of being in charge of "major bodily function," as it relates to the immune system is much more arbitrary than reported in the ADA.
[17] Kim E. Nielsen, *A Disability History of the United States*, (Boston: Beacon Press, 2012), 132.

Even at the microscopic level, laws often normalize certain mental and physical activities and behaviors, regardless of how appropriate that normalizing process is. In truth, the meaning of the term ‘disability’ has changed a dramatic amount over the course of the 20th Century, sometimes understood as a moral deficiency, sometimes as intellectual inadequacy, sometimes as a cultural deficit, and sometimes as a genetic defect. Furthermore, disability has been understood over the past 100 years, not in a vacuum of what “normal” might mean in relation solely to the body as a form.[18] Rather, it has been influenced by gender and racial expectations and norms, as well as subject to capitalist desires for greater profits (class norms). Here again, historians must recognize the permutation of these four forms of categorization and their function along an interconnected matrix of power in order to better understand the history of marginalized groups. Therefore, the medical model with which the healthcare system, schools, and the federal government understand disability must be called into question, and with it, the ways in which ‘normal’ people respond to the concept of disability, through a process of rethinking that category, as well as how ‘average’ people respond to persons labeled as ‘disabled’ in work about disability. Here, it must be noted that ‘normal’ and ‘average’ represent normative categories rather than actual majorities in the population.

One of the most common areas in which disability is misunderstood is the lives of people diagnosed and labeled as ‘severely’ or ‘profoundly mentally retarded,’ as well as people labeled as having ‘severe emotional or behavioral disorders’. This is true despite the massive deinstitutionalization movement during the 1960s through the 1990s, which sought medical and legal justice for thousands of Americans housed in asylums across the nation. The deinstitutionalization movement, which began in the 1960s, was largely a response to terrible

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[18] Margaret A. Winzer, *From Integration to Inclusion: A History of Special Education in the 20th Century*, (Washington D.C.: Gallaudet University Press, 2009), x.

treatment at asylums across the country, particularly to the treatment of students labeled as profoundly and severely mentally retarded at the Willowbrook State School in Staten Island, New York between 1951 and 1987. However, during that time, many legal reforms failed overall to address the needs of those individuals, and have not lived up to the dream of shutting down asylums across the nation. In order to make sense of these changes and their respective failings the historical canon needs to be broadened in order to analyze this period in the second half of the century along the lines of Deleuzian Control Societies, rather than Foucault's Discipline Societies. Specifically, historians should take into account Deleuze and Guattari's ideas of the collapse of the juridical in total institutions, Oedipalization, contagion, and the way that architecture functions in terms of smooth and striated spaces.[19]

The canon, as it currently exists, needs to be reformed. A folding must occur that, not only understands, but also uncovers new forms of subjectivity and subjectification that take place over time. This thesis will complicate the academy's current understandings of mental disability by engaging in a historical analysis of the various diagrams of location and their disciplinary functions. That is, the classroom, the home, the hospital, and the neighborhood. Asylums and group homes are unique places in which to investigate how people understand severe and profound mental disability over time precisely because they lie at the intersection of so many various social fields and forces. In studying the initial institutionalization of thousands of individuals into asylums and subsequent deinstitutionalization, one must delve into the changing nature of race, gender, delinquency, medicine, psychology and psychiatry, the changing role of the states and federal government, nationalism, the structure of the family, and even urban

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[19] Alberto Tuscano, "Capture," *The Deleuze Dictionary*, ed. Adrian Parr, (Edinburgh: Edinburgh University Press, 2005), 39 – 40.

policy. While this involves a tremendous amount of background work, and risks muddling the understanding of disability generally and deinstitutionalization specifically, it also offers the ability to perceive connections between areas that are often ignored.

Practitioners of Disability Studies, as a field, are often made up of sociologists, psychologists, anthropologists, philosophers, and literary theorists. While it would be incorrect to assert that historians do not take up a place in the field, their work is often overlooked. Again, it would be incorrect to assert that for all historians. David Rothman is a leader in the study of disability and the history of people categorized as disabled over time. However, to many non-historians, works by scholars like David Rothman, Kim Nielsen, Margaret Winzer, Michael Rembis, and David Goode are often overlooked out of either lack of interest, or are used selectively to portray the world with a stark vision of the past, while constructing the present as a beacon on a hill.

David and Sheila Rothman's classic *The Willowbrook Wars* is easily one of the most expansive and well-written accounts of the history of Willowbrook itself. However, David Goode points out, rightfully, that much of this historical record is about the legal proceedings themselves. Admittedly, much of this thesis also concerns itself with those same proceedings, but attempts to correct the mistakes that Goode points out by also investigating the daily life of residents and workers at the state asylum. This thesis will attempt to follow Goode in his attempt to uncover the daily life of residents at Willowbrook, as well as providing an understanding of what life was like after the school finally closed its doors, by continuing to study the creation of group homes throughout New York City until 2000.

David Goode, along with Darryl Hill and William Bronston, recently released a work entitled *A History and Sociology of the Willowbrook State School*, which takes as its theoretical model, an analysis of total institutions. These institutions attempt to destroy the individual's essence, or to break them down and build them back up, i.e. the factory attempts to destroy the individuality of the worker in order to turn them into a productive cog in the machine. They point to a disparity between total institutions such as prisons, monasteries, factories, schools and asylums. The first four try to create a new individual that will re-enter society. The institution, they argue, simply attempts to break down the person without building anything new. Certainly, they are correct when they state that Willowbrook functioned as a totalizing institution that dehumanized thousands of children and adults that stayed there.[20] Unfortunately, they do not wrestle with how the model of total institutions should continue, or can continue, in the age of deinstitutionalization where, not only have mental health facilities been reduced to no longer functioning as total institutions, but are largely institutions that function inside the community itself. Instead, the striations between the community and the institution are almost totally inseparable. Analyzing the deinstitutionalized group homes after Willowbrook by using control societies, as a framework will resolve this issue.

History is critical to the study of deinstitutionalization specifically, and disability studies generally.[21] Historians have only recently begun to work in this inter-disciplinary framework and my project intends to analyze and understand the changes in institutions and communities over time. This will provide practitioners in the field a better basis for future study, as well as an ability to understand the continuity between the period where total institutions were the primary place of residence for people understood to be severely retarded, and the point where they were

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[20] David Goode, Darryl Hill, and William Bronston, *A History and Sociology of the Willowbrook State School*, (Washington DC: American Association on Intellectual and Developmental Disabilities, 2013), and Michael Ely, "Book Review," *Journal of Intellectual and Developmental Disability*, 2015.
[21] Winzer, *From Integration to Inclusion*, vii – viii.

ultimately transformed to resemble the home, the sites themselves becoming more familial than clinical.

In order to understand the shifting objectives of asylums and group homes, I have chosen to analyze the period between 1960 and 2000. This is, admittedly, a large period of time for a thesis. However, it offers the best option for understanding how people's lives in and out of institutions have changed over time, while simultaneously allowing historians the opportunity to focus on continuity throughout several different historical moments. Furthermore, I will be analyzing national trends in light of one asylum, and the changes that affected those who lived and worked there, and the ways that those people affected the outside world in turn. Willowbrook State School is both exceptional and emblematic of asylums across the nation in the mid 20th Century, as are the areas around the school in all five boroughs of New York City where thousands of group homes were built following its closure in 1987. It was exceptional given that many of the challenges the residents at the asylum faced were certainly terrible, possibly worse than at any other institution of its kind, including isolation, physical abuse, mental abuse, neglect, rampant sickness, and medical experimentation. However, it is emblematic of larger problems across the nation. Dozens of other state schools that operated for the same purpose, i.e. housing individuals labeled as severely or profoundly mentally retarded faced similar problems, many of whom faced lawsuits similar to that filed against the administration of Willowbrook, and the New York State Department of Mental Hygiene in 1972, ultimately closing the school.

It is necessary to take stock of the language deployed when addressing disability. It is, a tool we use to aid in understanding larger concepts, or sense-making devices. Furthermore, the labeling of individuals has been a primary task in institutions throughout the 20th Century, especially as the field has become more professionalized. Even in social contexts there have been massive disputes about the appropriate way to refer to people understood to have disabilities. Where 'retarded,' 'feeble-minded,' 'idiot,' 'moron,' and 'invalid' used to be acceptable, in today's society they are incorrect.

Winzer details, rather well, that during the middle of the 19th Century, anyone viewed as 'retarded' could be labeled under the blanket term "idiot."[22] There was no distinction made based on actual condition or learning/retention ability. The labeling process took place on a much more ad hoc basis. This changed in the late 1850s and early 1860s as the term "feebleminded" was developed. This was seen as the less offensive term, and created striations between different classes of 'reprobates' and 'invalids.' A hierarchy was developed. 'Feebleminded' was the highest of the groups, and the most similar to "normal" people. The next category down was the category of "imbecile." This was developed to describe the form of 'weak mindedness' that many people were thought to have. This camp of people was sub human. They were thought to be able to accomplish miniscule tasks, but largely were not included in the camp of humanity itself. Finally, and again, there were the "idiots." They were thought to only be human in appearance. From birth, they were incapable of understanding the world around them, and due to their inability to communicate, of being understood by the world around them.[23] This total otherness, this creation of classes into those that were passable and those that were exotically foreign, inexcusably other, is precisely what Deleuze and Guattari describe in two ways. The first is the striation and location of groups within the larger macropolitical system in order to prevent and limit movement within a deterritorialized field. The second is the classification of

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[22] Winzer, *From Integration to Inclusion*, 36.

[23] Ibid., 37.

these systems and banishment of difference in order to create a useful hierarchy for the production of state desires. In more concrete language, categories are created in order to produce a smoother functioning social scene where certain groups can be included and others excluded for the benefit of those in power. Furthermore, these categories are used to create a system where actual material production can be realized. In this case, the feebleminded might be able to attend school, and work a job akin to those in general education classrooms. The imbecile might be able to work a menial job, but still produce something that could be bought and sold on the market. They were thought to be as functional as farm animals, but still functional to the purpose of the state all the same. The idiot could not be included, precisely because the idiot could not produce, could not work, could not even communicate. The idiot had to be limited in their mobility and appearance in society, precisely because of their uselessness to those in charge.

These classifications did not extend simply to the material realm, however. Imbecility was also a moral problem. During the 1850s, morality did not apply simply to doing good or bad deeds, but to being able to understand the duality of good and bad in the first place. It was assumed, through a long process of various pseudoscientific ideas, that people labeled as feebleminded, imbeciles, or idiots could not comprehend basic morality. For this reason, people who would now be labeled as mentally retarded were given a second label, "moral insanity."[24] This took place as focus on institutionalization was growing in American society. That is, immorality came to be defined in terms of intellect and as a condition of birth as a greater number of citizens were confined to institutions. This is not only important for historians studying institutions, however, because as asylums (though they had often abandoned that name by this time) were increasing in importance, special education facilities often began to look more like the strict institutions created earlier in the century. Here, we see the growing distinction

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[24] Ibid., 37 – 38.

between special education and general education classrooms, as well as the changing nature of special education classes from supposedly increasing a child's ability to participate in civil society, to being areas of containment and handicaptivity for the infirm.[25]

Furthermore, institutions were also charged with becoming as efficient as possible. Thus, "economic concerns" were regarded as seriously as "individual improvements."[26] It appears then that the convergence between conscience and convenience took place much earlier in American history than the deinstitutionalization period of the 1970s and 80s.[27] Rather, almost from the massive appeals to place individuals in separate institutions or classrooms, containment, and then efficiency were the sole purposes of the educational apparatus as it applied to people considered feebleminded.

The early twentieth century saw people understood as disabled as being born of "bad stock," used to characterize their "feeble mindedness." These ideas were created from prevailing ideologies at the time, and later scientific pseudo-explanations were added to justify them. The most obvious example is the eugenics movement. By the 1940s, however, scientists began to try to classify various forms of 'mental retardation.' They took it as their assumption that humans labeled retarded were a separate class than humans themselves.[28] It is here that Winzer is a bit too optimistic in her progressive view of history. The reason is because people labeled as 'retarded' are still treated as a separate class of people. Even if the labels have changed to become friendlier, the reality and lived experience of these people is overlooked due to the syntactic silence evoked with phrases such as "differently abled."

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[25] Ibid., 40.
[26] Ibid., 40.
[27] Rothman, *Conscience and Convenience*, (New York: Aldine, 2002).
[28] Winzer, *From Integration to Inclusion*, 110.

Today, language has taken on a different form as a result of the disability rights movement. Typically, people are referred to using the model of people first language. That is, "person with a disability," or "person with schizophrenia." This reinscribes the tie between the two, reproducing the dividual of disability. Rarely though, do we question the label of disability itself. This is necessary in order to discuss such a large swath of people. First though, it is necessary to investigate the historical basis for language surrounding disability over time. Even today, the people first language campaign individualizes and discredits people categorized as disabled. The phrase "people with disabilities," first individualizes disability by attaching a person to their disability. This makes it a part of that person, rather than a category applied by people in society. This effectively masks the process of categorization that takes place, as well as ignoring the way in which society disables people by creating certain spaces with a normalized physical or mental type in mind. Second, it discredits peoples' basic humanity with the phrase "with disabilities," calls into question how much of a human the "person" is. It effectively apologizes for their inclusion into humanity after introducing the person. Titchkosky is quite good at elucidating this problematic form of language, however, her alternative of a "politics of wonder" is left wanting when it comes to the process of signification.[29]

Essentially, she is making the argument, following Heidegger, that wonder is a critical component of remembering the way that people are treated in society, and how people understand the world around them. It is important, she states, to resist the urge to calcify any thought process or action, and be open to reinvestigate our assumptions. This is necessary in order to ensure that we do not continue to do bad things that hurt people. However, it does not resolve the issues associated with the phrase "person with disabilities." For this reason, I

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[29] Tanya Titchkosky, *The Question of Access: Disability, Space, Meaning*, (Toronto: University of Toronto Press, 2011), 51 – 52, and 132 – 150.

substitute the term “person labeled as disabled,” or some synonym for the term “label.” This reduces the individualization of the term, because it reflects the societal process of creating categories and perpetuating them, which also reflects the ways that society understands ability in the first place. Second, it does not attach disability to a person in the same way the term “with” does. The person is not someone who lives with disability, society disables them, because of categories that have been created and later used to build specific and real environments.

As stated previously, scholars who study disability often base their theoretical models on the works of Michel Foucault. The reason is quite good. He wrote extensively about deviance in mental illness and containment/confinement. While he may not have referenced mental disability as explicitly, ‘disability’ and ‘insanity/madness’ were understood to be the same for the greater part of the last 300 years. Furthermore, he wrote extensive genealogies about the State’s response to deviant behavior that challenged and innovated the ways historians understand the process of writing history overall. While his works are undoubtedly important, placing too much emphasis on them is misguided, especially in the second half of the Twentieth Century. More attention should be paid to two of his contemporaries, Gilles Deleuze and Felix Guattari. It is curious that historians have not been using their work for the past two decades, considering they wrote extensively about disability, deviance, and psychotic classification, respectively.

In fact, Foucault, himself said, that the 20th Century might come to be known as “the Deleuzian Century.”[30] It is somewhat understandable why historians might have some trepidation about including them. Deleuze and Guattari often wrote more about psychology, art, geology, philosophy, and science than they do history. They would often refer to themselves much more as geological thinkers, rather than temporal philosophers. Furthermore, reading their

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[30] Michel Foucault, *Negotiations*, by Gilles Deleuze, (New York: Columbia University Press, 1990), 88.

works is not an easy task. Their writing is difficult because Deleuze and Guattari put into action their alternative of connecting different things that normally might not be connected. This is why one can read their books and within a few pages encounter references to Judge Schreber, Antonin Artaud, Genghis Khan, and the appropriate way to fix a carburetor. Possibly their most important contribution, though, was Deleuze's statement that, in the 20th Century, we live in a society of control. Foucault famously argued that we adopted the disciplinary model of the past where confinement of deviance was key. Control societies differ, however, precisely because the state and capital function in conjunction with one another, and even the diminishing boundaries of separation and containment were for the express purpose of increasing capital, utilizing any and all surplus labor, and blurring the lines between the home and the prison/hospital.[31]

When using their theoretical model, we can highlight the uniqueness of the past 50 years, and map those changes over time. This political dimension is not an attempt to undermine Foucault or Deleuze's work on the way that knowledge and power operate, or even to undermine Foucault's articulation of how judgment and punishment have worked/are working. Instead, it is to suggest that punishment, judgment, separation, confinement, and reintegration now function in a way better articulated by Deleuze. This avoids the problematic position of disinterestedness where scholars avoid "taking their own disciplinary standards under critical historical investigation," and instead understand themselves "outside the reach of historical and political determinations."[32] This work undercuts this problem precisely because one of its major undertakings is to rethink historians' assumptions about the mid to late twentieth century, and in doing so, uncover the failures and successes of those histories, and then to refashion them into

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[31] Gilles Deleuze, "Postscript on Societies of Control," and Felix Guattari, *The Anti-Oedipus Papers*, ed. Stephanie Nadaud and translated by Kelina Gotman, (Cambridge: MIT Press, 2006), 62, and John Marks, "Control Society," *The Deleuze Dictionary* ed. Adrian parr, 53 – 55, and Kenneth Surin, "Control Society + State Theory," *The Deleuze Dictionary* ed Adrian Parr, 55 – 58.

[32] Deleuze, *Foucault*, translated by Sean Hand (Minneapolis: University of Minnesota Press, 1988), xiv.

something new. A new toolbox, to be utilized without being over arching, but instead, to better understand the circumstances that have developed dynamically over time, and that now characterize our modern age.

Furthermore, this thesis differs from other works on the nature of deinstitutionalization, particularly in terms of inclusion and exclusion, by focusing on the ethical arguments made in treatment about children labeled as mentally disabled, particularly in Willowbrook's lawsuit. It focuses on ontological presumptions made about those same individuals throughout the institution's period of operation, particularly concerning the coerced medical experimentation between 1956 and 1972. Finally, I question the epistemological relationships that shifted over time, specifically as Willowbrook closed and group homes were established across New York State.[33] This will ensure that issues of ethics are taken into account, rather than divorced from scholarship entirely. It will also avoid the trap of taking certain values as given, or of continuing the circulation of buzz words without any meaning or investigation of what those terms (read: inclusion, diversity) might mean in daily life.

Therefore, there are four major areas that Deleuze and Guattari's work ought to be utilized more in the understandings of disability generally, and deinstitutionalization, specifically. They are: the transition from discipline to control societies, their theories about Oedipalization as a socially repressive force, the fear of otherness as a form of contagion, and their distinction between smooth and striated spaces in the mid to late 20th Century.

The first nuance that scholars need to recognize is the delineation that Deleuze made in "Postscript on Societies of Control." Here, he questions Foucault's argument in *Discipline and Punish*. Foucault argues that the basis of punishment is focused on the soul, or the essence of an

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[33] Allan, *Rethinking*, 51.

individual often in prisons, asylums, sanitariums, etc.[34] In this way, the penal system has two elements. The first is the disciplinary element and the second is the juridical. It is often helpful to think of this matrix of power in three stages.

1.) Disciplinary (a) (coded)
2.) Juridical (decoded)
3.) Disciplinary (b) (recoded)

People are profiled, policed, and neighborhoods are patrolled. People are presupposed to be dangerous or threatening before any deviant action is taken on their part. This is the disciplinary stage (a). Following this stage, the individual may be arrested, taken in to custody, charged with a crime; bureaucratic paperwork will be filled out to ensure their confinement is lawful. Under the rule of law though, every person is guaranteed the right to a trial. Here, the accused, the jury, and all present, are told, "the person is not a criminal in their essence, but they did commit a crime." While the sincerity of this statement can certainly be questioned, the point remains the same. The judge and jury wear the mask of neutrality, and there is delineation between the person and the code, i.e. "criminal." This supposed neutrality is critical. This is the juridical step. It requires the institution of the court, the prison, the asylum, or the workhouse. Following the trial comes the judgment and the sentencing, again, the person's essence, their very personhood, becomes wrapped up in the code of "criminal." They are sent to a disciplinary institution, the prison, in order to pay their debt to society, and more importantly, to reform. The important point of this is that, in disciplinary societies, there is a moment no matter how brief, when the individual and the code can be separated from one another. In the society of control, however, this moment is gone. Instead, the individual and the code come to stand in for one another. There is a completely metonymic relationship between the two producing, what Deleuze refers to as, a

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[34] Michel Foucault, *Discipline and Punish: The Birth of the Prison*, (New York: Vintage Books, 1977), 16.

"dividual."[35] While Foucault and Deleuze specifically cite prisons as an example of this, it should be noted that their analyses are meant to go much further than that. They are describing the foundations of society far beyond some level of empirical analysis to reference the ways in which one institution works. Instead, they are implicating prisons, asylums, group homes, factories, offices, bureaucracies, the government, the police force, religions, because they exist along the power knowledge nexus to code individuals, and to define their essence. In terms of deinstitutionalization and group homes, children are consistently divided into series of identifiable classes. This explains the expressions "disabled child," and the current trend of referring to people as living "with a disability." While the latter is often regarded as a linguistic shift to reflect the personhood first, the disability is still tied to the individual. The code of disability comes to stand in for the child themselves, hence the phrases "the handicapped," "the disabled," and so on.[36] This is important for the study of disability precisely because it marks a shift in the way that society functions. Even if the statement of neutrality about a person's essence or worth spoken by the judge and jury is insincere, it still must be made. There is a brief moment where the code does not come to stand in for the individuals themselves. In relation to disability, however, even in disability rights movements, this is not the case. There is not a moment in which the child in question might stand apart from the label placed upon them before being reformed. The institution has faded away, and the institution is critical for the juridical moment in disciplinary societies. Instead, the two are always already wrapped up within one another. The play goes on, but no one bothers to wear the mask of neutrality. The audience is not interested in it anymore.

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[35] Gilles Deleuze, "Post-Script," 6, and Felix Guattari, *The Anti-Oedipus Papers*, ed. Stephane Nadaud, translated by Kelina Gotman, (Los Angeles: Semiotexte, 1970), 226 – 227 and 267 – 268.

[36] Jeff Roberts, "Bridging the Gap between What is 'Spoken' and What is 'Said' with Song—Over-Signifying with Personhood Against the Backdrop of Disease-Centric Discourse," Master's Thesis. Baylor University. 2007.

This is not the defining characteristic of a society of control, however. Another nuance must be made. Foucault also maintains that there are distinctions between various institutions of reform and discipline. He argues that the school, the church, the courthouse, and the prison, while all working in conjunction with one another, still operate independently. However, in societies of control, the institutions run into one another, the rigid lines between them become more and more porous. Here, the school, the factory, and the prison exist simultaneously.[37] This may sound abstract. When analyzing it in the context of group homes, however, it makes more sense. Group homes, in the era of deinstitutionalization, function not only as residences for individuals, but also as sites where they receive training to participate in the daily economy, and as places where they receive medical care. In this way, the home now operates as institution, factory, school, and hospital.

The second reason that Deleuze and Guattari should receive more attention from scholars is their focus on Oedipalization. The reason that this theory does not receive much attention presently is fairly obvious. They wrote much of their work, including the first part (AntiOedipus) of their two part series, *Capitalism and Schizophrenia* in response to psychoanalysts, specifically Sigmund Freud and Jacques Lacan. In that context, few historians paid any mind to the theory that society, over time, creates certain forms of Oedipalizing structures. That is, individuals are constantly in flux with other people, organisms, surroundings, etc. For that reason, it is improper to say that humans have one essence, when in fact they are constantly and dynamically changing. Oedipalization then is a process of social repression that attempts to stabilize and calcify human essence to a set level of characteristics, generally for the purpose of sustaining capitalism in its present form and/or allowing capitalism to evolve so that it, as a system, can become more all

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[37] Deleuze, "Post-Script," 5.

encompassing than it presently is.[38] It gets its name, noticeably, from the play Oedipus Rex written by Sophocles, later used to explain human desires and interactions by Freud. Freud stated, famously, that young men were subject to the Oedipus complex, in which they wished to kill their father and sleep with their mother based on a series of characteristics ascribed to each gender during infancy. This produced what Deleuze and Guattari refer to as "the Mommy-Daddy-Me triangle."[39] The problem with this form of Oedipalization is that it reduces all social determinations and interactions to one singular formula, that of the child's relationship with their parents. While this is a simple formula, it is far too simplistic. Instead, humans are consistently changing due to the dynamic nature of the world around us. As stated previously when discussing the normalizing or disabling nature of society, relationships with people and objects in the world is largely relational and situational, rather than set in stone due to our relationship with two people during our formative years.

This is important to institutions and deinstitutionalization because, in the earlier part of the 20th Century, intellectual disability was thought to be purely genetic. Over time, however, thinking changed, and people began to argue that the nuclear family was the most important factor in determining whether or not a child would be 'retarded.'[40] Oedipalization, while it can be applied to several different social systems, all of which might create determinations for individuals, or in the society of control, dividuals, the family is one of the most useful. This process, as it relates to special education, created the conditions necessary for educators to begin looking into familial conditions, and assigning given values to various family set ups. Furthermore, the creation of this value system, and the weight often placed on the mother to

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[38] Tamsin Lorraine, "Oedipalization," in *The Deleuze Dictionary*, ed Adrian Parr (Edinburgh: Edinburgh University Press, 2005), 194 – 196.

[39] Gilles Deleuze and Felix Guattari, *Anti-Oedipus: Capitalism and Schizophrenia Volume 1*, translated by Robert Hurley, Mark Seem, and Helen R. Lane, (Minneapolis: University of Minnesota Press, 1983), 67 and 157.

[40] Winzer, *From Integration to Inclusion*, 138 and 148 – 149.

establish good conditions for children, allowed for thousands of students to be placed into asylums across the country without having actually committed any crime whatsoever.[41] Rather, they were put into institutions because of the supposed likelihood that they might become 'feeble-minded.' Unless we understand the process of Oedipalization in the creation of values and determinations, and the ways in which that gets put into practice, it is difficult to explain the full story of institutionalization, and the subsequent creation of group homes over time. The impact is that it leaves historians incapable of accounting for the lives of thousands of people with accuracy and precision. If those accounts are incorrect, the silence surrounding children and adults who were kept veritable prisoners at places like Willowbrook will continue.

The third major reason to add Deleuze and Guattari to the historical canon is based on their idea that otherness is feared due to the possibility of it being a contagion. Deleuze and Guattari write about the expression of otherness as being monstrous. They are not saying this to categorize the other as actually being monstrous, but rather making a descriptive statement about how the other is perceived in society. Generally, historians analyze otherness in terms of how threat construction operates based on physical force, or mental acuity. For instance, a plethora of historians have analyzed the ways in which the US and Russia wrote about one another in textbooks disseminated to schools. This is passé. Deleuze and Guattari are unique in this area precisely because, they point out that it is not the force of the other that is frightening to those who are in charge of society. Rather, it is the fear that they might infect 'normal' people in society. Frequently, they use the metaphor of the vampire or the werewolf to illustrate their point.[42] The real fear surrounding these mythical creatures is not that they will overpower humans. Rather, it is that they will turn you into one of them via infection. Their strength is that

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[41] Ibid., 139.

[42] Patricia MacCormack, "Unnatural Alliances," *Deleuze and Queer Theory*, (Edinburgh: Edinburgh University Press, 2009), 144 – 145.

they can blend into society at nearly any time. They are not identifiable, but their movement is emblematic of contagion, or spread without defense. This, rather unexpectedly, relates well to deinstitutionalization and the creation of group homes.

Children labeled as feeble-minded, idiotic, or moronic were often removed from society, not because they had committed a crime, but because society was not built for them. There was a more sinister reason for doing so, however, it was often assumed that children labeled as being disabled might infect those around them, making their classmates “simple” as well.[43] It was asserted that students would distract, disrupt, and possibly change those around them, thereby preventing societies growth overall. Even into the 1970s commissions were created and laws passed in order to prevent ‘retardation,’ describing it as though it were a disease. Richard Nixon, while still president, went so far as to say that the nation needed to “combat mental retardation,” thereby allowing the populace to “reduce the incidence of retardation.”[44] It was under these auspices that politicians, teachers, reformers, church groups, and average citizens justified removing children from society, and segregating them in institutions and asylums. Descriptions of the other in disability that do not take into account this distinction between the forceful other and the other as figure of contagion will not be accurate in their description of the past. It is for this reason that Deleuze and Guattari need to be added to the historical canon.

Furthermore, it is impossible to understand the eugenics movement in the United States without understanding contagion on the microscopic level. The eugenics movement was created out of fear and a misreading of scientific theory. The fear was, again, not of a forceful other that might destroy US society through physical prowess. Rather, it was the fear of corruption on a genetic level, of infecting the blood and the genes. This was a pernicious threat that had to be

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[43] Winzer, *From Integration to Inclusion*, 24.
[44] Exec. Order No. 11776, FR 11865, 3 CFR, 1971-1975 Comp., p. 859.

weeded out by cleaning the gene pool itself; for fear that American institutions would crumble otherwise. Here, it is necessary to understand the ways in which contagion was constructed as a threat, precisely because it was the tool used to determine whether people in society were acceptable or abject. Without a clear understanding of the eugenics movement throughout US history, it is not only impossible to understand the incredible weight given to pseudoscientists that advocated for mass institutionalization, but it is also impossible to account for the power matrix whereby race, class, gender, and ability coincide. It was because of this fear that many eugenics scholars advocated for forced sterilization in cases like Buck v Bell; as well as stronger immigration policies that targeted racial and ethnic minorities, as well as men and women who did not fit the gendered norms of the time; and the institutionalization of thousands of American citizens who committed no crime.[45] Unless Deleuze and Guattari are added to the historical canon, these destructive policies and attitudes will not be understood by modern historians, producing inadequate scholarship that does not speak to the lived experiences of thousands of individuals.

Finally, the fourth reason to adopt Deleuze and Guattari into the historiography of disability is based on their theories of smooth and striated spaces, largely discussed in the second volume of their *Capitalism and Schizophrenia* double feature, *A Thousand Plateaus*.[46] Here, rather appropriately, it helps to think of smooth and striated muscles found in the body. Smooth muscles are those that control involuntary movement and do not have creases in them. Striated muscles, on the other hand control skeletal movement, and when looked at under a microscope have lines on them. In terms of society, a smooth space would be a space with very few barriers

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[45] Buck v Bell, No 292 274 US 200 (Supreme Court, May 2, 1927), https://www.law.cornell.edu/supremecourt/text/274/200, and Hornblum, *Against Their Will*, 33, and Nielsen, *A Disability History*, 102 – 110.

[46] Gilles Deleuze and Felix Guattari, *A Thousand Plateaus: Capitalism and Schizophrenia Volume 2*, translated by Brian Massumi, (Minneapolis: University of Minnesota Press, 1987), 412 – 423.

to entry. Walls or other architectural features that would prevent certain movement, on the other hand, might create a striated space. For instance, many government buildings now employ various cement structures around them to ensure that people cannot park vans too near the buildings themselves. This is a striated space. The government, to encourage various behaviors, can also use the smooth space. The streets of Paris, for instance, were widened by Hausmann to ensure easy passage of people, and to ensure that should a riot erupt, that barricades could not be created easily. This is not mere trivia, however. Instead, it is necessary to understand the ways in which society has produced a disabling world through the development of various smooth and striated systems.

Dr. Tonya Titchkosky explains that disability is a sense-making device. That is, "disability is a way of perceiving, a form of interpretation, a way to orient to not only to people but also to places, things, and events – especially if we understand those places, things, and events as unfortunate."[47] She is stating that disability as a construct gets interpreted and influences the ways in which society understands and responds to people labeled as disabled. In this way, it becomes part of the very forms of knowledge production that Foucault describes. This is not simply to suggest that disability is being shaped by popular beliefs rather than natural causes. Again, her claim is much more nuanced. She is asserting that people are not themselves disabled in created spaces. Instead, society is disabling. This is most apparent in everyday architecture. For instance, a person using a wheel chair is not disabled until they reach a flight of stairs with no ramp. The stairs do not change the person, however, only the conditions and possibility of their movement. In this way, society disables its own citizenry, and individualizes their inability to gain access to various resources under the term "disabled."[48]

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[47] Tonya Titchkosky, *The Question of Access*, 4 – 5.
[48] Ibid., 131 – 132.

This is important for disability generally, and studies about institutions specifically, because schools and institutions are themselves not neutral spaces. “Spaces are never neutral.”[49] They are designed to facilitate learning, and often in the case of US history, to separate students from one another, often based on socially motivated evaluations. The history of institutions, asylums, almshouses, community education programs, integration, and inclusion cannot be understood unless scholars take space into account. The ways in which legislation is passed, and judgments are made about who can be included and who cannot have very real effects, and often become a reality in the construction of social spaces. Deinstitutionalization cannot be understood then by analyzing the changing relationship of people to labels (codes), or the assignment of values to the family (Oedipalization), or even through changing relationships of comfort and fear (contagion). It also must be understood in terms of the architecture created to house the very real students being discussed, and the motivations for creating that architecture. Spaces are never neutral. Scholars would be remiss if they did not include Deleuze and Guattari to analyze the forms that schools take, and the justifications for those forms’ existence. The only other work that addresses special education in relation to Deleuze and Guattari, Julie Allan’s *Rethinking Inclusive Education*, is often not equipped to challenge many assumptions. The reason is because Allan often understands deterritorialization as an end point, rather than a political tactic of change and transformation that is, at least to a certain extent, inevitable. It should be noted here, that this is not meant to be an anti-realist statement where anyone can be anything that either they, or someone else imagines. Rather, it is an issue of relationality, where the disability is not located specifically in the individual, but is a product of the way that the individual interacts with people and objects in social spaces, as opposed to the world not shaped by humans (creek beds,

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[49] Jeff Roberts, “Ludlow Zero Zone,” (unpublished manuscript, Spring 2013), Microsoft Word file, and John Bodnar, *Remaking America: Public Memory, Commemoration, and Patriotism in the Twentieth Century*, (Princeton: Princeton University Press, 1993), 13 – 19.

mountains, etc.) This should then reflect back on the society that normalizes disability by assuming that the built spaces in it are neutral, as opposed to created with a specific user intended for them.

Unless scholars come to grips with and begin to utilize the works of Deleuze and Guattari, they will be unable to account for the removal of the institution in the second half of the twentieth century, meaning that works which take Foucault or total institutions as their model will not address the unique situation of the people they discuss, producing even more historical silence. Furthermore, writers will not be able to understand socially repressive forces or social stigma and fear as it relates to disability, skewing understandings of the eugenics movements, as well as missing out on the ways in which race, class, gender, and ability come to be mutually reinforcing systems of categorization, and at times, oppression. Finally, without understanding the way that social spaces get created, disability will continually be internalized and individualized, further stigmatizing thousands of people.

This thesis is split into six chapters. The first chapter is the introduction, which explains, briefly, the various findings of this thesis, namely that Willowbrook began the deinstitutionalization movement, that many parts of that movement ultimately failed, and that the historical canon needs to be widened to include Deleuze and Guattari, rather than just Foucault, when discussing deinstitutionalization.

The second discusses the opening of Willowbrook and the controversial hepatitis experiments conducted there between 1956 and 1972. There, I expand on the ethical justifications and objections to those experiments, and put them in national context, as they were part of a national trend that dehumanized thousands of children labeled as disabled. I will then explain the national response as they gained some popularity and the way that the realization that children were being used for medical experimentation with deadly diseases spurred some parents to action.

Chapter three begins with the parents' group formed at Willowbrook and their initial attempts to change the school, ultimately resulting in legal action. Here, I discuss the major claims made against the school, their responses to the parents, the courts decision to grant funding and push the school to hire more staff, and to decrease class sizes. Chapter four largely discusses the continued attempts to change Willowbrook until the school was ultimately shut down. This chapter ends with the closure of Willowbrook, and with the description of new group homes set up around the city.

Chapter five discusses the creation of those group homes, their challenges, and the strategies that various advocacy groups faced in and around New York City. The largest issue for many of these groups was funding, as the residents of Willowbrook were dying out, they sought new ways to secure previously agreed upon funding for children throughout the five boroughs.

Finally, chapter six discusses the legacy of Willowbrook both in New York City and throughout the United States. It details the successes, and ultimate failures of the deinstitutionalization as many group homes still struggle for funding, and hundreds of institutions still dot the landscape of the greater United States. Finally, it discusses the defunding of massive deinstitutionalization programs in New York State and the largely forgotten, and erased history of the Willowbrook State School, and the children and adults who lived there.

CHAPTER TWO: WILLOWBROOK OPENS ITS DOORS

From its outset The Willowbrook State School was managed incredibly poorly. There was little oversight from the state government, and conditions quickly deteriorated to the point where disease was common, individuals were often isolated from their peers for great lengths of time, pests ran throughout the school without containment, and residents were not cared for to the point where several were left naked or in their own feces. Dennis Felty, a former resident, described the asylum as more of a prison than a school.[50] Geoffrey Garin, a Harvard student who worked at Willowbrook for a summer wrote an editorial to *The Crimson* describing the physical and mental abuse students faced for getting out of their seats. He also described the shortage of personnel, as well as their lack of willingness to work with students, or to help them with the most basic tasks. According to Garin, attendants who were "proficient in the art of spoonfeeding can scoop a meal into the mouths of nine children in less than twelve minutes" in order to avoid spending too much time around the children themselves.[51] Given the severe negligence as well as abuse, and fighting between patients, it is little wonder that several residents at Willowbrook attempted to escape.[52]

As treatment became worse, the overcrowding led to outbreak of communicable diseases. This was especially problematic given that hygiene was not a major concern for the administration within the school. As children were left in their filth, and some had either accidents or fights that left them bloody, airborne diseases were not the only concern, but rather those that could be spread through bodily fluids. In fact, by the early 1950s, approximately

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[50] Amy Padnani, "Willowbrook Survivors Recollect Dark Days," SILive, May 7, 2010, http://www.silive.com/news/index.ssf/2010/05/willowbrook_survivors_recollec_1.html
[51] Garin, "For a Friend in the Snake Pit," 1 – 2.
[52] Padnani, "Willowbrook Survivors Recollect Dark Days."

ninety percent of children at Willowbrook had Hepatitis A, B, or both.[53] One of the most common and drastic problems associated is that they developed jaundice due to liver failure.

In order to combat the spread of the disease, the administration at Willowbrook hired Dr. Saul Krugman and his partner Dr. Joan Giles to treat, and hopefully develop a cure for, the disease. The two hypothesized that gamma globulin, a cocktail of antibodies that occur naturally in the body, could be used to treat the disease, and over time might "decrease susceptibility" to both Hepatitis A and B.[54] The first tests were simple enough. The doctors took students who had the disease, quarantined them in a special ward, and began giving them gamma globulin. The test was a success, and the new doctors at Willowbrook found that the concentrated antibodies could indeed treat the disease. A cure eluded them, but the treatment was available and the children were safe.

However, as often happened on that patch of land in Staten Island, the children would not be safe from the administration. Soon, Krugman and Giles began a new series of tests in an attempt to concentrate the disease itself in hopes of finding a cure. Their aspirations, while noble, did lead them into uncharted territory and ethical debates that they would be involved in long after they left Willowbrook.

In order to find a cure for the disease, a goal, which they estimated would help people across the world, the doctors began infecting students with hepatitis, who previously did not have it. While before, they were treating children who contracted Hepatitis before their arrival and some who naturally contracted it during their tenure at the school; this shift marks a unique

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[53] Ely, "Disinterestedness at Willowbrook," 2 and Saul Krugman, "The Willowbrook Hepatitis Experiments Revisited: Ethical Aspects," *Reviews of Infectious Diseases* 8, no 1, (Oxford: Oxford University Press, 1986), 156 – 162.

[54] Ely, "Disinterestedness at Willowbrook," 5 and Saul Krugman and Joan P. Giles, "The Natural History of Viral Hepatitis," *Canadian Medical Association Journal* 106, Ottawa: Canadian Medical Association, 1972), 443 and Krugman "The Willowbrook Hepatitis Experiments Revisited," 159 – 160.

moment. It marks a shift from the doctors treating the disease that they did not, at least actively, cause, to becoming the distributors of disease and difficulty. They gave students the disease by injecting them with “the processed feces and serums” of students previously sick with Hepatitis.[55] The question must be asked, “how could this be justified, not just to Krugman, but how could he have the authority to do this? Where were the students parents?” This is a reasonable question. The authority came from the parents themselves.

Prior to conducting the experiments in which Krugman and Giles infected children labeled as disabled with Hepatitis A and B, they did indeed receive permission from the parents. It is reproduced here:

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[55] David Rothman and Sheila Rothman, *The Willowbrook Wars*, 261 – 263, and Mount Sinai Medical Community for Human Rights, “Experimentation at Willowbrook,” 1972, 3.

November 15, 1958

Willowbrook Study Staten Island, New York

Dear Mrs. __________:

We are studying the possibility of preventing epidemics of hepatitis on a new principle. Virus is introduced and gamma globulin given later to some, so that either no attack or only a mild attack of hepatitis is expected to follow. This may give the children immunity against this disease for life. We should like to give your child this new form of prevention with the hope that it will afford protection.

Permission form is enclosed for your consideration. If you wish to have your children given the benefit of this new preventive, will you so signify by signing the form.[56]

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[56] Rothman and Rothman, *The Willowbrook Wars*, 265 – 266.

In studying this form, it is clear that the doctors are suggesting that they are providing treatment for the disease itself, rather than introducing the disease and then choosing certain children who will receive gamma globulin, while others will receive no treatment whatsoever. This misleading characterization is compounded when one considers that many of the children at Willowbrook had parents who were poor and could not afford a lawyer to review the document for them. It is also important to note that many of the children were members of racial minority groups and would be incapable of attending many other state run institutions due to pre-existing racial discrimination.[57] This left the children and their parents in a rather precarious position. In another version of the letter, parents were further informed that their children would receive special access to a closely monitored ward if they took part in the experiments, while they may be unable to stay at the school if they did not.[58] Here, parents were made to choose between allowing their children to receive experimental medical treatment, though the extent of which they were unaware, or possibly having their children released from the school entirely. The second was often not an option due to the low-income status of many of the families in question, as well as the aforementioned racist discrimination in society writ large.

It is important to note though, that these experiments were not only problematic due to the deceitful nature with which they were carried out. They also prevented any input from the children in question. While it is true that many children had trouble communicating, the point of the school overall was to help them learn communication skills, as well as involve them in some average activities of every day life. By removing his patients from the decisions that would affect them, in order to chart their “incubation periods,” or the time it took for the Hepatitis he infected them with to result in jaundice, he continued to dehumanize an already disproportionately

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[57] The Progressive Labor Party, “The Willowbrook Experiments,” 1972, 1 and Ely, “Disinterestedness at Willowbrook,” 10.

[58] H.H. Borman, “Letter to Mrs. Alyce Mustor,” 1958 and Rothman and Rothman, *The Willowbrook Wars*, 266.

disaffected group of people.[59] This transformed Willowbrook from a school into a "living Hell on Earth."[60] The use of these children's bodies as a form of experimentation, while extreme, does indicate the ways that people, even professionals, considered disability and people labeled as disabled. Patients at Willowbrook were to be used. Their bodies became productive, despite the fact that they could not be productive in society, at least in the way society was set up at the time. Even if their labor could not be extracted in the factory, the lines between the institutions blurred creating a society of control in which the body would be the site of production itself. This helped initiate a period where the school, the hospital, the factory, and the site of discipline became one and the same.[61]

While David Rothman and David Goode have written about this study briefly, and while it is certainly unethical, it is not singular. In the 1940s through the 1960s, it is estimated that approximately 40 different institutions for people labeled as retarded, insane, and several criminal reform institutions conducted similar medical experiments on patients, many of whom were incapable of describing their symptoms, calling into question level of consent these experiments were conducted with.[62] These individuals were targeted largely because they had no way of defending themselves. Many, especially at Willowbrook, would not have been able to return home. Furthermore, there was very little support in the community for the protection of these children and adults, and very little political traction to build support networks on. Their bodies were used as fodder, then, for the advancement of scientific advancement.

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[59] Krugman and Giles, "The Natural History of Viral Hepatitis," 159 – 160.

[60] Edward I Koch, "Letter to John E Cone," Congress of the United States of House of Representatives, Washington D.C., 20515, February 7, 1972.

[61] Deleuze, "Postscript on Societies of Control," and Bray, "Chemical Control."

[62] Mike Stobbe, "Ugly Past of US Human Experiments Uncovered," NBC Online News, Last Updated February 27, 2011, http://www.nbcnews.com/id/41811750/ns/health-health_care/t/ugly-past-us-human-experiments-uncovered/#.VMLcPy7F95w.

Again, this form of experimentation was incredibly pernicious at Willowbrook, however it was not unique. Across the nation, asylums and state hospitals were performing experiments on children labeled as “mentally retarded” for the purposes of gaining new insight into diseases and other phenomena. Frequently, patients’ rights were taken for granted. In fact, doctors often drafted agreements meant to strengthen their own claims to a patient’s body, and cut down on the importance of consent. This was the case in 1964 with the Declaration of Helsinki. One may wonder how doctors could justify this behavior, or how society writ large could allow children to be experimental subjects. Frequently, these experiments were part of a larger nationalist trend where doctors stated that they were conducting experiments “’intimately and directly associated with the War effort.’”[63] By tying desires to secure the nation from the Communist threat abroad to the bodies of children who were plentifully stockpiled in supposed schools across the nation, doctors were free to do as they like with the permission of the National Institutes of Health including crack down on the consent patients would have to provide under the Nuremberg code. This allowed doctors and researchers to do as they wished, regardless of the child or family’s protestations because, as they decided, consent did not matter nearly as much as “the effort to minimize ‘loss of life, illness, or permanent injury from these diseases’” given that those losses were seen to “’outweigh any disadvantage to a child’s rights.’”[64]

The military was not ignorant, however, they were actively supporting those medical experiments. In fact, medical investigators in the US army asked Krugman for “’preblood sera’” from the Willowbrook children in order to advance their own experiments. Krugman may have sent the doctor some of that sera, but could not send much because, as he claimed, his “’subjects

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[63] Hornblum, *Against Their Will*, 46.
[64] Ibid., 60 and 68.

are children." This limited his ability to get "' large quantities of blood.'"[65] In other parts of the country, children diagnosed as mentally retarded, and some adults diagnosed as mentally ill were given experimental medicine. Dr. Ewen Cameron, funded by the CIA, produced a multifaceted treatment that he thought would cure schizophrenia. It largely included the administering of LSD, electroshock therapy, and experimental behavioral therapy. In Sonoma California, children held at Sonoma State Hospital diagnosed with cerebral palsy underwent procedures with pneumoencephalograms whereby air was injected into the spinal cord itself and pushed through the brain with the help of x-rays. The procedure is very painful. Dr. Nathan Malamud, and a team of researchers from the University of California carried out the procedures in order to find the cause of cerebral palsy. The doctors frequently injected radioactive material into the spines of those children as well. Many children died at a young age. The cause of death was likely that they died of radioactive poisoning. Several of the students had their brains removed in autopsies for further study. The reason for injecting that material was to understand the effects of radiation on the human body, fueled by social fear during the Cold War.[66] These experiments were done across the nation and involved the lives of thousands of children. Here, students' bodies were used for the benefit of researchers and psychometric testing and products were used to extract the value from students' veins. Here again, scholars can analyze and understand the permutation of the school, the hospital, and the factory that took place as the United States institutions shifted into sites of control.

Following these experiments at Willowbrook, doctors and parents began to demand change. As previously stated, the administration was slow to alter nearly any conditions of the asylum. The parents had only one course of action, as they understood it, they took the

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[65] Ibid., 101.

[66] Ibid., 52 – 58, and 76 – 77.

administration and several city officials to Court. This turned out to be one of the most important court cases of the mid twentieth century, as it laid the foundation for national deinstitutionalization.

CHAPTER THREE: ORDER IN THE COURT

Following the post war period, groups of people labeled as disabled began demanding greater reforms throughout society based on claims to civil rights.. In order to bolster these claims, many groups began protesting throughout the country.[67]

This carried on into the 1970s as a greater number of people categorized as disabled argued for structural changes, especially in architecture to allow for greater access throughout the US, as well as changes in attitudinal barriers, so that people classified as having disabilities would not be castigated as pariahs throughout society.[68] This was an incredibly apt moment to do so as the number of people labeled as disabled steadily grew over time as new categories were created. In fact, between the period of 1884 and 1967, the population of people labeled mentally retarded grew from 456 to 27,500.[69] That is a growth of 1,658%. Here, people designated as disabled also began to question medical definitions of disability. They claimed that disability was socially constructed and that the stigma associated with disability acted to unfairly target and prevent people from gaining equal access to social benefits.[70]

These changes in ideology and structure took place at the same time as the movement for independent living, a vital and important part of the disability rights' movement overall.[71] This resulted in people actively pushing for changes in living and transportation availability for people identified as having disabilities, culminating in the move for deinstitutionalization. This shift was part of a larger trend in which people's individual autonomy was stressed when it came to daily life, eventually resulting in the deinstitutionalization of the 70s and 80s. In total, "the

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[67] Nielsen, *A Disability History*, 161.
[68] Ibid., 161.
[69] Frederic Grunberg, "Affidavit, Grunberg," New York State Association for Retarded Children, Inc. et al., and Parisi et al., v Nelson A. Rockefeller, et al. 356/357 NY, 12.
[70] Nielsen, *A Disability History*, 162.
[71] Ibid., 162 – 163.

number of people institutionalized in public asylums fell by 60 percent: from 475,000 to 138,000" throughout these two decades.[72] This is, yet another, reason that Foucault's model for understanding disability and deviance is no longer an appropriate one for the study of mental and intellectual disability within the twentieth century. Instead, utilizing Deleuze's model of control societies, it becomes possible to uncover the ways that juridical systems of power have become more and more removed from systems of either domination or reform. Instead, the onus is placed on the individual to fail or succeed, while those in charge of changing society writ large are removed from focus.[73] This has allowed for the abandonment of many people marked as disabled who became homeless as a result of lack of funding for deinstitutionalization, as well as the millions (nearly half of all) of prisoners with a mental disability of some kind.[74]

Continued change came about in 1973 when the US government passed the Rehabilitation Act of 1973. Like many changes in the treatment of disability before it, this act was necessitated by the rise in disability amongst veterans returning from Vietnam. The language of the law, especially in section 504, did not limit itself to veterans, however. Instead, the bill was written to declare all discrimination based on disability illegal for any entity operating off of federal money.[75] However, the law was written without any enforcement mechanism, pushing challenges throughout the mid 70s. Among the most impressive was a 25 day sit in at the Health, Education, and Welfare offices in Washington D.C. in 1977.[76] After the sit in, HEW created an enforcement mechanism to ensure that discrimination would be dealt with on the basis of disability. At this sit in, it became clear how deeply disability intersects with other protest groups

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[72] Ibid., 164.

[73] Gilles Deleuze, "Post Script on Societies of Control," and Abigail Bray, "Chemical Control."

[74] Nielsen, *A Disability History*, 164, and Michael Rembis, "The New Asylums: Madness and Mass Incarceration in the Neoliberal Era," *Disability Incarcerated: Imprisonment and Disability in the United States and Canada*, (2014), 139 – 159.

[75] Nielsen, *A Disability History*, 165 – 167 and Rehabilitation Act of 1973, PL 93-112, 93rd US Cong. (1973).

[76] Nielsen, *A Disability History*, 168.

at the time. Many of the leaders of the disability rights movement learned how to effectively organize while fighting for racial equality, gender equality, equality for people of various sexual orientations, as well as protesting the war. Furthermore, many groups, including the Black Panthers who fed every protester at the event at least one meal a day, aided protesters, making it possible to effectively lobby for change.[77]

The Hepatitis experiments continued into the 1960s as Krugman and Giles infected even more children, despite the fact that Baruch Blumberg found a way to isolate and treat the disease using gamma globulin in 1968, a feat for which he won the Nobel Prize. Even if Blumberg had not figured out the secret to treating the disease, the use of the school children themselves was unnecessary, because researchers "would have learned almost everything" they "needed to know about Hepatitis B in the laboratory."[78] This lack of foresight and cruel treatment was not limited just to the doctors performing the experiments, however. Rather, it was indicative of the institution overall. Despite the fact that admissions were closed at Willowbrook in 1972, the school still had a massive overcrowding problem. The school was understaffed, under qualified, under funded, and under a great deal of scrutiny from the local community. However, it stayed open for those already admitted. Among them was a student body made up of children, 20% of whom were "non-ambulatory," 2% needed wheelchairs, 15% "walk(ed) with difficulty." Nearly half of the students did not utilize any form of speech and approximately a quarter were difficult to understand when they did speak, meaning that approximately 75% of the students at Willowbrook could not be understood when they spoke, if they did at all. Handicaptivity at Willowbrook was also racially biased with 22% of the school made up of black children, 9%

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[77] Ibid., 169.

[78] Rothman and Rothman, *The Willowbrook Wars*, 267.

Puerto Rican, and “3.1% other or blank.”[79] This was an institution built to house the individuals that society did not want participating in daily life with the rest of the community. This was institutionalized discrimination.

The Community Resources for the Developmentally Disabled (CRDD), similar to the National Association for Retarded Citizens (ARC), began as a group of concerned parents in 1954, after several parents found the conditions at Willowbrook to be deplorable.[80] They began petitioning the school’s administration, the school board, the Department of Mental Hygiene, the Governor’s office, and any governmental body they thought might be able to produce change at the site. Eventually, however, with too little change, from their perspective, they sought change through the courts and began a three-year legal battle with the School Board, the Governor’s office, and the School itself that ultimately resulted in the New York Courts to demand the closure of the school.

The reason was simple; the conditions had gotten untenable at Willowbrook. Students were receiving little to no training. The staff was marked by a high rate of absenteeism, so that students could not receive individual attention, even in intimate settings. Showers were “given communally in open stalls.”[81] Children were secluded as a form of punishment, including at least one boy who had a relatively high IQ, which made him eligible to attend public school. That student bit an attendant, and as punishment was placed in isolation for a full year.[82] Another young woman was put in isolation for two years. Some residents were kept in their rooms naked, many with little to eat. As a result, many contracted diseases, and one student went blind. The diseases spread throughout the student body, often without diagnosis, because, according to

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[79] Judd Memorandum, 7. It is not clear what “blank” means in this context.
[80] CRDD, “Building Proposal,” 1991, CUNY CSI Archives.
[81] Jane Kurten, “Willowbrook Inside the Cages,” Staten Island Advance, November 16, 1971, http://www.silive.com/news/index.ssf/2007/09/willowbrook_inside_the_cages.html.
[82] Ibid.

workers at the school, doctors were too afraid to approach the students, and would observe them from afar.[83] Here, again, it is impossible not to recognize the stigma associated with disability. Doctors, experts trained in the field of treatment, were afraid of catching a non-communicable disease, something that is not even a disease itself. This indicates the fear of contagion manifest in the body of people labeled as disabled. Even experts in medicine were frightened by the foreignness of the disabled body. It appears that Deleuze and Guattari were correct and the terror of errant subjects is not the terror bound in might, but rather the horror that you might become like them in close proximity. The world, however, would soon find out what went on behind closed doors.

In 1972, Willowbrook was shaken by a report from a young upstart journalist named Geraldo Rivera. He revealed the mistreatment of patients in every day life, and in nearly every section of the school.[84] His ground breaking expose, more gruesome than any treasure that might be found in Al Capone's bank vault, helped turn public sentiment so that average people began to identify with the students at Willowbrook, and their parents.

Beginning in 1972, the New York State Association for Retarded Children (NYS – ARC), and its Willowbrook Chapter, the Benevolent Society for Retarded Children, joined by dozens of parents including Lena Steuernegal who represented her daughter Patricia Parisi, a student at Willowbrook filed suit against Governor Rockefeller, Alan Miller, and Miodruy Ristic. Miller was commissioner of the New York State Department of Mental Hygiene and Ristic, the Director of Willowbrook. The parents argued that conditions had gotten so bad at Willowbrook that they constituted a veritable prison, especially given the likelihood of forcible restraints and solitary confinement, common at the school. Among their demands in the lawsuit were:

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[83] Ibid.

[84] Geraldo Rivera, *Willowbrook: A Report on How it is and Why it Doesn't Have to be That Way*, New York: Random House, 1972.

1.) “the immediate hiring of 134 nurses, and the hiring of 422 English speaking nurses over time.

2.) 125 mid-level supervisors

3.) At least 25 more maintenance workers

4.) Substantially more personnel employees

5.) Ward Attendants

6.) Take all steps necessary to stop the use of seclusion

7.) Prepare and post schematic evacuation plans and conduct fire drills”

8.) Hiring more “physical therapists

9.) An additional 21 full-time MD physicians licensed to practice medicine in the state of New York

10.) Develop and implement an adequate orientation and in-service training program for all old and new resident care workers

11.) The assignment of named residents to named resident care attendants

12.) Begin immediate to subdivide large daycare and activity areas

13.) Make maximum use of all currently unavailable and unused space, especially in the basement areas and the hospital buildings

14.) Repair toilets, showers, sinks, drinking fountains, and all exposed heating units”

15.) Purchase “adequate house keeping supplies

16.) Eliminate the ‘improper use of physical and chemical restaurants’ [sic] and take special steps to ensure the safety and well being of any resident so restrained

17.) Eliminate cockroaches, rodents, and other pests”

18.) Purchase “toileting and personal hygiene supplies”

19.) Implement “outdoor exercise”[85]

The administration asked for an injunction from the courts so that they could make changes, without the case moving forward. Frederic Grunberg, the Deputy Commissioner of the New York State Department of Mental Hygiene in charge of Mental Retardation and Children’s Services, and speaking for the state, said in an affidavit to the court in 1972 that the demands of the parents were made up of “unrealistic high expectations,” that defines the “whole history of mental retardation.” According to him, special education and institutionalization have always been bound between two poles. The first is the period of optimism in which reformers push for change. This is “followed by poles periods of unjustified hopeless pessimism both among the professional and the lay community.” Instead, he argues, the history of disability within the United States has progressively gotten better.

With that in mind, he denied that a great deal of changes the parents wanted were in fact underway, though does signal that some of them are already underway. For instance, he states that while “seclusion as defined in the Accreditation Standards…was discontinued at Willowbrook on June 15, 1972…isolation has not been discontinued and there are no plans to do so.”[86] The reason he gives for the continued practice of isolating students is that it was medically beneficial to do so, given that it helps fight the spread of contagious disease. This, of course ignores the fact that, many of the patients got those contagious diseases from Drs. Krugman and Giles. Even if they did not, the administration did little to change the material conditions of the

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[85] Louis J. Lefleewitz, “Post-Hearing Memo,” New York State Association for Retarded Children, Inc. et al., and Parisi et al., v Nelson A. Rockefeller, et al. 356/357 NY, 38 – 62. It should be noted here that in the original document, the number 13 appeared twice, it has been corrected in this re-presentation. Point 16 states that the plaintiffs would like to remove “physical and chemical restaurants.” It is safe to assume that they argued for the removal of restraints, especially given the use of the word “restrained” later in the same sentence.
[86] Grunberg, “Affidavit, Grunberg,” 2.

school, favoring instead to isolate children from their peers. It is little wonder why so many of the children did not develop language skills to meet the standards of the asylum.

Grunberg argued that the use of medical restraints that parents complained about were actually for the children's benefit. He stated that many of the children were violent, and that they may hurt others or themselves if they were not restrained. He did not state how long patients were restrained for, or what types of restraints were used. It would be irresponsible to make assumptions about either of those fields, but given that he states that "six students are in continuous seclusion, four in frequent seclusion, and one in occasional seclusion," it is likely that the students were restrained for quite a bit of time, at any one point in time.[87] He does state that behavior modification programs were established in mid June of 1972 and that those residents in continued seclusion "were assigned to it."[88] Among the staff in the behavioral modification programs is "a full time psychologist, a full-time occupational therapist, a half-time recreational therapist and thirty nine resident care workers who are presently being trained by the psychologist," and that all patients currently secluded, would be moved to the behavior modification program by July of 1972.[89]

While it should be apparent that behavioral modification programs inherently utilize psychology at its core. It is important to note that this extension of psychology as a method of reform in order to overcome the problematic practices of bodily discipline marks a shift, not just for Willowbrook, but throughout the nation overall.[90] Prior to the emergence of psychology at the institute, as per their own admission, students were reformed by subjecting their bodies to punishment either through seclusion or restraints. These undoubtedly had psychological impacts,

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[87] Ibid., 2.

[88] Ibid., 2.

[89] Ibid., 2 – 3.

[90] J. Corbett, "Aversion for the Treatment of Self-Injurious Behavior," *Journal of Intellectual Disability Research* 19, issue 2, 1975, 79 – 95.

but it was the control over the body that was important to the principals, administrators, and nurses. However, this shifted to control over behavior through the use of repressive psychology.[91] This control through the psyche is not only a form of Oedipalization that Deleuze and Guattari describe, but also the shift from disciplining the body, to controlling the behavior that Deleuze describes in "Post Script on Societies of Control." It appears then that as early as 1972, Willowbrook was making the shift from a disciplinary society that Foucault described, to a control society as described by Deleuze. This should functionally alter the way that historians create their frameworks for understanding disability and medicine within institutions and asylums in the US in the mid twentieth century.

He also claimed that the parent's arguments about a lack of staff were being addressed, as somewhere between 2100 and 2150 jobs were being filled at the time of the trial. The jobs were only vacant, he claims, due to a "hiring freeze," that began in December 1970.[92] Despite the increase in hiring, Grunberg testified that the parents' demand to hire more nurses, particularly resident care workers, was unreasonable, because the administration was actively trying to decrease the population of children at the school, and that hiring more nurses would only act as a disincentive to that process.[93] He states that, even if, they were not trying to reduce the schools population, Willowbrook officials would still be incapable of filling all of the nursing positions given that few licensed nurses wanted to work in an institution for students labeled as disabled, the proof of which was that Willowbrook still had 78 vacancies in 1972, after the hiring freeze ended, despite having hired every single nurse that applied.[94]

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[91] Repressive here is not a value statement. Rather, it is the Deleuzoguattarian form of "repressive," in which the given trajectory of a line of flight, or a way of being, is ultimately altered by other beings around you.

[92] Frederic Grunberg, "Affidavit, Grunberg," 3.

[93] Ibid., 3.

[94] Ibid., 5.

He argued that, without spending the money to increase the staff, the ratio of attendant to patient would be 1:2 within two months of his affidavit.[95] This rate does not apply to physical therapists, however, due to the fact that persons in that profession were difficult to recruit, and even if they were not, Grunberg was unconvinced of the need for "208 recreation people," especially given that the attention recreation therapists were able to give to students would increase as the population of the school decreased.[96]

In preparation for the decreasing population, the Willowbrook administration sought, and received, a federal grant in order to have a medical team sent to the grounds in order to ascertain which students would be "ready for community placement, and the specific needs of the residents remaining in the institution."[97] The priorities of the team were to evaluate who could be placed in the community, which could be provided they received increased attention and training from the staff, which children and adults would have to be institutionalized for long periods following their departure from Willowbrook, which might need "long-term rehabilitation" in order to re-enter the community, and which were "severely disabled with multiple handicaps."[98] The last task of the visiting medical team seems curious given that many of the patients at Willowbrook had been there for several years. It seems that an institution with multiple doctors, and more than one hundred nurses would be able to evaluate whether or not their students had "multiple handicaps," and certainly which ones were "severely disabled," especially if, as Grunberg says, they received training upon entering the school. The lack of coordination over these basic understandings of the needs of the children and adults held in handicapitivity at the Willowbrook asylum points to a much larger systemic failure. That is, many did not have regular

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[95] Ibid.
[96] Ibid., 4.
[97] Ibid., 7.
[98] Ibid.

access to medical care, and very few checkups were done. Grunberg himself admitted that evaluations could not be provided for all patients within the six month time period that the parents asked for, despite the fact that, according to him, evaluations were already underway at the school.[99]

In response to a request for hearings over the validity of transfers out of Willowbrook, Grunberg said that he thought they would be "cumbersome and duplicative." He went so far as to say that the doctors at the school, along with the nurses, would make that decision without the parent or legal guardians help, and that the transfer would occur whether or not it was approved by the legal representative for the child in question. Furthermore, he stated, if the representative did not communicate with the administration fast enough, their silence would be assumed, as a form of consent, and the transfer would continue.[100] This, again, seems incredibly strange. While it follows that doctors would make the recommendation for transfer from the facility, and that nurses would be consulted, it is strange that neither the legal representative of the person in question, or the person themselves, would have input in the matter. Furthermore, even if someone raised an objection, the doctors and nurses would actually trump the person being transferred or their legal guardian, an especially odd feature given that an external decision making body had to be brought in so that the doctors could determine the nature of people's ability in the first place. It is even more strange considering that many institutions and group homes were difficult to transfer people into, or could not be found, and were incredibly difficult to establish, citing the fact that in the past, "public acceptance" has been hard to develop in the establishment of halfway houses.[101] It seems that the administration, given its understaffing,

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[99] Ibid., 8 – 9.
[100] Ibid., 10.
[101] Ibid., 10 – 12.

would welcome input from the students and parents. That option, however, was not afforded to them.

Grunberg, after addressing the complaints specifically, attempted to put Willobrook into context for the parents suing the school, as well as its director, and the governor of the state. He stated that there was cause for optimism and hope that “by applying psycho-physiological methods, most of the mentally retarded could be returned to the community upon completion of their institutional education and training.”[102] Here again, the confluence of psychology in institutionalization during the mid twentieth century becomes apparent. Previously, clinical and specialized psychology, while still utilized, did not take a central role in the education of people deemed disabled. However, by the mid twentieth century, this was no longer the case. The adoption of that system into the curriculum and implementation of various educational institutions still affects students to this day.

Furthermore, he argued that the direction of the school was progressing. He stated that by 1960, Willowbrook housed more than two thousand children, but by 1972, decreased that number to 907 and finally 700 by 1972, and that this indicates that the Department of Mental Hygiene was not “wedded” to the process of institutionalization as critics charged.[103] This is an odd statement given that several pages later in his affidavit, he states that the “resident population of Willowbrook” in 1972 was approximately 5,000, more than 1,000 over its official capacity.[104] Regardless, he is correct that change was indeed brewing. The 1960s and early 70s were characterized by the overturning of assumptions about various peoples, places, and institutions. He also says that public attitudes were changing surrounding people labeled as

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[102] Ibid., 15.

[103] Ibid., 16.

[104] Ibid. It should be noted that other affidavits confirm Grunberg’s second estimate of approximately five thousand students.

disabled, despite the fact that he refers to those people as "beings afflicted by serious insults of nature." This appeal is indicative of a larger shift happening in the United States at the time. Deinstitutionalization was indeed growing in popularity, and a shift toward control societies was taking place in the decreasing number of forced confinement in asylums. However, that new regime still utilized the same fear of otherness that institutionalization did before it, as evidenced by the Grunberg's own characterization of disability as an "insult of nature." Furthermore, it indicates that Deleuze was correct in his pronouncement that the individual was indeed disappearing. Individuals were not understood apart from their assigned disability, but rather attached to it, creating the dividual, the "being afflicted by serious insults of nature."[105]

By putting Willowbrook into its context, and highlighting the changes taking place, Grunberg cites five specific problems that still presented themselves at the school, as well as ways that they would be fixed without a decision from the court.

The first, overcrowding. Grunberg said that by closing admissions, the school population would remain stagnant while they also expanded their "resettlement and relocation" programs by sponsoring "community-based" facilities for former residents, and that those plans were in development since 1965.[106] The residents would be moved, according to Grunberg, to facilities in one of the five boroughs: 200 between the King's County School and the Williams burg Residential and Training Center in Brooklyn, 150 between the Bernard Fineson Social and Vocational Habilitation Unit and the Howard Park Unit in Queens, 150 in the Sheridan Unit in Manhattan, and fifty at the Bronx's Children's Psychiatric Hospital in the Bronx, all by March 31, 1973.[107] Furthermore, the school planned to transfer approximately 300 of its adult residents

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[105] Ibid., 16 – 17, and Deleuze, "Post-Script," 3.

[106] Frederic Grunberg, "Affidavit, Grunberg," 16 – 17.

[107] Ibid., 20 – 22.

to "Gowanda, Middletown, Harlem Valley, and Creedmore State Hospitals."[108] Another 79 adults and children would be transferred to their county of origin with 58 relocated to Suffolk county, 1 to JN Adam, 5 to Rome, NY, 2 to Witton, 3 to West Seneca, 1 to Sunmount, 6 to OD Heck, and 3 to Syracuse.[109]

The second issue he highlighted was the need to reorganize the administration at Willowbrook. Grunberg argued that the director made too many decisions and second level directors that could be made by lower level employees. He lays out a plan to decentralize the bureaucratic structure of Willowbrook within the coming years. This would require that Willowbrook be broken up into "ten units, each handled by a chief of service," and would be accomplished by Halloween, 1972.[110] Again, Grunberg is correct in stating that the school operated as a bureaucracy for far too long. This structural change does not point to a disparity between the understanding of the problems in the institution, and the assumptions and determinations of its administrators, but rather at a larger shift occurring in mental health overall. This decentralization is indicative of a shift away from some sovereign control of the disabled body, and toward a more free moving society of control. Here, there are fewer striations in the institutions of power, and the development of smooth spaces to enable more efficient functioning. This signals another shift from Foucauldian disciplinary society and into Deleuzian control societies that historians must take into account in their histories of disability.

The third problem that Grunberg highlighted was that the administration was attempting to tackle the "elimination of dehumanization."[111] Again, he asserted that the decentralization of power would go a long way in reducing dehumanization at the institution. He also believed that

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[108] Ibid., 22.
[109] Ibid.
[110] Ibid., 30 – 32.
[111] Ibid., 32.

the prohibition of seclusion as a method of “containing and maintaining residents” would end in exchange for “an active behavior-shaping program for residents who were formerly contained by means of restraints and seclusion.”[112] The school also began a review committee in order to evaluate the ethical decisions made by doctors and nurses at the facility. It is not clear whether or not this was a response to Krugman’s experiments, but it is likely that they played a part in this decision.

Grunberg stated that the staff would increase their training in order to reduce the stigma surrounding disability, including continued training for staff throughout their employment.[113] This shift in behavior also marks a shift toward a society of control. The increased training and behavior modification for the “severely and profoundly retarded” is indicative of a shifting point of view where dominance is demonstrated through the subtle alteration of human character, rather than through its physical enforcement. While that in and of itself is not a full shift from what Foucault describes, that matched with the training for workers to decrease the stigma surrounding disability is. This is because; workers were being trained to accept the essence of the students, as the administration understood them. That is workers were being trained to understand that there was no disconnection between the students as humans and the deviance of their disability. Again, the two came to be understood in a metonymic relationship where the student was their disability and the disability was the student. The inseparability of the two to produce a “dividual” as Deleuze described it is indicative of a society of control.

Lastly, Grunberg addresses the concerns of the parents. He splits these concerns into two camps. The first is the lack of care that many students received, or did not receive for that matter. He denies multiple complaints that some students lost an excessive amount of weight at the

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[112] Ibid.
[113] Ibid., 33.

institution and reaffirms that the students were receiving excellent care at the facility.[114] While Grunberg may be correct that the six students he references were receiving adequate care, it is unlikely that he could find as many flaws as he did and ensure that all students were being cared for under state standards. It is even more unlikely that at an institution that housed approximately five thousand students, and had to have an entire section in a lawsuit charging them with negligence and malpractice about the ways that they were attempting to decrease institutionalized and ingrained dehumanization, that the majority of students at Willowbrook were as fortunate as the six students he identifies. It is likely that a great number of children at Willowbrook did not receive adequate treatment given "the high rate of absenteeism" at Willowbrook, which was so wide ranging that "there (were) rarely enough individuals on any one ward, on any shift, to properly care for the patients."[115] This was an especially serious issue given that approximately 10% of students had "two or more grand mal seizures per month," and 29% "need(ed) to be fed."[116] If the absenteeism was so pernicious and so prevalent that most wards could not care for children during sleeping hours, it is unlikely that the majority of students received adequate care during breakfast, lunch, or dinner, and very possible that many did not during a seizure. Absenteeism was not the only issue, however. Between 1965 and 1972, Willowbrook actually had more vacancies in nursing than it did filled positions. In fact, in 1972 the psychiatric staff was understaffed by 54%, the psychology ward by 100%, the social worker faculty by 40%, occupational therapy by 60%, physical therapy by 111%, recreational therapy by 32%, nursing by 124%, and support by 15% with a student body of 5,152 children.[117] It is

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[114] Ibid., 34.

[115] J Judd Memorandum, April 10, 1973, 8. CUNY CSI Archives.

[116] Ibid., 7.

[117] Grunberg, "Affidavit, Grunberg," 24.

therefore extremely unlikely that the vast majority of children received adequate care approaching what Grunberg details.

The second major area of focus is on the lack of training that several parents charged the employees of the school with in terms of training their children to behave in certain ways. Much like his responses to parental concerns, he states that the majority of children at Willowbrook are receiving adequate care, and that that care is individualized to fit their needs. This is quite unlikely given that approximately 60% of students were "not fully toilet trained."[118] However, he states that certain children did in fact regress after admittance to the school, and that that regression was due to the institutional failures of Willowbrook, but that blame should also be shared with the family for separating the child from their home.[119] There are two important points here. The first is that the application of blame for a child's psychological well being almost completely to the family mirrors the, often sexist, assumption that the family determines most social relationships throughout society. This Oedipalization should signal, not a shift from discipline to control societies, as much as a form of despotism, in which the prevailing ideas in society change on face, while remaining the same in actuality. The second is that this regression due to institutional failure undercuts a great deal of his testimony about the adequate treatment at Willowbrook. Even if most students did not regress, the fact that wide ranging institutional failure allowed some students to regress indicates that the facility was not equipped to effectively teach the school, and was not a place of education, but rather a repository for the abject in American society.

The next year, Louis J. Lefleewitz, the defense council for Willowbrook echoed the sentiments of Grunberg and took issue with a number of the arguments made by the plaintiffs,

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[118] Ibid.

[119] Ibid.," 35.

and their attorneys. He makes the first claim that Willowbrook only functioned because the parents of the children at the school wanted them there, and therefore any analogy to Willowbrook as a prison was incorrect, when in reality it was a social service offered, not guaranteed, by the state of New York. Lefleewitz went on to argue that there was no basis in the constitution for the state to provide that social service in the first place, let alone "state provide(d) services…at a certain level," to the students at Willowbrook.

Given that the Education for All Handicapped Children Act was not passed until 1975, three years after this document was submitted to the court, there was technically no law that guaranteed education to children labeled as severely disabled as many of the children in Willowbrook. It appears then that the parents' organization was arguing for education, regardless of the pupil, to be a right, and for that education to be substantive, rather than a meaningless one that did not provide the student any opportunity to grow. This is a radical idea in United States history, following the momentum of the Civil Rights Movement, in which parents began arguing that all levels of elementary and secondary education were a right that ought to be guaranteed, regardless of race, sex, religion, socioeconomic status, or ability.

Lefleewitz goes on to argue that the plaintiffs had no Constitutional right to bring the case to court in the first place given that the 11th Amendment states that "The Judicial power of the United States shall not be construed to extend to any suit in law or equity, commenced or prosecuted against one of the United States by Citizens of another State, or by Citizens or Subjects of any Foreign State."[120] This is a somewhat dubious claim given that there is little indication that any of the parents of the children at Willowbrook were residents of another state, let alone a foreign one. Furthermore, even if that were the case, the NYS-ARC, as an organization based in New York, certainly had a right to sue the state over issues, especially ones

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[120] U.S. Const, Amend XI, and Lefleewitz, "Post-Hearing Memo," 2 – 3.

as serious as human rights abuses, which they claimed in relation to solitary confinement and medical treatment.

Finally, he argued that a great deal of the complaints made against Willowbrook are non-unique, given that the school was already addressing, and in some cases already alleviated, the concerns raised by several of the parents at Willowbrook. He argued that if the school already began fixing those problems, then there was little to no point in continuing with a trial.[121] Lefleewitz makes these three arguments in order to defend Willowbrook from the largest lawsuit that it ever faced. He goes into depth with these three lines of logic in order to defend an institution, that just a few years previously was overcrowded by approximately two thousand children, and which received massive ethical complaints from the medical community for participating in, some argued, coerced Hepatitis experiments that often resulted in jaundice. It is therefore vital to understand the ways in which he analyzed these arguments in the context of the prosecution in order to understand the decision reached by the court, which shifted the country's policy regarding disability from asylums and institutions to group homes and deinstitutionalization.[122]

The first argument is that the children in question had no guaranteed Constitutional right to education, given their status as "disabled," and furthermore that Willowbrook was not, as plaintiffs claimed, similar to a prison. The simple reason was, many parents did not seek to remove their children from Willowbrook, which he stated would be the "obvious alternative," and that no parent involved in the trial was forced to place their child at the school.[123] In fact,

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[121] Lefleewitz, "Post-Hearing Memo," 3.

[122] Rothman and Rothman, *The Willowbrook Wars*, and David J. Rothman, "Were Tuskegee and Willowbrook Studies in Nature?" *The Hastings Center Report*, 12 No. 2 (April, 1982). 5 – 7, and Stephen Goldby, Saul Krugman, M. H. Pappworth, and Geoffrey Edsall: The Willowbrook Letters, "Criticism and Defense"; Paul Ramsey, "Judgment on Willowbrook", The Lancet, April 10, May 8, June 5, and July 10, 1971, and M.H. Pappworth, "The Willowbrook Letters," *The Lancet*, June 5, 1971.

[123] Lefleewitz, "Post Hearing Memo," 4.

less than half of the residents at Willowbrook were there involuntarily. What is more, a Willowbrook employee, Dr. Hammond, sent a letter to each of the parents involved to discuss transferring their children out of Willowbrook or releasing them, and the plaintiffs sought "an order restraining transfers." Furthermore, he stated that there was no legal basis for the case, given the patients' voluntary status. While Lefleewitz is correct, the children in this particular case were not being held at Willowbrook involuntarily, it is important to remember that release was not an option for most parents due to their low socioeconomic status. Furthermore, transfer was somewhat unlikely that even after a great deal of reforms, only 2500 students would be transferred from Willowbrook to institutions, some of which were still being built at the time of the trial. It is unlikely that many of the transfers would have been accepted, and could be difficult for many parents to go to those institutions in order to visit their child. It seems that Dr. Hammond's suggestion that the children involved in the trial be removed, was not an offer to fix the problems created, but rather a form of retaliation against the parents who asked that their children's academy be reformed.

There are two important revelations from Lefleewitz's opinion to the court. The first is that he says the case has little importance or basis, given that, while it was illegal not to offer education to children, many of the students in the case are exempt from that anti-discrimination law because of their disability status. This created a very real state of exception for children labeled as disabled where they were excluded from the rest of society based on arbitrary principles, and refused legal protection. This creation of abject personhood makes clear the precarious position that these children were placed in, and the wide-ranging stigma that affected them. The second important point is that he stated that education was not the true purpose of

Willowbrook State School.[124] This statement ought to throw the history of the institution into stark relief, given that in legal proceedings, the major representative for the asylum indicated that the school was not concerned with education, but rather with separating these individuals from the rest of society and raising them in handicaptivity without full rights. This confirms the form of despotism that the institution fulfilled. Even after it was no longer called an asylum, it functioned the same way.

The second argument was that the Eleventh Amendment barred the parents and children from raising the suit in the first place. Again, most if not all of the children represented were New York State residents, so it is curious why the Eleventh Amendment would not enable them to raise suit in regards to their protection. Lefleewitz made a somewhat compelling argument in relation to funding, however. He stated that federal courts could not force state institutions to pay more money from its own coffers for a specific program. While that may in fact be true, the parents who raised the suit were arguing that their children's constitutional rights to protection from cruel and unusual punishment, and full citizenship rights. Since that was the case, the question is not one of funding, but rather one of treatment. He goes on to cite Judge Friendly, stating that more money for people labeled as disabled would mean less money for other children, and for "families that had shown more restraint in procreation."[125] Again, scholars are confronted with the trope of the negligent family who selfishly had a child in a society that would determine was disabled. This invocation of eugenicist style thought reveals the beliefs that the defense was invested in. This is another form of despotism, much like the first argument, in that the state claims nuance and tolerance, while reinforcing the same damaging descriptions and determinations that have disproportionately disadvantaged communities described as disabled for

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[124] Ibid., 8.
[125] Ibid., 15.

decades. Furthermore, Lefleewitz, citing Friendly, states that anyone who believes the Fourteenth Amendment applies to the children at Willowbrook "is indulging in dangerous self deception."[126] It is unclear why full citizenship would not apply to this group of children. The implication is clear though. To the state, these children were second-class citizens. Their school would not function as a guarantee of education, but instead a special form of segregation.

The final argument is that a preliminary injunction ought not be granted. Lefleewitz argued this stating that the injunction is too large for federal authority and had no precedent in the court system. He furthermore states that the idea that "every retardate, no matter how disabled had potential for growth was disclaimed by the profession as recently as 1961."[127] The reason he said this is that parents hoping to prevent further harm to their children sought the injunction. He is attempting to functionally make those arguments non-unique by claiming that the majority of children could not be taught as a function of their own biology, but even if they could, too few of them were admitted after the "Standards for care of the retarded were promulgated" in 1964. This does not indicate that no harm could come to a child, however. It instead elucidates the fact that, as Lefleewitz states, "2,854 of Willowbrook's residents…had been there for over 20 years; 3,145 for over ten years, 4,461 for over five."[128] In 1973 with 5,152 total students, that means that 55% of the school's student body had been in Willowbrook for over 20 years. Nearly 3,000 men and women were kept in the same institution from the Truman until the Nixon Administration. It seems then that not only was Willowbrook an institution concerned with the handicaptivity of people who ranked too lowly on the Binet-Simon IQ model, but was also incredibly effective at it.

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[126] Ibid.

[127] Ibid. I have not read every piece of evidence produced by the medical community in relation to the category of mental retardation or its treatment, but I have not run across this claim in professional settings, and it seems rather nebulous.

[128] Ibid., 21.

All of these, Lefleewitz cites as reasons to refuse an injunction at the school. He states that plaintiffs were not giving the administration enough credit for the decreases in the population due to transfers, or in the treatment of children given that there were only "74 resident deaths in 1972, a considerable decrease over previous years."[129] It is unclear how many students died in previous years, however it seems that if a school uses its decreasing death count to demonstrate evidence that they are effectively protecting children and treating them fairly, that that school is not actually any good at protecting children and treating them fairly. This is especially true if, as was previously suggested, the school is not concerned with education, and is staffed primarily by medical professionals.

The Defense also utilized the expertise of doctors in the field. Dr. Stanley A. Slawinski, Chief of Service at Willowbrook, sought the help of Herbert Grossman in 1974, asking him to write a summary of a meeting held with Dr. Natarajan at the school in hopes that the Defense could use his summary in testimony for the court case.[130] This letter was preceded by a detailed list of changes occurring at Willowbrook in terms of programs offered and housekeeping reforms already underway at the school, as well as the shift from "oppressive overcrowding to just overcrowding" that the administrators were marking as a sign of positive change.[131] Slawinski had to write to inform Grossman of the changes at Willowbrook, as opposed to having him visit, because Grossman did not live in Staten Island. He did not live in New York, or on the East Coast. Grossman lived in Chicago and visited Willowbrook for one day before being asked to provide expert testimony for the Defense. His testimony helped push the trial back until December 9th.[132] Two days after the trial where Grossman provided his testimony on the

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[129] Ibid., 27 – 28.
[130] Stanley A. Slawinski, Letter to Herbert Grossman, November 4, 1974.
[131] Stanley A. Slawinski, Letter to Herbert Grossman, November 2, 1974.
[132] Stanley A. Slawinski, Letter to Herbert Grossman, November 14, 1974.

advances made by the school and their lack of culpability, he was invited to join a team of experts who would travel to the school twice a year in order to provide advice on changes that could be made. While Grossman would not be paid for his work, given that it was funded by a government grant, he would be reimbursed for "travel, lodging, and food."[133] It is not clear if this is nepotism. However, it seems odd that Willowbrook would seek to employ a doctor half way across the country for advice on what changes it was making and could make in the future. Furthermore, it speaks to the lack of oversight at the institution that they would value the judgment of a doctor who visited previously for only one day, and would make his testimony part of the basis of their defense. Furthermore, it suggests a serious lack of concern for the future that they would create a team to meet only twice a year in order to ensure the safety of the patients that they housed every day. These details did not escape the Courts.

After hearing the defense from the school, the courts made a "preliminary injunction" in order to determine the history of the case, the "nature of Willowbrook," the problems with the institution, the standards that the asylum operated under, the scope and effectiveness of actions taken by the school to curb parental concerns, the plans the school had yet to carry out, and the problems inherent "in the institution."[134]

By July, 1972, the Courts already described the conditions at Willowbrook as "largely inhumane."[135] The major reason that the school had so many problems, the courts found, was that the school was severely understaffed. This contributed to a great deal of neglect at the asylum, where, by 1973, a majority of residents had not had an evaluation since "1965 or

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[133] State of New York Department of Mental Hygiene Rockland State Hospital Research Center, Letter to Herbert Grossman, December 11, 1974.

[134] Judge Judd, "Decision," New York State Association for Retarded Children Inc. et al., and Patricia Parisi, by her mother Lena Steurnagel, et al., against Nelson A. Rockefeller, individually and as Governor of the State of New York; Alan D. miller, MD, individually and as Comissioner of the New York State Department of mental Hygiene;…Miodruy Ristic, MD, individually and as Director of Willowbrook State School et al., 72C-356/72C-357, 1973, 3 – 4.

[135] Ibid., 11.

earlier."[136] It was found that "75% of the residents in building 25 needed medical consultation." This would also help in the attempt to transfer patients, as "95% of those evaluated were suitable for foster-care." Greater examinations would likely increase that number. They would not overcome a second problem, however. To that point, with a 95% acceptable foster-care evaluation, the administration at Willowbrook managed to place only one student in a home.[137]

Furthermore, the Willowbrook administration did not have control over their staff. The ward attendants were incapable of protecting students from one another, reporting approximately 1,400 fights between March and December, 1972. That is an average of 4.57 fights per day, and those were only the fights reported. In order to retain some sense of peace, the attendants often resorted to using thorazine, a tranquilizer, to subdue students. The court found that its use was often unnecessary. It is undoubted that greater order could have been established at the school had they had increased staff. The administration was correct in stating that they had hired more employees. However, approximately "15% of the scheduled ward attendants were absent without notice each day."[138] It is little wonder that those who did attend their jobs were regularly incapable of sustaining order. Furthermore, despite the defense's claim, the courts found that seclusion continued as a method of discipline "as late as October, 1972." Conditions were so bad that "Dr. Richard Koch, former president of the American Association on Mental Deficiency (said) that the locked buildings 'seemed like a virtual prison.'"[139]

This interpretation was confirmed for the courts when, on February 12, 1973, Justice Judd, the lawyers from either side, and a law clerk visited the school and toured buildings 2, 6, 7, 8, 16, 20, 22, 28, 29, 32, and 78. It is not clear why those buildings were chosen. Judd recounts

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[136] Ibid., 13

[137] Ibid.

[138] Ibid., 14.

[139] Ibid., 15 and 18.

that the school resembled “a mental hospital,” stating that many residents were incapable of moving, and those that could were incapable of doings so freely.[140] Furthermore, he stated that the AAMD standards for rooms to be 70’ by 80’ were not met. The spacing of bedrooms was not the only issue. During the visit, the court found a young boy in building 7 with a swollen eye, blood covered forehead, and several open wounds. The nearest attendant had no explanation for what had happened to the child or when, and nothing had been logged in the “incident book.”[141] Residents were also incapable of attaining certain resources. The courts found that toilet paper was not readily available, and residents would have to “obtain it from an attendant when they needed it.”[142] As one might guess, this created delays, and in building 8, the court found approximately 30 young boys waiting to use the restroom. This was not simply due to toilet paper availability, however. The school’s plumbing was in shambles, so much so that the court found that “delays in plumbing repairs (were) not merely an inconvenience but a detriment to teaching or maintaining personal hygiene.”[143] The impact of all of these failings is by 1973 “the institution (was) still far short of the 1964 AAMD standards.”[144] It was clear to the courts that change was needed.

The courts ruled that the AAMD standards classification II should be observed, meaning that there needed to be one attendant to every five patients. The school took it upon themselves to fire 112 staff members for “offenses such as absenteeism, child abuse, violence to employees, or drinking at work.”[145] The courts then found that the Willowbrook administration ought not worry about finances, and stated that Dr. Ristic, Director of the school, was free to hire as many

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[140] Ibid., 20.
[141] Ibid., 22.
[142] Ibid., 23.
[143] Ibid.
[144] Ibid., 25.
[145] Ibid., 30 and 33.

people as necessary to conform to AAMD standards. The justification for this advisement from the judicial branch was not based in the plaintiff claim for equal protection. In fact, the court found that the children did not have “a constitutional right to treatment either independently or on due process grounds.” They did “have a right to a reasonable protection from harm,” and that did not violate the Eleventh Amendment.[146] In fact, the judge stated that the student’s Eighth Amendment rights had, in fact, been violated citing the precedent Ragsdale v Overholser and the 1964 Hospitalization of the Mentally Ill Act which stated that a judge could weigh the adequacy of treatment in asylums, and if s/he found that treatment to be inadequate, then they could demand the release of the patient in question.[147] This confirmed that children labeled as disabled did in fact have a right to constitutional protections, though not to treatment or education, similar to their peers and would act as a landmark in the fight for civil rights in the disability movement.[148] This sentiment would soon be reaffirmed, and the right to education and treatment would be confirmed at the national level, ensuring that regardless of the severity of disability, all children would be eligible for an education.

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[146] Ibid., 48 – 49.

[147] Ibid., 52 – 57.

[148] Ibid., 60 – 63.

CHAPTER FOUR: DEINSTITUTIONALIZING DIFFERENCE

In 1975, the United States recognized that all children, regardless of disability, had a right to an education. It is little coincidence that this occurred just a few months after Judge Judd signed the *Willowbrook Consent Decree*. Following the decisions reached in 1973 and 74, whereby the Courts held that all children, regardless of diagnosed disability, had a right to protection from harm, guaranteed by the 8th and 14th Amendments, in the decision that came to be known as the *Willowbrook Consent Decree* marked a shift in popular thought about children labeled as disabled.

Judd ordered that Willowbrook would be forced to create a review panel with two members chosen by the defense, three by the plaintiffs, and two experts in institutional efficacy and in the placement of children labeled as disabled. All nominees would have to retain approval of the courts in their placement. That review panel would have to submit reports detailing the school's progress to overcome the systemic problems detailed by parents in the three year long hearing.[149] There was a larger shift than just attempting to reduce the harm of Willowbrook to young students. The court declared that any person who interfered with the panel would be in contempt of court.[150] This marks a dramatic shift in the culpability of bureaucrats in the education of children understood to have disabilities, and certainly demonstrates the importance that the courts felt this case warranted. Furthermore, it gave the courts the ability to enforce their rulings; something that the defense previously said was impossible.

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[149] New York State Association for Retarded Children Inc. et al., and Patricia Parisi, by her mother Lena Steuernagel, et al., v Hugh L. Carey, individually and as Governor of the State of New York and the New York State Department of Mental Hygiene, et al., 72C 356 and 72C 357, 1975, http://www.library.csi.cuny.edu/archives/pdfs/consent%20decree.pdf, 6.

[150] Ibid., 7.

The decree also gave parents and legal guardians the ability to raise issues about the care of their children to the review board, and guaranteed that the board would have to respond.[151] This marks a major shift from the previous relationship the school had with parents' organizations. Previously, the school treated parental concerns as more of an inconvenient suggestion that could be, and often was, ignored. Now, however, the courts mandated that parental concerns would have to be taken seriously, and that they warranted a response, even if that response was to not conform to parental wishes. The truly dramatic changes in treatment come, not from the review board, but in the steps outlined by the Courts.

The first changes came about in terms of "residential living." The Courts ruled that all residents would have to "be provided with the least restrictive and most normal living conditions possible."[152] This did not just concern the dormitories that the students slept in, but their clothing, meals, and even their level of contact with the outside world. Furthermore, their education would shift to lessons that would teach them "how to make choices necessary for daily living."[153] As has been stated previously, this shift from total segregation into a smoothly operating space where partitions were consistently disregarded marks a transition to a Deleuzian society of control, whereby the deviant would be reformed through general contact, and would have some freedom of movement.

This is evident in section two of the residential living portion where the Court states that all residents will be able to move from "more to less structured living" arrangements and that the ultimate goal of the program is the inclusion of all residents at Willowbrook into the larger community. For this purpose, small groups would be created at around the same age and the same skill level, and the arbitrary segregation of various residents would cease, and the school

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[151] Ibid., 9 – 10.
[152] Ibid., 16.
[153] Ibid.

would be forced to standardize treatment along group needs.[154] This marks, not only the changing nature of the profession as standardization was ushered in under federal mandate. Proof of this is in the treatment of the "multiply handicapped," which the courts determined would have to spend a good deal of their day out of the bedrooms, and would be made mobile with technology provided by the school.[155] This change in the treatment of people who previously were left in bed for most of, if not all of the day, signals a rising change in the understanding and treatment of people labeled as disabled that would be realized on a national scale the same year. The courts further mandated that the environment of the school must change. Among the most important changes declared by the court was that the administration would have to protect and safeguard the dignity of patients at the asylum. This would require accessible and clean lavatories, available resources for personal hygiene, training in personal hygiene so that residents would be able to care for themselves, increased individual space to store belongings, "spacious…sleeping areas," better ventilation and climate control, and areas to store "clean and dirty linen(s)" separate from one another.[156] Furthermore, sleeping areas would be limited to eight students at a time, and should be made accessible to all residents. Occupants would only be placed on the floor for therapeutic reasons, ending the negligence that had characterized Willowbrook for much of the school's history. Technological advancements such as hearing aids and mobile technology would be made available to residents, as would toys.[157]

In terms of care, the administration would have to guarantee that each resident "receive appreciable and appropriate attention each day from the direct care staff."[158] Decisions would be made via interdisciplinary teams of staff members. The Court also declared that aides would be

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[154] Ibid.

[155] Ibid.

[156] Ibid., 17.

[157] Ibid.

[158] Ibid., 18.

responsible for different groups depending on the needs of those groups, and limited the amount of students each aide was responsible for, with each aide responsible for no more than eight residents. The school was given 13 months to reach the numbers the Court specified. This, again, marks a dramatic shift from the negligent treatment that thousands of individuals faced in the past, and was meant to guarantee that residents would receive the best possible care, and the school would be held accountable.

Preceding the Education for all Handicapped Children Act (EAHCA), the *Willowbrook Consent Decree* (WCD), mandated that all children at the institution would be required to receive an Individualized Education Plan (IEP), and that their education would be carried out according to the findings therein. Furthermore, each resident would require the creation of both short and long-term goals, and would require at least six hours of "program activity per weekday."[159] Here, the day becomes more structured for residents, and the field increases its professionalism from being a loosely understood and poorly run program, to a highly specialized field. There would still be room for disagreement about the plan, however, and for possibly the first time, residents would be able to object to their "individual development plan."[160] This marks a monumental shift in the ability for individuals labeled as disabled to determine what worked best for them. It also individualizes the trajectory of their education, and attaches them to their development in a way that was previously unavailable, as all decisions were supposed to be made by the school or by their guardians. This increased power in decision-making marks a large shift from disciplinary to control societies.

Furthermore, separation and segregation could not be used as a form of punishment. Instead, "behavior(al) modification" would be the leading method of discipline and reform. In

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[159] Ibid., 20.

[160] Ibid.

this way, the child would remain included within the educational atmosphere. This has two major impacts. The first is that it puts into law the ban on seclusion that parents complained about, and continued even after the school mandated that the practice cease. This concern for the dignity of patients is a dramatic transition from the direction and practice of the school in previous decades. The second is that it, again, marks a shift toward a society of control where the dividual would be consistently included in the reform of their deviance, with fewer partitions mandated by the state.

The administration would also be charged with the task of hiring qualified employees, and for ensuring their continued training to decrease the stigma associated with disability.[161] Much like the previous changes in the school, this has two impacts. The first is the concern for the dignity of the students in question. Previously, the school was not concerned with the stigma associated with their residents, as much as it was in confining those residents. However, it was now one of the primary tasks of the institution. The second major impact is that it completes the process of the removal of the juridical component inherent in societies of discipline.[162] Here, the staff is supposed to understand the essence of the students as somewhat deviant. It should be stated that this is not a nefarious goal on the part of the Willowbrook administration or the courts. This was not an attempt to demonize an entire population of people. Rather, it is a descriptive statement that the students were now completely inseparable from their disability. It was bound to them, and others were made to be sensitive to that condition of being.

The Courts reaffirmed that students, regardless of disability, were capable of learning and positive change. There was a much more dramatic shift, however, in the court's decision. Not only would education be provided all year long, but also students capable of transferring to public schools could do so, and the Willowbrook administration was tasked with informing those

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[161] Ibid., 21.

[162] Deleuze, "Post Script on Societies of Control," and Foucault, *Discipline and Punish*.

schools of the child's intention to do so. This shift into the community indicates the decreasing partitions to inclusion throughout society, and the transition away from confinement to mobility descriptive of a society of control.

The school also agreed to provide "annual psychological evaluations" for each resident at the school. This was an incredibly important change. Many students did not have access to the school's psychologist, and some went nearly a decade without an evaluation. Furthermore, the court's insistence that the field of psychology become central to the evaluation of students, as opposed to a related project, indicates the growing importance of psychology at the heart of special education for children and adults labeled as profoundly retarded. Here, discipline was transforming. Students were no longer beaten or separated. Those punishments were made illegal.[163] It is not fair to call psychology a punishment, but rather it is a new form of evaluation and insurance that students are modifying their behavior according to state regulations. In this way, the cane faded out of special education, and the notepad of the psychologist replaced it, in order to ensure that the student internalized correct behavior.[164] The growing trend of psychological internalization is indicative of the Oedipalization inherent in societies of control.

There were also changes in medical and psychological treatment to residents. Experimental treatment could only take place with the resident's consent or with the consent of a parent, provided the resident could not reasonably consent. Furthermore, taking into account the Hepatitis experiments performed at the school, the court mandated that "no physically intrusive, chemical, or bio-medical research or experimentation shall be performed at Willowbrook or upon members of the plaintiff class."[165] The justification for this was a redefinition of the asylum into a place of learning concerned with the "programmatic needs" of the residents in question.

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[163] Ibid., 32.

[164] Bray, "Chemical Control," and New York State Association for Retarded Children v Hugh L. Carey, 35 – 36.

[165] New York State Association for Retarded Children v Hugh L. Carey, 34.

After over a decade of experimentation and provoked jaundice, doctors at the school would be incapable of changing the chemistry of a child's body for their own research purposes.

Furthermore, labor would not be a condition for "privileges or release from the institution."[166] If residents chose to work for the school, the administration would be required to pay them at least minimum wage. That policy did not apply, however to the student's completion of vocational training necessary under their IEP, or to basic housekeeping that residents would be expected to complete in order to ensure that their individual living area was kept clean.

Finally, the Courts demanded that within six years, Willowbrook would reduce the population of its residents to 250 or less, and would only be occupied by residents of Staten Island. Within one year of the Consent Decree, Willowbrook administration was charged with the creation of at least "200 new community placements to meet the needs of Willowbrook's residents and of the class."[167] The facilities created could not function as new asylums themselves, however. Instead, they would house no more than 15 residents, and would do so within the general community, rather than separately at a private institution, removed from the public. This massively shifted the purpose of Willowbrook from repository for the abject into preparation for "each resident, with due regard for his or her own capabilities for development, for life in the community at large" requiring the school and all institutions that it would create to "develop a full program of normalization and community placement." Here, the shift between discipline and control societies appears obvious. The courts mandated a change in purpose and definition about the primary goal of Willowbrook from a veritable prison into a transitional institution that would promote the inclusion and integration of people labeled with disabilities throughout their society. The sovereign made the housing of the body in containment illegal, and

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[166] Ibid., 33.
[167] Ibid, 42.

instead immersion was the new method of state evaluation and involvement. The Courts indicated that this change was to be permanent, placing an indefinite moratorium on Willowbrook State School in April 1975.[168] The state essentially took away its own power to place deviants in panoptic structures, and instead rendered power increasingly dispersive. This push to close Willowbrook signals the beginning of deinstitutionalization throughout the United States.

The Governor's office obliged the changes, recognizing the problems with Willowbrook. There was a second reason that Governor Carey, who by this point had taken over for Rockefeller, the Governor at the time the case was first created, agreed to the stipulations defined by the Court. The reason was simple. The changes at Willowbrook would allow New York to continue to receive federal money.[169] This decision making calculus was commonplace at the time, especially after the EAHCA was passed in July, 1975, which stated that all funding for special education would be handled by the federal government, and state governments and local school boards would be entrusted with its allocation.[170] Here again, it is impossible to understand special education outside of the bounds of capitalism. While, it is certainly noble to argue for the equal treatment of all persons within society, regardless of ability, it must also be understood that in the era of deinstitutionalization children in special education became something other than just students, or residents in an asylum sectioned off from the rest of the world. Now, they engendered citizens in the community, and more importantly for the leaders of the New York government, sources of increasing capital. The body of people labeled as disabled would be investments. This is a reformation, rather than a transition to, a system of handicapitalism, where the student's body is converted to a profitable basis. This not only functions as another system of

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[168] Ibid., 43.

[169] Rothman and Rothman, *The Willowbrook Wars*, 122.

[170] The Education of All Handicapped Children Act of 1975, 20 USC § 1401 (1975).

dehumanization, but also brought with it the drive to increase representation in special education, and reinscribed racist assumptions about the intelligence of people of color, given how easily segregated they were into special education rooms. This despotism is the changing guard that Deleuze and Guattari describe. The face of the institution may have changed, its function, however, remained relatively similar in that it ensured the disproportionate disaffecting discrimination along arbitrary lines.[171]

Unfortunately, however, the task force mandated by the Court following the WCD was incapable of accomplishing the majority of the goals set out for them by the courts. Infighting and continued negligence, as well as a lack of clear objective, meant disaster for the board members themselves, and even more so for the students that they were supposed to provide for.[172] Too much energy went into trying to fix the problems at Willowbrook carte blanche, and little to measured proposals that would make life better for those residents still housed at the institution.[173] For the administration at Willowbrook, it was business as usual. It was because of these oversights that Luis Ramirez, a resident of Willowbrook for 13 years, got out of his ward on Christmas eve, 1976, strolled onto the grounds, and was found dead of exposure five days later. Despite missing for several days, no search party was formed until December 28th. Even though this negligence was noted by the administration, only low-level employees were suspended.[174]

The mismanagement of Willowbrook continued, despite efforts to reform the institution. One major shift did occur due to the language of the consent decree, however. Increasing numbers of residents were moved out of the institution, and into residential centers. State

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[171] Ibid., and Bray, "Chemical Control," and Sleeter, "Why Is There Learning Disabilities?" and Deleuze and Guattari, *Anti-Oedipus*, and Guattari, *The Anti-Oedipus Papers*, 242.
[172] Rothman and Rothman, *The Willowbrook Wars*, 133.
[173] Ibid.
[174] Civil Service Leader, 36, no. 42, January 6, 1976, 4.

officials, led by Barbara Blum, continued the admission freeze at Willowbrook, and began moving residents out. The first six months, approximately only thirty-five students were removed from the school and placed in community centers.[175] Over the next few years, however, thousands would be taken out of the harsh asylum, and given other lodging. Across the nation, deinstitutionalization was central to new patient treatment initiatives, possibly made most famous in President Reagan's signing of the Omnibus Reconciliation Act. While that law would affect people understood to be mentally ill, local, state, and federal agencies were recognizing the need to move away from institutions built to house people labeled as developmentally disabled as well. By 1978, the population of New York residents in developmental institutions decreased from 27,000 in 1967 to 16,447. To this extent, Governor Cuomo in 1980 announced that the New York Office of Mental Retardation and Developmental Disabilities (OMRDD) would close the Willowbrook State School. Preparations were made, and by 1985, they finally reached a population of 250. This was the amount of students Judge Judd ordered the school to reach a decade earlier.[176] The school was finally closed in 1987, and a new era of care was brought in for those formerly held at, what Robert Kennedy referred to as, a "snake pit."

Instead, community centers would be developed throughout the state, over a hundred of which would open in Richmond County where Willowbrook stood, and where many of its buildings still stand today.[177] These reforms were part of wide sweeping changes across the country to repeal and reform the deinstitutionalization system that had been popular since the

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[175] Rothman and Rothman, *The Willowbrook Wars*, 135, and Deborah Young, "Official Who Led Fight to Close Staten Island's Willowbrook State School Dies at 82," SI Live, October 13, 2012, http://www.silive.com/obituaries/index.ssf/2012/10/retired_state_official_who_fou.html.

[176] Mary Beth Pfeiffer, "At $4,566 a Day, N.Y. Disabled Care no. 1 in Nation," Poughkeepsie Journal, June 20, 2010, http://archive.poughkeepsiejournal.com/article/20100620/NEWS01/6200374/At-4-556-day-N-Y-disabled-care-No-1-nation, and Rothman and Rothman, *The Willowbrook Wars*, and Goode, et al., *A History and Sociology of the Willowbrook State School*.

[177] Association for Children with Retarded Mental Development, "Community Residential Facilities: Alphabetical List," September 4, 1987, 1 – 21.

19th Century. The reason was simple; community placement programs were more humane. They would allow residents to live close to their family and have "normal life-enriching experiences."[178] Many of the first residents to occupy these new residential centers were "former residents of State developmental centers," though not all were. While these new facilities would still house people categorized as disabled, there are two major differences separating them from Willowbrook. The first is that it was their stated intention to care for people, including their dignity, at the outset of their creation. This was not a concern at Willowbrook until the Consent Decree, and one could argue, was never really a concern for administrators there at all. The second is that they would house far fewer people. Willowbrook, at its largest size, housed nearly 6,000 people. Some of the new sites opening would house as few as four people.[179] This was a massive shift in the regulation of programs for people identified as being disabled.

While the state had the right to determine where people would live, the community could also take part in the discussion, signaling, at least in some way, the diminishing power of the sovereign to determine people's living environment, another signal of a shift to a control society, away from a disciplinary one. That is not to say, however, that community groups would be able to reject any plan by the state. That would most likely result in, at least some, discrimination against the new tenants based on their diagnosed disability. Instead, complaints had to satisfy three requirements. They first had to reject the site itself, they would then have to suggest "one or more alternative sites," and they would have to prove that the new residence would change the "nature and character of the neighborhood," due to an overabundance of state residential sites there already.[180] While this last part might suggest that the state was intending to ensure that

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[178] James Walsh, Letter to Jack Potenza, August 18, 1983, CUNY CSI Willowbrook Archives.
[179] Association for Children with Retarded Mental Development, "Community Residential Facilities," 8.
[180] James Walsh, Letter to Ms. Maxine Spierer, Office of Mental Retardation and Developmental Disability, November 29th, 1984.

neighborhoods they approved of did not change, while poor neighborhoods would be subject to state mandate, the records do not suggest this. Rather, it appears that the OMRDD pushed for this statute to prevent the development of disability ghettos that would resemble Willowbrook, but in apartment buildings rather than separate grounds.

Another difference between Willowbrook and the new sites was their planning. Willowbrook had little oversight, and far too often did not follow through with stated goals and objectives. Even after the Consent Decree, many administrators did not think that the six hours per day training that each resident was supposed to receive applied to residents over the age of 21.[181] The new facilities were different, however. They were explicitly created for specific goals, some with residents of all ages, some specifically for children or adults. Some were created as coed facilities, and some were created just to address the needs of women. Quite possibly the most distinct difference in this new organizational structure was the creation of specific homes for vocational training or everyday living.[182] This converted them from a repository for societies unwanted, to training facilities so that individuals could be productive.

These facilities were not the only changes in conditions and living, however. The experiences of families at Willowbrook proved to many lawmakers that the home was the best place for people understood as disabled. However, that was often not a possibility. A great deal of the students at Willowbrook could not be cared for at home due to their family's socioeconomic status. This was the reason that the parents of more than 5,000 children staying there did not want their children released in the early 1970s. In an attempt to correct the unfair burden placed on poor families, lawmakers passed Chapter 461 in 1984 in order to give money to families who wished to care for their children. They added to a total of $1.15 million between

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[181] Rothman and Rothman, *The Willowbrook Wars*, 135.
[182] Walsh, Letter to Ms. Maxine Spierer.

1984 – 85, and $9 million between 1985 and 1986.[183] Furthermore, an increasing number of non-profit organizations were being created to help fund care programs for individuals identified as disabled, among them were the groups Eden II and United Cerebral Palsy.[184] Here, again, it is evident that power was becoming more decentralized as discipline societies were becoming outdated.

Despite the changing political climate, and the utopian ideals of many activists, the 1980s would not prove to be a period of salvation for people disaffected by Willowbrook. The school did close its doors in 1987, after reaching a population of only 250 in 1985. However, they would still have to be housed somewhere, and the cost of deinstitutionalization was incredibly high. In 1985, President Reagan began cutting funding for the Staten Island Development Center by $20 million dollars. Workers protested the cuts, arguing that Reagan was attempting to save money, even if it meant cutting useful programs, and that he was also trying to "embarrass Governor Mario M. Cuomo."[185] Arthur Webb, Commissioner of the OMRDD, stated that the Federal Health Care Financing Administration (HCFA) was engaging in a nation wide program to discredit "the nation's mental retardation programs" in order to reduce government spending. It is unclear whether Reagan did in fact want to besmirch Cuomo. It is clear that as conservatism was becoming a growing political force across the nation, and fiscal conservatism a popular political strategy, funding was being cut drastically for special education programs.

This uniquely affected residents in New York given that New York received approximately "20% of all Medicaid funds for mental retardation services, and treat(ed) 17% of the nation's mentally retarded."[186] This was not the first time that "Willowbrook residents (were)

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[183] Aruther Webb, Letter to Assemblyman Eric N. Vitaliano, June 6, 1985.
[184] Ibid., A12. CUNY CSI Willowbrook Archives.
[185] Julie Mack, "Connelly: SIDC Cuts are Political," July 6, 1985.
[186] Ibid.,

used for political purposes."[187] It is the first time that affected them in their own homes, however. Now, it appears that handicapitalism moved from the asylum and into the suburbs.

The makeup of who would receive that funding is incredibly important. In another letter to Assemblyman Eric N. Vitaliano, Webb stated that a "substantial" portion of funding that the federal government did not cut would be used to "conduct outreach and provide services to ethnic and racial minorities, and unserved and underserved disability groups."[188] Of the $9 million cleared for use between 1985 and 86, approximately 1/3 of the OMRDD's funding would go to "new funding support services."[189] This is indicative of a larger issue, the identification of minority students as being disabled on a greater scale than their white counterparts. Despite the problems with funding, the OMRDD continued to find, develop, and house a great deal of former Willowbrook patients.

Increasingly, they received push back from the community, most likely people unfamiliar with disability, and certainly unfamiliar with the students at Willowbrook. However, working with state officials, the OMRDD continually maintained a hard and fast resolve to ensure that individuals would have a place to live. By 1988, the OMRDD was able to develop 126 residential facilities in Richmond County alone.[190] In response to push back from the community, however, the OMRDD often voluntarily attended hearings over the opening of various sites throughout New York City. They argued against speculation from community board members, and criticized attempts to segregate people labeled as disabled into specific areas.[191]

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[187] Ibid.

[188] Arthur Webb, Letter to Eric N. Vitaliano, January 14, 1986.

[189] Ibid.

[190] Association for Children with Retarded Mental Development, "Community Residential Facilities: Alphabetical Index," 1 – 26.

[191] Elin M. Howe, Letter to Ms Joan Hodam and Mr. Alfred J. Brumme, September 24, 1990.

This afforded thousands of individuals throughout New York, many of whom had spent nearly their entire lives at Willowbrook to find new lodging.

This was not an isolated series of events. Rather, it was part of a larger push across the nation for deinstitutionalization, and one that would define the treatment of people labeled as disabled, and as mentally ill, for the rest of the 20th Century.

The Education for All Handicapped Children Act, precipitated by the criticism of asylums nationwide, as well as the closure of those same asylums, marks a monumental shift in the understanding of disability and the appropriate type of education offered to students, especially those labeled as profoundly or severely retarded. This is because, prior to the passage of this law, public schools only provided education to approximately one in five students labeled as disabled.[192] Furthermore, it demonstrates a seriousness of purpose in this increase of federal power by giving the commissioner a deadline of 125 days after enactment to "publish in the Federal Register such rules as he considers necessary to carry out the provisions of this section and section 611."[193]

The reason for expanding federal power in the area of education is explained within Congress' finding of purpose, where they state that:

1.) "There are more than eight million handicapped children in the United States today;
2.) The special educational needs of such children are not being fully met;
3.) More than half of the handicapped children in the United States do not receive appropriate educational services which would enable them to have full equality of opportunity;

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[192] Nielsen, *A Disability History*, 167.

[193] The Education of All Handicapped Children Act of 1975, 20 USC § 1401 (1975).

4.) One million of the handicapped children in the United States are excluded entirely from the public school system and will not go through the educational process with their peers;

5.) There are many handicapped children throughout the United States participating in regular school programs whose handicaps prevent them from having a successful educational experience because their handicaps are undetected;

6.) Because of the lack of adequate services within the public school system, families are often forced to find services outside the public school system, often at great distance from their residence and at their own expense;

7.) Developments in their training of teachers and in diagnostic and instructional procedures and methods have advanced to the point that, given appropriate funding, State and local educational agencies can and will provide effective special education and related services to meet the needs of handicapped children;

8.) State and local educational agencies have a responsibility to provide education for all handicapped children, but present financial resources are inadequate to meet the special educational needs of handicapped children; and

9.) It is the national interest that the Federal Government assist Tate and local efforts to provide programs to meet the educational needs of handicapped children in order to assure equal protection of the law."[194]

This is the basis for providing special education funding with federal money, a good idea, surely, but one abused now to ensure racial segregation throughout schools by unfairly targeting minority students for special education, so that more local, state, and property tax money can be used for students in general education. This became apparent by 1982 when Patrick and Daniel Reschly found that researchers must understand "mild mental retardation" in terms of "social

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[194] The Education of All Handicapped Children Act of 1975, 20 USC § 1401 (1975).

system(s) rather than (as) a medical model."[195] They found that, states with higher IQ requirements for general education often have lower numbers of mild mentally retarded and severely mentally retarded levels in special education, because those states also generally have lower levels of students of color. That is, despite the fact that many states use low IQ numbers to determine who needs special education, and who does not, they still have higher numbers of students that they identify as moderately or severely mentally retarded. Clearly then, the data suggests that there must be outside influences. The Reschlies provide them. More important than actual IQ in determining placement in special education is socioeconomic status and racial makeup of the state. In fact, the majority of states with lower IQ scores had higher rates of mental retardation because they had higher numbers of students of color, and the testing process was, and in many ways still is, biased toward ensuring white students were labeled learning disabled, while black and latin@ students were, and are, labeled mentally retarded.[196] In order to understand the ways that this system of racial discrimination could continue, however, it is first necessary to delve into the text of the EAHCA itself, to understand the ways in which it could be implemented, what it would change, and what it might leave the same.

It is important to note that policy and legislation can be read as both a "text" and a "discourse." It is read as a text precisely because it contains "contestations" over the very real material world that we live in. Laws are a subject of discourse as well, because they produce an effect on the people and systems that they are written in relation to.[197] This is important because it allows scholars to understand the ways in which the world is presented through law, i.e. which areas are embattled, and the ways in which those laws affect the people who fall under their

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[195] Patrick J. Reschly and Daniel J. Reschly, "Relationship of State Education Criteria and Demographic Variables to Prevalence of Mental Retardation and Public Education," *American Journal of Mental Deficiency*, (1982), 14.
[196] Ibid., 12 – 14, and Sleeter, "Why Is There Learning Disabilities?, 211.
[197] Allan, *Rethinking*, 26.

jurisdiction. This reading is key in order to comprehend the effects of any system of articulation as it concerns subject groups, or those groups who attempt to define themselves.

In order to understand the shifting atmosphere in relation to people labeled as disabled, one need look no further than the "Definitions" section. The bill was amended before being incorporated into United States code so that "crippled" became "orthopedically impaired," and "impaired children," became "children with specific learning disabilities."[198] The question that must be asked, of course, is what is the relationship here between what the bill is saying, and what is said. Here, it is important to remember that the text of the document is dealing with the material, while it is a discourse because it is affecting that material world, and the subject of discourse, because it is implicated in the material of push and pull.[199]

In this section, Congress has identified special education to mean public education created for the specific purposes of "meet(ing) the unique needs of a handicapped child, including classroom instruction, instruction in physical education, home instruction, and instruction in hospitals and institutions."[200] Here, a few things stand out. The first is that special education is defined in fairly nebulous terms without an understanding of what handicap actually means. The second is that child is secondary to their handicap within the text of the legislation itself. Here, it becomes clear that Robert's analysis of language is correct. The disability comes to stand in for the child themselves so that they are a condition first, and a child second.[201] This is made more apparent by the fact that nearly all institutions discussed in terms of special education are those meant to, if not cure, then at least alleviate the most obvious negative effects

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[198] The Education of All Handicapped Children Act of 1975, 20 USC § 1401 (1975).

[199] Allan, *Rethinking*, 26.

[200] The Education of All Handicapped Children Act of 1975, 20 USC § 1401 (1975).

[201] Roberts, "The Rhetorical Structure of Disability," 7.

of a child's disability. There, again, disability becomes a problem to be cured, dealt with, and diminished as much as possible.[202]

This last point is true too when understanding the term "related services." Here, the 94th Congress defines services offered to children categorized as disabled as those that might diminish the most obvious, and potentially harmful effects of that child's supposed disability. This includes the "identification and assessment of handicapping conditions in children."[203] The medical model of understanding disability then took on a new form in the law. This is process Deleuze and Guattari consistently refer to as despotism. The old guard fades from the spotlight, precisely by taking a new form, combining the arborescent, or rigid, stratifications of the earlier era, while simultaneously becoming more encompassing. This is the beginning of the diagnostic model, in which the counselor can become the doctor, and the classroom the examination room.[204] This is apparent in a number of schools in which psychologists became indispensable workers in the administration.[205]

Amazingly, nowhere in the definitions does it cover what a "handicapped child" is. In "native language," it offers a reference to another act of Congress. There are two separate areas within the definitions section of this bill where the members of Congress discuss costs, and not one where they discuss what makes a child handicapped in the first place.[206] This is curious indeed as the definition for handicap itself is central to determining who actually receives various services, and how they shall receive them.

In order to be eligible for federal funds, states must prove to the commissioner that they are providing free education to all students, regardless of handicap. They must also create and/or

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[202] The Education of All Handicapped Children Act of 1975, 20 USC § 1401 (1975).
[203] The Education of All Handicapped Children Act of 1975, 20 USC § 1401 (1975).
[204] Ibid., and Deleuze and Guattari, *Anti-Oedipus*, 213, and Abigail Bray, "Chemical Control."
[205] "TSD Administrative Structure," *The Lone Star*, January 15, 1976, Austin History Center Archives.
[206] The Education of All Handicapped Children Act of 1975, 20 USC § 1401 (1975).

amend existing plans for education to comply with the EAHCA. The plans must have an IEP for each child including providing a full education, a timetable for providing that education, and a list of all personnel and resources necessary throughout the state for that education. Furthermore, all education ought to be provided, according to the EAHCA, to individuals between the ages of three and twenty-one, however, these laws are unenforceable if they conflict with state laws already in place. In order to do so, the EAHCA states that a method must be determined by which to "identify, locate, and evaluate," the development of students, as well as which students were receiving necessary educational tools, and which were not. Then on, "policies and procedures" were established in order to do so.[207] This required that time tables be established for helping children with disabilities, beginning with children receiving no education, then with children "within each disability, with the most severe handicaps who are receiving an inadequate education."[208] While this is certainly a noble pursuit, to help the most disaffected of children, the question must be asked how these determinations can be made if there is no definition for what a handicap is in the first place, and very little delineation between what severe and mild handicaps might be.

It is the responsibility of each state accepting federal funds for the education of children in question to keep records of each individual child.[209] The Act also tasks individual states with ensuring that students are placed in general education classrooms, not to be removed except "when the nature or severity of the handicap is such that education in regular classes with the use of supplementary aids and services cannot be achieved satisfactorily."[210] However, there is no defined standard metric to determine when a child is so severely handicapped. There is also no

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[207] Ibid.

[208] Ibid.

[209] Ibid.

[210] The Education of All Handicapped Children Act of 1975, 20 USC § 1401 (1975).

standard to determine the success of supplementary aids, or how long, if at all, schools must attempt to integrate students before removing them from general education classes entirely. The Act does say that state "educational agenc(ies)" are in charge of making sure that children are not determined to have a handicap, or a more severe handicap than the one they actually have, along racial or cultural lines. Those agencies are also tasked with providing any materials necessary to a child within their "native language," except when it was unfeasible to do so. However, the Act lays out no way of ensuring that racial and racist determinations are not used, or which body of government is meant to oversee each state's education agency, in order to ensure they are complying. It seems here that more work has been done to highlight the tracking of individual students than has been done to make sure that that tracking is not done in a racist way. This is ultimately problematic because, as the Reschlies pointed out in 1982, the medical model that state education is structured under often misses the point that the categories of mild and severely mentally retarded are social, rather than medical. Furthermore, states that have higher IQs, which one would expect to mean that they have a greater population of students in special education, is in fact incorrect. States with lower IQ standards have greater numbers of special education students due to the fact that they also often have students with lower socioeconomic status, and a greater number of black and latin@ students. The racist undertones that guide education in these states makes for a greater number of students labeled as mentally retarded by almost one hundred percent.[211] It appears then that, while the old guard has changed on paper, the new guard holds onto the same policies.

In order for states to receive funding, they must devise certain plans including a plan detailing how such funds will be spent, detail how funds shall be used, and are expected to comply with the Elementary and Secondary Education Act of 1965 as well as the Vocational

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[211] Patrick J. Reschly and Daniel J. Reschly, "Relationship of State Education," 11 – 14.

Education Act of 1963. Schools must also describe the procedures that they will put in place, as well as the training given to teachers.[212] The Act also guarantees that children in private schools, after having been referred there by the State or local officials, will receive education consistent with the IEP guidelines, and will do so at no cost to the child or the family. The State also has the power to determine whether or not private schools are satisfactorily meeting the requirements listed above.[213] This ensures that schools such as Willowbrook would fall under federal guidelines, rather than exist in a state of exception to them.

The Act also states that schools would "recover any funds made available" to children who are unnecessarily labeled as having special needs. There is no clear indication concerning who states ought to collect money from, however, or how they are supposed to do this. Furthermore, there is no metric given for how states are supposed to determine whether or not a child has been falsely diagnosed. There is also no section detailing how children are to be re-integrated into general education classrooms after they have studied in special education classrooms. Here, again, it becomes apparent that precision in the law is important, because the vague nature of these laws allows schools to operate with little oversight, making racist determinations about who ought to be identified as having special needs, and is not held accountable for how those children might be included, after having been excluded in the first place.

These problems are exacerbated in the application section of the bill. Here, as directed, the States will also be responsible for "assur(ing)" that the funds will be used for their intended purposes. This requires, according to section 614 1(A), that schools "identif(y), locate, and evaluate" all students who need special education, "regardless of the severity of their handicap."

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[212] The Education of All Handicapped Children Act of 1975, 20 USC § 1401 (1975).

[213] Ibid.

This is important for a few reasons. Substantively, the language of the law still evaluates disability in terms of the medical model of previous generations, in which disability is something that lives within the human being, can be located, and then treated as a disease. This encourages the supposedly benign conditions of exclusion and evaluation, that actually establish people with disabilities in terms of their disability first, and their humanity second. This is a form of dehumanization, the effects of which are "almost incalculable."[214] Second, this passage is important for historians' theoretical understandings of how society's respond to disability, while remaining similar in terms of its use of the medical model, practices a new modality of power. The use of location, evaluation, and identification of a person treated as nothing more than their disease is emblematic of the control societies that Deleuze predicted would come to pass as Foucault's discipline societies decreased in importance. Foucault is far more concerned with the actual physical control of the human body, as well as the internalization of systems of power, and their continued prevalence after a subject has been released from schools, prisons, asylums, and other areas of discipline. Deleuze is undoubtedly also concerned with these forms of state power, he is more concerned with how they operate as the juridical element of control becomes more abstract.

For instance, in modern society, and with the help of the Education for All Handicapped Children Act, more students identified as having disabilities became integrated in public schools than ever before. While this is undoubtedly a good thing that millions of children received and are receiving an education, the ability of the state to locate their supposed disease and thus dehumanize a greater number than ever before cannot be ignored. However, movement throughout the school, especially between general education and special education classrooms must be taken into account. In this way, it appears that many of the barriers to entry have largely

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[214] Roberts, "The Rhetoric of Disability," 7 and 25.

disappeared, while the logic of the system writ large remains similar. It becomes clear then that Deleuze was describing, and did predict, the new modality of power in the modern era. Here, it is clear that the shift from discipline to control became written into the law. Following this line of logic, schools must also provide frequent reports to allow the commissioner to better do their job, and ensure that those reports are correct. Here, the connection between the educational system and state approval does not go away, but becomes more bureaucratic than before.[215] This theoretical understanding of disability and the shift between discipline and control societies is necessary for historians to accurately understand the ways in which systems of thought are created and put into effect, and the ways that they then affect the material lives of very real people.

In order to keep States from undercutting local schools, hearings must be held, or time must be given for hearings, before applications may be sent in to the federal government, about the use of federal funding for special education classes, resources, and training.[216] After receiving that funding, they must provide proof that federal funding is not being "comingled" with funding from the state and/or local coffers. Federal funding can "supplement" those funds, however, provided that states prove they are using said funding for the education of all children equally.

Furthermore, the federal government requests that evaluations of the effectiveness of programs ought to be done and submitted annually to ensure that children are being offered the education promised by the state.[217]

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[215] The Education of All Handicapped Children Act of 1975, 20 USC § 1401 (1975), 784.

[216] Ibid., 785.

[217] Ibid.

If the federal government finds that any school or school district has been remiss in their duties to provide for the children under their care, the government will withhold funds until the school or district in question has rectified the problems with their application process.
Section 614A (d3) also includes a portion which allows for the state to determine, apparently without consultation of the family, whether a child is fit or not for public schools, and would "best be served" by a state institution "to meet the needs of such children," provided that the school is either "unable or unwilling" to put into place the necessary programs to teach the child in question, or is "unable or unwilling to be consolidated with other local educational agencies" in the first place.[218] It is unclear what the term "unable or unwilling" actually means. It appears that schools may essentially have an opt out clause, in which they can refuse federal funds, if they do not want to include children labeled as disabled. More importantly, however, is that the federal government has reserved the right to determine whether or not children will be sent to a specialized institution. In this way, the age-old option of the separate school for the child labeled as disabled, the one that must be excluded under the auspices of "new partition(s)," is allowed to continue.[219]

Here, it is unsurprising that the law continues to treat children as a disability, rather than a person. This is not the only thing that must be noted about the application process of the EAHCA. Like the "Definitions" section, the application process is written to protect funding to a great extent. In the twenty nine paragraphs in the section, ten paragraphs explicitly, and nearly exclusively, relate to funding, while the other nineteen range from the understanding of disability, the creation of plans for students identified as disabled, detailing the rights of parents

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[218] Ibid., 787.
[219] Jean Baudrillard, *The Transparency of Evil*, Trans. James Benedict, Verso: New York, 1993, 129.

and the community at large, and coordination between local, state, and federal governments.[220] The reason is apparent; it became clear in the 60s and 70s that the federal government, in order to increase inclusion, and force integration, needed an enforcement mechanism. The answer was simple, funding. In this way, capital came to be the missing link between freedom and persons who were previously excluded from society. However, this strategy largely failed as the inconvenience and difficulty of providing funding often overcame the conscious effort of individuals to do what advocates of reform regarded as the right thing.[221]

Following these definitions and funding questions, it is necessary to analyze the section titled "procedural safeguards" in order to understand how enforcement mechanisms might resolve some of the issues raised. It seems here that some of the vague language from the application portion is pre-empted, as children and their parents are supposedly "guaranteed procedural safeguards" as they relate to "the provision of free appropriate public education by such agencies and units."[222] These include the parents' and/or children's right to review the records kept on them, as well as to receive "an independent educational evaluation" for the child.[223] If the child does not have parents or guardians who can be reached, or if the child is a ward of the state, the State has the ability to "assign an individual…to act as a surrogate for the parents or guardian." The State must notify the parents or guardians of the child if they are plan to use a surrogate parent or guardian, however, and parents/guardians do have a right to refuse that change, and have the right to be notified within their "native language."[224] It seems odd, however, that in Section 615 (b), which initially guarantees freedom of information for a child in special education, to lump in a portion about the State's right to determine a suitable guardian for

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[220] The Education of All Handicapped Children Act of 1975, 20 USC § 1401 (1975), 784 – 788.
[221] David Rothman, *Conscience and Convenience*, 2nd Edition, New York: Aldine Transaction, 2002.
[222] The Education of All Handicapped Children Act of 1975, 20 USC § 1401 (1975), 788.
[223] Ibid.
[224] Ibid.

the child, if they find the parents or guardians in place at the time, unless the child is a ward of the state, are unfit to do so.

It must be noted here that, as of yet, there are very few rights laid out for the child in question. While the rights and responsibilities of educators, state and local officials, parents and guardians, and schools are clearly stated, the child has yet to be mentioned in terms of how the hearing ought to be conducted. Furthermore, all attempts to appeal decisions made by the hearing only seem to be written in such a way that allows parents, guardians, educators, or others involved to appeal. No mention is made of the child's right to appeal decisions about their own education.[225] Furthermore, there is no framework laid out for the ways in which children might be treated differently based on the determination and application of their disability. Here, again, it seems that children are separated from the systems of power that determine their educational lives, as teachers and administrators are given greater power to do so.

In case there is a failure to comply with the determinations and judgments of the hearings and/or appeals, the state commissioner is charged with "notifying the state educational agency," to "withhold any further payments to the State under this part," and after notifying them, may withhold all payments under the federal funding section above. The states do have the right to appeal within sixty days.[226] Here, the actual mechanism of enforcement is revealed. Money is key to ensure that children receive an education that the federal government deems appropriate. While it is certainly noble to argue for an education for all children, this mechanism has the

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[225] Ibid.

[226] The Education of All Handicapped Children Act of 1975, 20 USC § 1401 (1975), 790. It should also be said that this section is written in gendered form, where the commissioner is always male. While this is important in terms of understanding legislation, it may not be incredibly important in terms of understanding how this law relates to children with disabilities overall.

unfortunate effect of making specific children symbols of monetary value, and creates the basis for purposeful misidentification to garner more federal dollars.[227]

In order to evaluate the effectiveness of the new law, the commissioner is charged with "measure(ing) and evaluat(ing)" the effectiveness of the programs put in place, as per Section 618(a).[228] This requires that the National Center for Education Statistics

> "provide(s)…each House of the Congress and to the general public at least annually…(A) the number of handicapped children in each State, within each disability, who require special education and related services; (B) the number of handicapped children in each State, within each disability, receiving a free appropriate public education and the number of handicapped children who need and are not receiving a free appropriate public education in each such State; (C) the number of handicapped children in each State, within each disability, who are participating in regular educational programs, consistent with the requirements of section 612 (5) (B) and section 614 (a) (1) (C) (iv), and the number of handicapped children who have been placed in separate classes or separate school facilities, or who have been otherwise removed from the regular education environment; (D) the number of handicapped children who are enrolled in public or private institutions in each State and who are receiving a free appropriate public education, and the number of handicapped children who are in such institutions and who are not receiving a free appropriate public education; (E) the amount of Federal, State, and local expenditures in each State specifically available for special education and related services; and (F) the number of personnel, by disability category, employed in the

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[227] Bray, "Chemical Control," and Sleeter, "Why is there Learning Disabilities?"

[228] The Education of All Handicapped Children Act of 1975, 20 USC § 1401 (1975), 791.

> education of handicapped children, and the estimated number of additional personnel needed to adequately carry out the policy established by this Act."[229]

Here the importance of categorization in terms of the code that Deleuze identifies in "PostScript" is clearer. It becomes apparent that scholars are not dealing with individuals who must be addressed in terms of their individual selves, i.e. Michael Ely, as well as their numerical selves, i.e. Michael Ely's social security number. Rather, society is dealing with a system that takes as its aim "dividuals," or bodies which are coded in a mass. These bodies can still be traced within the axiomatic of the capitalist order, but are also free floating. They can be integrated and segregated at will, and it is fairly easy to do so.[230] Here, we are also met with Rothman's fairly convincing argument that, it is about the money when it comes to how the State, and society at large, treats people labeled as disabled. That is, the code (Cerebral Palsy) comes to stand in for the individual (John Smith). The two are no longer separated in terms of individuality and deviance. Rather, they are one and the same, and can be included and excluded at will by sending John Smith to special education classes at certain points, while retaining him in general education at other points. The determining factor, however, tends to be money and Smith's worth to the school in a specific place at a specific time. Here, capital still determines the relationship of the school to the individual.

The commissioner is also tasked with "provid(ing) for the evaluation of programs and projects assisted under this part through – (A) the development of effective methods and procedures for evaluation; (B) the testing and validation of such evaluation methods and procedures; and (C) conducting actual evaluation studies designed to test the effectiveness of such programs and projects." There is no elucidation here, however, on what effective tests

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[229] Ibid., 792.

[230] Deleuze, "Post-Script on Societies of Control," 6.

might mean, and which methods and procedures are to be used. While the Act certainly cannot go into what each IEP might mean, or even more generally, how students are to be evaluated overall, given that each state must come up with a form of evaluation and testing on their own, it does not state how students with disabilities will be evaluated in terms of their other peers. Here, there is a group without a referent, generally a group that is absent as the referent, now being given the center stage, without a supporting cast with which to share the stage.[231]

This finally brings us to the ultimate question of the EAHCA. That is, how do the payments work? Where does the money go? Who determines who gets it, and how? The bill is written so that states will get payments and dole them out accordingly to the local agencies.[232] In Section 620 (b) (1) "The Commissioner of Education" is given the ability, within a year, to

> "prescribe (A) regulations which establish specific criteria for determining whether a particular disorder or condition may be considered a specific learning disability for purposes of designating children with specific learning disabilities; (B) regulations which establish and describe diagnostic procedures which shall be used in determining whether a particular child has a disorder or condition which places such child in the category of children with specific learning disabilities; and (C) regulations which establish monitoring procedures which will be used to determine if State educational units are complying with the criteria established under clause (A) and (B)."[233]

Essentially, this section authorizes the commissioner to determine whether or not states are utilizing the appropriate metrics to determine whether or not children are being diagnosed correctly with disabilities, and then power to overturn those definitions if they are not. Ostensibly, this might prevent some discriminatory forms of categorization to prevent the

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[231] The Education of All Handicapped Children Act of 1975, 20 USC § 1401 (1975), 792.
[232] Ibid., 794.
[233] The Education of All Handicapped Children Act of 1975, 20 USC § 1401 (1975), 794.

segregation of students into special education classrooms or institutions due to other factors, i.e. race, class, and gender. However, as has been demonstrated, these misdiagnoses continued. What is more curious, however, is that this section seems to be buried in the "Payments" portion of the law, rather than as a corrective measure in the "Definitions" section, or even in the "Evaluation," or "Procedural Safeguards" section. The next subsection demonstrates this more clearly, but it seems that the categorization of children who would receive federal money is of more importance than ensuring the accurate evaluation of those children.

It is also here, that the term "children with specific learning disabilities," is finally defined. It is found to mean:

> "children who have a disorder in one or more of the basic psychological processes involved in understanding or in using language, spoken or written, which disorder may manifest itself in imperfect ability to listen, think, speak, read, write, spell, or do mathematical calculations. Such disorders include such conditions as perceptual handicaps, brain injury, minimal brain dysfunction, dyslexia, and developmental aphasia. Such term does not include children who have learning problems which are primarily the result of visual, hearing, or motor handicaps, of mental retardation, of emotional disturbance, or environmental, cultural, or economic disadvantage."[234]

Here, it becomes blatantly apparent that the subsection is meant to curtail discrimination based upon disadvantages within the school district. Again, it seems odd that this is covered in the payments section, and demonstrates large concern from the federal government in how much it must spend, rather than actual concern about discrimination and segregation. It also marks the confluence of psychology and psychiatric determinations in the development of the law, marking a significant moment in a trend that had been occurring for years, that is, psychology, education,

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[234] The Education of All Handicapped Children Act of 1975, 20 USC § 1401 (1975), 795.

and the law came to be fused, at least in discussions about people understood to be disabled. Furthermore, it creates a hard and fast distinction between the categories of learning disabled and mentally retarded that has, over time, been used to artificially exclude children of color from general education classrooms, while ensuring that white students who often accomplish the same amount of work, are not excluded. This delineation is then used to justify and continue racial and racist discrimination in the American classroom.

CHAPTER FIVE: CONSUMERS IN THE CITY

Deinstitutionalization, as an implemented process, was in full swing by the time the Americans with Disabilities Act was signed into law in 1990. Institutions were being phased out across the nation as stash houses for people labeled as disabled. In fact, the very understanding of disability was being called into question. The residences that replaced large asylums were smaller community based locations, housing sometimes less than a dozen individuals. Furthermore, people were no longer understood as "retardates" or even as "victims of nature," as they previously had been. Instead, they were "consumers."[235] Children and adults were no longer just patients receiving care in the field of mental hygiene. They were active purchasers of training and education. A shift appears to have occurred. The Disability Rights Activists and leaders in the field of special education were not only concerned with the rights they felt ought to be afforded, but with the ability to participate in the market. In this way, the rights argued for just thirty years before, became commodities to be purchased. The right to participate in society became the right to participate in the market, and the system of handicapitalism became inextricably linked to the disability rights.

This is why the New York City Bureau of Mental Retardation/ Developmental Disorders (NYC BMRDD), at a member meeting, stated that their primary goal for the early 1990s was funding. They sought to increase federal dollars used for care of consumers so that "620/621 Funding" would not only be given out to former Willowbrook residents. The reason was simple, there were no new Willowbrook residents, so many were already receiving funding, and the former Willowbrook residents themselves were dying, resulting in less funding to New York

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[235] Staten Island Retardation and Disabilities Council, Ninth Annual Legislative Luncheon Program, Friday November, 1990.

residents through the federal programs established.[236] These funds would then be used for increased training and technology for individuals with "complex medical needs," and their families, many of whom were forming support groups to speak to one another given the "exhaustive" work of caring for their children.[237]

Groups also fought to ensure that previous legislation would be respected. For instance, the NYC BMRDD fought Governor Cuomo's Early Care Bill which would increase early detection and investigation programs for students understood to be "at risk," due to parental drug use or homelessness. This program was especially important, argued Cuomo, due to the high level of children born HIV Positive in New York at the time. The NYC BMRDD was supportive of the spirit of the bill. The issue, again, was funding. The draft form of the Early Care Bill stated that there would be "third party billing" in order to ensure the efficacy of the law. The group argued that many parents in Staten Island, and others throughout the city would be unable to pay such high costs. It was their estimation that the government ought to pay for those services as they are defined in the EAHCA as constituting a part of children's educations.[238] Here, again, it is evident that these rights are bound in funding, and that the fight for greater special education was not simply a fight against stereotypes and understanding.[239] Rather, it was often a question of the purse, and inclusion could only be guaranteed with fiscal incentive.

This was also true of transportation services throughout New York. Activists involved in the organization of group homes and community care following the closure of Willowbrook and its related services argued that citizens around New York were not receiving adequate

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[236] Ibid.
[237] Ibid.
[238] Ibid.
[239] James Lawler, "The King Must Die: Pataphysical Exigesis of an American Presidency," *International Journal of Baudrillard Studies* 9, no. 3. http://www.baudrillardstudies.com/contents/volume-nine-number-three/lawler-the-king-must-die/.

transportation, and that this was negatively affecting their lives, as well as their ability to receive an adequate education. In response, they called for increases in funding for travel services, as well as for training to use public transportation.[240] There are two important points here. The first is to reiterate that inclusion in public spaces was often, at the time, not a movement against the sentiments of people. Rather, the struggles for inclusion in this era were struggles for funding. The second is that it speaks to the shift from a discipline society to a control society. The barriers, or striations, that kept people separate were being diminished. Now, people were free to use public transit, residential homes were opening up in neighborhoods across the city, and a great deal of special education was centered around daily skills that people would use in the community. This was a shift toward smoother spaces where the barriers to entry were, not non-existent, but certainly reduced from where they once were. This shift is necessary for historians who wish to understand the changing nature of society over time as it relates to disability studies overall.

Furthermore, a great deal of this change was also concerned with having "greater family focus."[241] While the allocation of disability was still largely individualized within society, this increased family focus indicates that the Oedipalizing tradition of concerning oneself with the family as it relates to the essence of one's life. Oedipalization is the use of a generalized framework to establish repressive ideas on individuals. For Deleuze and Guattari, this is commonly played out in the psychoanalytic tradition of stating that a person was shaped almost entirely by the family. The family is certainly important, and no one would argue otherwise. However, the establishment of the determining factor in the essence of humanity is misguided,

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[240] Staten Island Retardation and Disabilities Council, Ninth Annual Legislative Luncheon Program, Friday November, 1990.
[241] Ibid.

and severely limiting in understanding the multiplicity of factors that affect human beings.[242] This is important for discussions centered on disability because they provide the ability to question the nature of assumptions made about individuals, and to throw into relief facile arguments about the nature of disability itself.

The Oedipalization of individuals is important in a very real context, given that it contributed to the creation of CRDD Programs for children between 2 – 5 years old, depending on need, often determined by facts about the family.[243] The family, here, was not only important in the justification of the need for the program, but also in its design. The classes themselves were supposed to be set up according to small sizes, with a "small family like atmosphere."[244] Parents were also invited to work closely with staff to work on their children's language skills, as well as to develop IEPs for their children. Here, the formation of and justification for early identification and training programs was bound up within the structure of the family. It appears that the decade long Oedipalizing influence of understanding disability as rooted in the family continued on even after reform came to so many institutions.

There was massive change occurring throughout the country, however. Fewer and fewer children were being sent to institutions, more residential houses were opening up, and the New York Department of Mental Hygiene (NY DMH) recommended in 1990 that all development centers, many built much like Willowbrook, be closed by 2000. Governor Cuomo announced plans to do so in 1991.[245] In their place, the city would continue to repurpose various apartments, houses, and other sites as residential homes and training centers, and erect some new areas to serve as schools that would "enable the program participants to develop their potential as

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[242] Deleuze and Guattari, *Anti-Oedipus*, 48 – 49, 120 – 122.

[243] Community Resources for the Developmentally Disabled, "CRDD Pamphlet," CUNY CSI Archives.

[244] Ibid.

[245] Pfeiffer, "At $,4,556 a Day," http://archive.poughkeepsiejournal.com/article/20100620/NEWS01/6200374/At-4-556-day-N-Y-disabled-care-No-1-nation.

individuals, as members of their families, and as productive citizens in their communities."[246] The services offered would differ based on age and necessity.

Toddlers and young adolescents would receive a great deal of focus on language development and early socialization programs. "Severe(ly) and profoundly mentally retarded adults," some of whom were previously held at Willowbrook, would qualify for Day Treatment. The proposed sites would also include some residential areas within the training facilities. The purpose would be to, not only provide housing, but to provide training in every day living skills "within a home-like atmosphere," where residents would stay at the facility 5 days a week. Many adults would also qualify for vocational programs where they would learn real work demands and skills to help them become "productive." The ultimate goal of the program was to allow participants to move into "competitive employment."[247] This marks another major shift in special education. The body of the student, or in this case, the consumer becomes a site of productivity. Previously, in institutional care, students were often not understood as contributors. In the era of deinstitutionalization, however, the goal of education was to make them consumers and contributors in the daily economy.[248] This is evidenced by the fact that in advanced workshop courses, students would enter into "sub-contract agreements with local industries for which clients are remunerated."[249] The body was no longer a thing to be contained within the secluding structures of the disciplinary society. Instead, it was to be made to produce in societies of control.

Meanwhile, more residential centers were opening across New York as three major developmental centers closed, including the Bronx Developmental Center, established and built

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[246] Community Resources for the Developmentally Disabled, "Building Proposal," November 20, 1991, CUNY CSI Archives.

[247] Ibid.

[248] Bray, "Chemical Control."

[249] Community Resources for the Developmentally Disabled, "Building Proposal."

to take in Willowbrook residents after the Consent Decree was signed. While there was some push back from the communities around New York, Department heads at various institutions often over ruled complaints that the facilities would change the character of the neighborhoods they were established in.[250] Despite all of these changes, and administrative organization. There still remained quite a bit of work for leaders in the field to accomplish.

By January, 1993, Governor Cuomo signed the Early Intervention Bill into law, and according to the EAHCA, there would need to be facilities in every borough of New York to provide day care centers for children between the ages of 2 and 5. Despite the fact that the bill would go into effect in under nine months, the Staten Island Retardation and Disabilities Council (SI RDC) had yet to find suitable venues for children to learn.[251] Organizations around the city were also wrestling with hospital administrators to fairly compensate children "injured" at birth under Cuomo's Impaired Infant Legislation.[252] The bill itself was designed to reduce the amount of time families would have to seek relief from the courts, and instead make compensation an administrative task. However, hospitals were often giving too little money to the families affected.[253] Here, too, it appears that the fight for inclusion and equality was no longer a question of being included in various spaces around the city, but rather of receiving funds. The fight for disability rights was a fight over capital, and less a fight over treatment or isolation. Bureaucracy had overtaken much grass roots activism throughout the nation, and according to the SI RDC, "behind the façade of a plan to help impaired infants is a bureaucratic nightmare which will overwhelm the endurance and resources of all but the most skilled at navigating muddied

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[250] Pfeiffer, "At $4,556 a Day," and New York State Association for Retarded Children, "Decision," and Elin M. Howe, "Letter to Mr. Lou Carvone and Mr. John P. Welch," October 25, 1991, and Elin M. Howe, "Letter to Robert Witkowsky," March 26, 1992.
[251] Staten Island Retardation and Disabilities Council, "Eleventh Annual Luncheon," January 15, 1993.
[252] Ibid.
[253] Ibid.

bureaucratic waters."[254] This signals the administrative takeover of deinstitutionalization and community services, an outgrowth of the increased public attention and state response of change in the 1960s and on. Even the solutions identified by organizations and activists were often bureaucratic.[255] The fight for disability rights had become bound in finance, and administrative in its practice.

This is the reason that across the nation, experts cited the growth of "consumer empowerment" as a "national trend" in special education and services offered to individuals understood to be disabled.[256] Here, there is an interesting shift. Just 20 years earlier, attorneys for the state were arguing that individuals in Willowbrook could never be educated or included within the general public. In 1993, committee leaders argued that the same individuals were consumers in society, and that services should be geared toward their desires. It appears that in tying change for individuals labeled disabled to funding, economic concerns dictated the conversation to the point where those affected were not referred to as people or citizens. Instead, they became customers. By 1993, there were 13 different customer councils around the city to determine what individuals and their families wanted services to do.[257] Even in the most general of conversations, it was assumed that individuals labeled as disabled were always already consumers ready to purchase.

These changes continued throughout the 90s, ensuring inclusive education in public schools, as well as in ensuring efficient residential training programs. Unfortunately, however, conditions for workers in special education were still poor. Many were paid too little, resulting in high turnover rates of qualified workers. This was an especially large problem at private

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[254] Ibid.
[255] Ibid.
[256] Ibid., 4.
[257] Ibid., 4 – 5.

institutions throughout the city.[258] Outside of private schools, however, a growing number of children were entering general education classrooms enabling greater socialization for children of all ability. [259] Unfortunately, many of those children were unable to pay tuition rates in 2000, given that the funding they received had not been updated since 1994, when inclusive education throughout the city began.[260] Furthermore, many school districts were not providing the universal pre-kindergarten programs promised by the government. By 2000, only 99 of 241 (41%) eligible districts provided services to children four years or older. That fact meant that schools could not provide services to the now 27,298 children in special education programs around the city.[261] Despite these challenges, the barriers to entry for children changed dramatically from even six years previously. The shift toward socialization itself marks a decrease in striation in the education of people labeled as severely or profoundly mentally retarded, signaling the transition from discipline to control societies that Deleuze theorized.

That shift to an increasingly inclusive system was celebrated May 2, 2000 at the 25th Anniversary Celebration of Willowbrooks closure. By this point, several institutions around the city, some meant to house former Willowbrook patients, had closed. The city was not able to complete closing all asylums, however. Fiscal concerns prevented the closure of several institutions in 1998.[262] There, attendants gathered at the former site of Willowbrook, now a sprawling college campus where the College University of New York Staten Island is located. They made speeches thanking the government for closing the former institution, even though several of the old buildings still stand, some of which house classes that college students take in a number of subjects. Celebrators extoled the government for their part in ensuring the safety of

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[258] Staten Island Developmental Disabilities Council, “Legislative Breakfast,” March 10, 2000, 5.
[259] Ibid., 6.
[260] Ibid.
[261] Ibid., 8.
[262] Pfeiffer, “At $4,556 a Day.”

Willowbrook residents in what they described as a singular "government act that has had such a profound impact on society."[263] They highlighted the changes in special education across the nation over the past 40 years, and linked them all to the decision made about the Willowbrook State School.

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[263] Planning Committee, "Social Justice Has Prevailed," Willowbrook Consent Judgment 25th Anniversary Celebration, May 2, 2000.

CONCLUSION

Today, the City University of New York College of Staten Island (CUNY CSI) sits on the former Willowbrook campus. Along the East side, passers by can see, the now dilapidated, buildings across from the library parking lot. They stand without students, behind a chain link fence in order to keep out trespassers. There is virtually no significance attributed to these buildings. No markers to inform people what they are walking by, or how those structures affected the lives of thousands of people.

Figure 2: Willowbrook, Building 27, Photo taken by Michael Ely. Edited by Jordan Nerison. November 23, 2014.

There is one memorial on campus, however. It is a plaque located on the 3S building, formerly building 19, in which many of the university's science classes are taught. The "19" is still painted on the South Wall of the building, just above where a plaque hangs. This symbolic gesture to permanently highlight the importance of those buildings, of that institution, is undercut, however, by the placement of the symbol itself.

The plaque is located on the side of the building least likely to attract heavy foot traffic. What is more, the color blends in superbly well with the red brick building it is mounted on, making it less likely to alert people of its presence who are not looking for it to begin with. Finally, a bush in front of it obstructs the view of the plaque. This is incredibly odd, considering that it is the only bush on any side of the building. To clarify, there are no other bushes on any side of the Building 19, except for one, in front of the only symbol that might explain the significance of this historic site.

Figure 3: Willowbrook Plaque, Close-up, Photo taken by Michael Ely, November 23, 2014

Figure 4: Willowbrook Plaque. Mid-Range. Photo taken by Michael Ely. November 23, 2014.

Figure 5: Willowbrook Plaque. Far Away. Photo taken by Michael Ely. November 23, 2014.

Figures 6 and 7: Willowbrook Building 19 South Side (Top), Willowbrook Building 19 West Side (Bottom). Photo taken by Michael Ely. November 23, 2014.


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Figure 7: Willowbrook Building 19 East Side. Photo taken by Michael Ely. November 23, 2014.

It is incorrect to presume the intent behind this curious intrusion of nature on an otherwise beautifully manicured campus. It does appear, however, that even if by accident, "those who struggled" at Willowbrook are still struggling to have their story told.

Today, reform in state and federal policy in terms of people labeled as disabled has grown tremendously, and a field of research has sprung up that revolves around those questions. Possibly the largest example of this is the continued revision of the Individuals with Disabilities Education Act, most recently updated in 2004. This act ensures that children will no longer be sent to asylums or institutions in order to receive an education, and states that, when possible, children diagnosed with disabilities ought to be integrated into general education classes.

However, scholars still understand that there are problems with the legislation. Gregg Beratan argues that one of the major issues is that the IDEA of 2004 uses the phrase "appropriate" when talking about educating students understood as having disabilities in classrooms with students who are not labeled as disabled, i.e. students categorized as having disabilities should be in general education classes to the greatest amount appropriate. However, the law never defines the modifier "appropriate." This specificity in the law matters precisely because, it places the "onus" on the child labeled as disabled to fit into the general education class once they have secondary tools and resources, without questioning the set up of the class to begin with.[264] Here, lawmakers and educators continually pre-suppose able-bodied and minded students are the norm, and that anyone who falls outside of that has the burden of fitting in with their general education peers, and not the other way around. This establishes an assimilationist model, which immediately sets up a hierarchy with general education students on top, and students placed in special education on bottom.

Furthermore, this lack of definition allows for the continuation of segregation of non-white students in special education classrooms. To this day, young black male students are 2.8 times more likely to be placed in special education classes than their white peers.[265] While it may be possible that in certain schools, there is legitimately a higher percentage of young black male students who ought to be labeled as having a disability, this larger systemic issue suggests that educational institutions are continuing the special segregation of a great deal of their students. Despite the stated intent of the IDEA 2004 to do away with racial disparities in the special education system, it does not go far enough in practice, which allows schools to continue racist

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[264] Beratan, Gregg D. "Institutionalizing Inequity: Ableism, Racism and IDEA 2004." Disability Studies Quarterly 26, no. 2 (2006). http://dsq-sds.org/article/view/682/859.

[265] Ed. Daniel J Losen and Gary Orfield, *Racial Inequity in Special Education*, (Cambridge: Harvard University Press, 2002).

policies while proclaiming that they are fighting to create a more equal society. It appears then that special education today has reinscribed the segregation that Brown v Board of Education was supposed to do away with.

One of the reasons for this is that the IDEA 2004 gives "full trigger funding" meant to crack down on disproportionate racist classification.[266] However, this only applies to intent, rather than outcome, and actually acts as an incentive to give schools more money for more IEP's that they produce resulting in more students in special education classes. Furthermore, schools can have the state and federal government pay for the costs associated. These are costs they otherwise would have had to pay for. In this way, the IDEA 2004 incentivizes special segregation, rather than reducing its prevalence. Furthermore funding has been cut across the nation for special education, resulting in fewer advances overall.

Furthermore, cuts in funding across the board threaten the continued services previously made available to individuals labeled as disabled. In 2013, Governor Andrew Cuomo announced that there would be a 6% budget cut across the board for non-profit providers of services to individuals diagnosed with developmental disabilities. He made the announcement at CUNY CSI, the former site of the Willowbrook Asylum.[267] The irony, it appears, was lost on the governor. The battle for meaningful and appropriate special education continues, as does the fight to remember the past.

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[266] Beratran, "Institutionalizing Inequity."

[267] New York Nonprofit Press, "Hundreds Protest DD Cuts During Cuomo Speech at Willowbrook Site," February 27, 2013. http://www.nynp.biz/index.php/breaking-news/14081-hundreds-protest-dd-cuts-during-cuomo-speech-at-willowbrook-site.

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