

Disinterestedness at Willowbrook

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Children at the Willowbrook State School in Staten Island, New York received free room and board between 1938 and 1987, due to the fact that they were severely mental retarded, and unable to care for themselves. Families who qualified were either unable or unwilling to care for their children at home, and could not afford to send them to a private institution. Major problems plagued Willowbrook during its fifty years of operation, however. Among the most severe was its understaffing, with approximately one half of the necessary doctors, nurses, and related caregivers required, compounded by overcrowding. At its highest attendance level, the school housed over six thousand students, while maintaining only four thousand beds in incredibly cramped quarters, sometimes with only a few inches between each bed. Hygiene at the school was atrocious, many children, were left in their own filth. In these conditions, disease ran rampant, causing the board of visitors to declare the conditions at Willowbrook a “critical situation.”¹ With so many people worried about the state of affairs the administrators began looking for any way to solve the institution’s mounting problems.

In the early 1950’s, more than ninety percent of children in Willowbrook would, at one point or another, contract either Hepatitis A, Hepatitis B, or both.² Noting these conditions, the school board hired Dr. Saul Krugman, a well-meaning man, to provide care for the youth in any way he saw fit. In 1956, he began a series of experiments by infecting children who were mentally retarded with Hepatitis A. He did so, not to treat the disease, but rather to chart its progression in the children’s bodies, so that he could ostensibly come up with a cure for the disease later. The experiments continued, largely without treatment, until 1971, despite ethical protests from various medical professionals,

¹ Lee L. Landon, “Letter to Nelson A. Rockefeller,” State of New York Department of Mental Hygiene, Staten Island, NY 14. October, 28. 1971.

² Saul Krugman, “The Willowbrook Hepatitis Studies Revisited: Ethical Aspects,” *Reviews of Infectious Diseases*, 8 no. 1 (Oxford: Oxford University, 1986). 156 – 162.

on the basis that they would help mankind.³ In fact, they continued even after Dr. Baruch Blumberg discovered a treatment for hepatitis, a feat for which he won the Nobel Prize.⁴ The question then becomes, how could a doctor infect patients with a disease, and then refuse to treat them?

Krugman's research continued according to the dictates of a "disinterested" notion of thinking which made the students being experimented on merely docile bodies in a laboratory, subject to the observations of the analyst Krugman.⁵ Krugman was not a monster bent on hurting children, instead, his unethical practices stemmed from a desire to do good things, hence his belief that his work would help the entire human race, however, this desire enabled an "ends justify the means" style of thought. This lack of concern for one's own patients is characteristic of a disinterested, utilitarian point of view, which fashions itself objective, but in reality, only re-inscribes hierarchical authority, while diminishing the autonomy of those subject to the good doctor's desires.

This paper adds to the scholarship of medical history as well as the history of the retarded by exploring the ways in which the state-medical-apparatus has utilized a form of disconnection, allowing doctors to separate themselves from the real lives of their subjects and the effects various treatments might have on them. This recognition of "disinterestedness" borrows from a variety of post-structuralist thinkers and attempts to display the ways that subjects within a state, particularly within hospitals, can be converted into docile bodies. This transformation occurs despite the state's intent,

³ H.H. Borman, "Letter to Mrs. Alyce Mustor," State of New York Department of Mental Hygiene, Willowbrook State School. November 14, 1958.

⁴ David J. Rothman and Sheila M. Rothman, *The Willowbrook Wars: Bringing the Mentally Disabled into the Community*, (New Brunswick: Aldine, 2005). 276.

⁵ 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 Mark Koslow, *The Empire of the Intellect and its Victims: Pictures and Patterns of Knowledge/Power and the Role of Knowledge and Power in Atrocities*, (Cleveland: Cleveland State University, 1997).

whether real or simply professed, to help all mankind. Furthermore, it sheds light on the history of children, who are often forgotten. These children have been displaced from society's collective memory despite many public outcries about the school's conditions, not the least of which includes Robert Kennedy's visit to Willowbrook where he condemned the school as a "snake pit."⁶ Finally, it will challenge one of the leading historians of the disabled, David Rothman, who states that when treating the retarded, institutions always have to weigh what is conscionable against what is convenient.⁷ It is the assertion of this paper that, at least in the minds of Dr. Krugman and his associates, the two poles were one in the same. Utilizing an understanding of disinterestedness is necessary to understand this tradition because it undercuts the medical establishment's supposed objectivity, and allows historians to question the motives of those who conducted the experiments, rather than just their stated outcomes.

Before studying the justifications for the Willowbrook experiments, however, it is necessary to have a larger discussion about disinterestedness so that theory and content do not become muddled. Disinterestedness is the idea that one can and should order the world as if from above. This notion applies particularly to scholarship in which academics attempt to fully understand the world by separating themselves from it, in short, pure objectivity, total separation from the world around you. "Interested" stems from the Greek "inter esse" meaning "in the midst."⁸ Thus, being disinterested is not merely being uninterested, but rather is the belief that one is not affected by the world, or can at least occupy a space outside or above the world. Similar to a cartographer looking

⁶ Celia W. Dugger, "Big Day for Ex-Residents of Center of the Retarded," *New York Times*, March 12, 1993, <http://www.nytimes.com/1993/03/12/nyregion/big-day-for-ex-residents-of-center-for-the-retarded.html?pagewanted=all&src=pm>.

⁷ David J. Rothman, *Conscience and Convenience: The Asylum and Its Alternatives in Progressive America*, (New York: Aldine de Gruyter, 1980).

⁸ William V. Spanos and Christopher Spurlock, "William V. Spanos: An Interested Debate Inquiry," <http://kdebate.com/>.

at a map in order to think of the world as an object of their own making, Krugman discussed students as objects of study, commonly talking about “incubation periods” before hepatitis would result in jaundice, without referencing the fact that the incubation was not happening in a lab, but in another person, and that he himself was causing it. His characterization of Willowbrook as a “natural laboratory,” itself supported by his claims that all students would inevitably contract the disease, discursively represent the school as a place, not for students to learn, but a place to learn from them, specifically to learn from their biological reaction to disease. Their bodies became, not a repository of knowledge, but simply biological material to be used.⁹ In this way, students were not children to be cared for, but cadavers to be studied.

Hepatitis A experiments began in 1956. They began as an attempt to see if, as had been claimed, gamma globulin, a concoction of naturally occurring antibodies, could decrease susceptibility to the disease. It was first tested on children who had already contracted Hepatitis A, and the results confirmed that concentrated antibodies could reduce serious risks for humans. Soon after, however, Krugman, along with his partner Dr. Joan Giles, began infecting children with the disease by utilizing the “processed feces and serums” of previously infected students. They then began experimenting with gamma globulin, because, for them, treatment of the disease meant prevention in the future and a possible cure.¹⁰ This notion of objective well being, despite the fact that Krugman and his staff were actively infecting students with the very disease they wanted to prevent, was the beginning of the studies disinterested approach. In claiming to help

⁹Saul 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 Studies Revisited: Ethical Aspects,” 159 – 160.

¹⁰Rothman and Rothman, *The Willowbrook Wars*, 261 – 263, and Mount Sinai Medical Committee for Human Rights, “Human Experimentation at Willowbrook,” 1972, 3.

all of society, while simultaneously converting students themselves into objects of study, Krugman and Giles were acting in, what they thought, was society's best interest. For them, conscience and convenience came to become one and the same thing. However, this was a pernicious form of medical malpractice. In order to more fully understand the reasons that this could continue, it is necessary to understand the major ethical objections made, and their justification by Krugman and Giles.

Dr. Stephen Goldby wrote to *The Lancet* on April 10th, 1971 denouncing Dr. Krugman's methods voicing one of the central challenges made against the Willowbrook experiments. He cites the World Medical Association Draft Code of Ethics on Human Experimentation, which states that humans in mental hospitals cannot be experimented on just for the purpose of obtaining general knowledge.¹¹ Krugman responded by describing the benefit to the world that a hepatitis cure would bring. While Krugman is correct in this assumption, it displays a disconnection from the lives of the children that he is around, certainly far more than the majority of people an infection would harm. This global view may be necessary for doctors to think in some larger picture, however, masking that global view under the purview of objectivity is ultimately problematic, especially in Willowbrook because it turned children, not into students or even into wards of the state, but rather into lab rats. He then goes on to describe the success he and his colleagues, most notably Joan Giles, had in eradicating measles within the school, effectively ending infections after 1963.¹² This focus on past success ignores the processes that ultimately went into treating the disease, particularly the process of converting children into petri dishes by giving them an infection, and charting its

¹¹ 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.

¹² *Ibid.*

progression, rather than treating it. Furthermore, Krugman cannot claim to be acting totally objectively, when his peers at the time were calling for a more interested approach that would focus on his “patients lives and health.” They claimed, instead, that the “professional values” such as the “focus on the disease, not on the patient, results in a medical tyranny that glorifies the researcher and the research-oriented practitioner,” while leaving the child as nothing more than medical fuel for experimentation, and later, medical waste to be discarded.¹³

Krugman continued defending his methods by stating that students who were infected would be given access to separate units with better care, and a decreased chance of getting other diseases. This ignores the fact that he provided better care to children in a school plagued with problems on the basis of coercion, and that that coercion could have disastrous consequences for children’s health. This problem is compounded given that some of the children may have had difficulty explaining new symptoms they see arising, due to physical problems that make speech difficult. Furthermore, Krugman cannot accurately state that he was providing better care when it became clear that his patients “were exposed to doses of (the) virus carefully titrated to produce jaundice in more than ninety percent of cases.”¹⁴ Finally, the notion that a doctor is providing better care in a facility overrun with problems obscures the fact that Krugman and his colleagues had the power to improve conditions at Willowbrook during their tenure at the school.¹⁵ Krugman’s disinterested outlook, not only shielded him from culpability in the children’s sickness. It also acted as a tool in the permutation between moral righteousness, the ability to help retarded children, and convenience, the large size of

¹³ Mount Sinai Medical Committee for Human Rights, “Human Experimentation at Willowbrook,” 1972, 5 – 6.

¹⁴ *Ibid.*, 3.

¹⁵ *Ibid.*, 6.

students available to experiment on. For Krugman and his colleagues, consciousness and convenience were not in opposition with one another as historians often suppose.¹⁶

Instead, they were two sides of the same coin.

The second major criticism of Krugman's work came from M.H. Pappworth, a British scientist, who criticized Krugman's analysis that children at Willowbrook would inevitably contract Hepatitis A, B, or both. This inevitability, argued Pappworth, disproved Krugman's supposed "natural laboratory." He went on to cite the fact that the State Department of Mental Hygiene had, during the time of the experiments, concluded that gamma globulin inoculations would reduce the risk by eighty percent, essentially curing the majority of the children.¹⁷ Thus, there was no need to continue injecting them with the virus even if Krugman may have been right that many of the children would contract the disease inevitably. However, Krugman's analysis that, because disease was rampant within the institution, it didn't matter where they got it from, removes all responsibility from the medical staff, and essentially seals the children's collective fate. This justification is a tool of disinterestedness because it occludes focus on agency, i.e. that Krugman could control the children's biology, while they could not. In this way, he constructed himself as separate from the experiments, despite the fact that he was actually the one in control, and placed the burden on the children, regardless of the fact that they had little to no say in the matter whatsoever. This idea that the children were responsible for their own sickness and that doctors were more important than "subnormal groups" in the area of analysis is the "cornerstone of the urban medical center."¹⁸ That is, it represents the total separation of those charged with making society and individuals

¹⁶ Rothman, *Conscience and Convenience*, 1980.

¹⁷ M.H. Pappworth, "The Willowbrook Letters," *The Lancet*, June 5, 1971, and David J. Rothman, "Were Tuskegee and Willowbrook Studies in Nature?" 5 – 7.

¹⁸ Progressive Labor Party Medical Section, "The Willowbrook Experiments: Medical Fascism," 1972, 1.

better, from the very patients they are supposed to be curing. It makes the vulnerable nothing more than carcasses to be used. It makes daily life a sterile laboratory, in which nearly any action can be justified so long as it is for the greater good.

Doctors also challenged Krugman, saying that infecting children with a dangerous disease would have serious and deleterious long-term effects. His justification was that the children were likely to be immune to the disease after infection. This ignores, however, the major issue that it is not a doctor's place to infect a child, even if they can be benefitted later in life. Furthermore, Baruch Blumberg had already solved the puzzle of isolating the virus in the laboratory, without the use of human subjects, by 1967, and used this knowledge to treat the disease. There is no doubt that Krugman, as a leader in the field, would have heard of his work. While it is likely that Krugman was acting in, what he thought was an ethical paradigm; his method was almost totally unnecessary. Even if Krugman's experiments put the field ahead by a few years, scientists "would have learned almost everything" they "needed to know about Hepatitis B in the laboratory."¹⁹ It appears, then, that the bulk of Krugman's methods were unnecessary, and only surpassed his colleagues in one way. He excelled at separating himself from his own actions, which undoubtedly allowed him to continue transforming children into findings, life into hypothesis. This is most evident when Krugman details the pattern of hepatitis to cause jaundice in children. Rather than refer to children as patients, students, or wards, he refers to them in cold medical terminology, and to the time it takes them to contract jaundice as an "incubation period."²⁰ The fact that he could refer to a deadly contraction as merely an incubation period, and ignore the fact that he not only caused the

¹⁹ Rothman and Rothman, *The Willowbrook Wars*, 267.

²⁰ Saul Krugman, Robert Ward, and Joan P. Giles, "The Natural History of Infectious Hepatitis," *The American Journal of Medicine* (New York: American Journal of Medicine, 1962).

progression of jaundice, but could also have prevented it, points to a total disconnection from his patients. This is the violence of disinterestedness that Krugman perfected in his lab. He was unsuccessful in isolating the hepatitis virus without a human subject, but absolutely successful in isolating himself from focusing on the human subjects he used.

Krugman and Giles made the final justification for the ethical case at Willowbrook together. They said that the tests were ethical because they had received parental consent from all children involved. This is true. In studying the consent form, however, it is clear that it was written to suggest that the doctors were giving inoculations, not the disease itself.²¹ This is especially misleading when considering that the parents of the children in Willowbrook were not highly educated or wealthy enough to afford an attorney to look over the documents, given that they could not afford to keep their children at home, or send them to a private school. Furthermore, many of the parents and children were racial minorities incapable of being admitted, due to de jure or de facto discrimination, at most any other institution within the state.²² Even if parents were aware of Krugman's true intentions, it is unlikely that they would have been able to afford transferring their children to another institution. The letters also relied on deceitful coercion. They open with an appeal to fear, clearly meant to make parents concerned over their children's health. Then, parents were told in the second and third paragraphs that their children would be given access to a special ward if they participated in the experiment, making them believe it was in their child's best interest.²³ Some were even told that if they placed their children in the special wards, they would be able to stay at

²¹ Saul Krugman, "The Willowbrook Letters," *The Lancet*, May 8, 1971, and Krugman, "The Willowbrook Hepatitis Studies Revisited: Ethical Aspects," 156 – 162., and S. Rothman and D. Rothman, *The Willowbrook Wars*, (UK: Cambridge, Harper Collins) 1985, 266, and H.H. Borman, "Letter to Mrs. Alyce Mustor," 1958.

²² Progressive Labor Party, "The Willowbrook Experiments," 1972, 1.

²³ H.H. Borman, "Letter to Mrs. Alyce Mustor," 1958.

Willowbrook, but if they did not, the institution would send their children home, due to overcrowding.²⁴ Finally, it takes all consent away from the children themselves, completing the process of removing them from their right to determine their own fate. In this sense, Krugman utilized textual authority and disconnection to override human autonomy. This is the very notion of disinterestedness as it provides the basis for converting humans into sub humans, for the supposed benefit of society writ large, effacing the walking corpses that Krugman created. His delusion was most likely not meant as a sadistic act towards retarded children. Rather, he most likely believed he was benefiting the world. But, had disconnected himself so much from that world, that he could not understand the ethical implications of his own actions. It allowed him to turn Willowbrook into a “living hell on Earth” and his patients into its damned.²⁵

The experiments conducted at Willowbrook present a unique question to historians. How is it possible that Drs. Krugman and Giles could justify giving children hepatitis under the auspices that they were in fact helping those children? In examining the testimony given in response to people making ethical objections, as well as by studying the documents they used in their experiments, specifically consent forms, it is clear that they practiced a disinterested form of treatment, that is, disconnected from the very subjects of their study, in a supposedly objective manner. This then transformed the children that Krugman and Giles were so ready to protect from invasive diseases into nothing but matter to be studied, a total dehumanization from students to studied, analyzed to analysis, and for all intents and purposes, living to dead.

²⁴ Rothman and Rothman, *The Willowbrook Wars*, 266.

²⁵ Edward I Koch, “Letter to John E. Cone,” Congress of the United States House of Representatives, Washington D.C. 20515, February 7, 1972.