

Ex-director defends Willowbrook experiment

The writer of the following article, a psychiatrist who lives in Port Richmond Center, is a former director of the Willowbrook Developmental Center, then known as Willowbrook State School.

By HAROLD H. BERMAN

On Sept. 26, the Advance published an excerpt from a book written by an assistant professor of philosophy at Wagner College, headlined "Human experimentation at Willowbrook immoral? Researchers said No!" Were I to allow this illogical and false reasoning, false accusations and false acclamations to go unanswered, I should be derelict in my obligation to the parents of the children who were entrusted to my care at Willowbrook State School when I was director and to the doctors who worked with me, both the resident doctors and the consulting doctors, to my nurses, to my employes who worked far beyond the call of duty to render service to our patients.

This book is a total and complete disservice to the cause of mental deficiency. Where should I begin? He talks about "inoculations being dangerous and committing assault and battery on people." He talks about "immunizations being such that they are victimizing the recipients." Let me ask this reverend gentleman, who is wrapped in his divine cloak and makes divine pronouncements, "Dear Sir, Were you vaccinated against smallpox? Were you vaccinated against measles? Do you have children? Was your daughter, if you are so blessed, before she got married, vaccinated against German measles so that she would have immunity against giving birth to a mongoloid? These are introductions of organisms into the body."

You may go way back to Jenner when he first inoculated people with what was then known as cowpox. He made people sick with cowpox, but in making them sick with cowpox, he made everybody, including those who were inoculated, immune against smallpox. This professor might shake his head in amazement with Wagner von Jaureg who administered malaria to patients who were sick with syphilitic brain disease. Following his findings, I made people sick with

malaria to cure their syphilis of the brain and successfully so.

When I was in medical school, I was taught that tuberculosis was hereditary, and when I came into state service in psychiatry, the fact that the prevalence of tuberculosis within a mental institution, of 5 per cent, was accepted as wonderful. It was supposed to be associated with mental sickness but we found that it was being transmitted from newly admitted patients to other patients. We eradicated that and in the course of this eradication we used tuberculin.

If we accepted the professor's reasoning that no assault should be made on sickness, then what are we doctors working for? What are the nurses working for? What are the people in the hospitals working for? To be upbraided and to be challenged by such illogical reasoning based on a false premise?

Is it a false premise? Yes. Basically and fundamentally his premise is absolutely false. He attacks the staff of New York Medical College. Does he or anybody think that this indefinite "staff of New York Medical College" was working in a vacuum? Does he pronounce that there is no benefit to the individual receiving what he calls experiments, what I call immunization?

If he had had the duty to stand beside the autopsy table the way I did and be there when my pathologist was performing an autopsy on one of my poor patients who had died, and have the pathologist turn and pronounce the cause of death as being broncho-pneumonia or that the cause of death was nephritis, which was all we could prove at that time, he would not be so dogmatic. But my pathologist and I and the other doctors around that table knew that the cause of that death was in some unknown way due to what was then known as catarrhal jaundice.

If this professor wants to go back to those days, and have an institution run on those principles, then the advancement in the study of disease should be halted. You do not want doctors, you want exactly what you are getting at Willowbrook now. School teachers and social workers and psychologists are running an institution caring for sick people, and believe me, mentally defec-

tive patients are sick in spite of all the pronouncements to the contrary made by the modern trend.

Let me advise about the parents of my patients when I was director of the institution. When I came first to Willowbrook State School in 1949, a delegation of parents asked to see me. When I told them that they did not have to ask to see me, to just walk in, the door was always open, they were amazed. They told me that no doctor before had allowed anybody to talk. The sum and substance of that meeting was that they delivered me, not an ultimatum, but a pronouncement that they wanted me and my staff to work toward the end that what had happened to them would never happen to any other family.

How different from the loud mouthed people of today, who seem to have such control and such a throttle over the operation of an institution like Willowbrook Developmental Center. My people suffered the pangs of conscience, of guilt, of remorse. They went through all of the misery associated with the disappointment of parents who have born to them a child hopelessly mentally deficient or hopelessly deformed. They felt the sense of guilt as though this unfortunate birth into their family was punishment enough and they wanted to prevent it happening again.

Now, Mr. Professor, put yourself in their place. When I arrived at Willowbrook we had a resident population of about 200. This population was expanded to about 6,500. Where did these patients come from? Do you know? They came from attics, from closets, from basements, from all sorts of restrictions and concealments. Mental deficiency bore a strong stigma. It was a shame and a disgrace. Thank God that by our work and teachings, we were able to remove a great deal of that stigma prevalent then. The family had to live in secrecy and fear of exposure that there was a mental defective in the family. These people came from all walks of life, from all five boroughs and from Long Island. One mental defective member residing in the family made that family overcrowded in every sense of the word.

Willowbrook was originated to give these people relief, and during my administration it was our opinion that if there was going to be any overcrowding,

let it be with us and let the family develop as it should without constriction by a mental defective growing up in it. How much in the community was mental deficiency accepted as illness? As these patients were admitted from all of this area, they brought with them diseases which were endemic in those populations. During the poliomyelitis epidemic in the early 1950s, the commissioner of mental hygiene gave to New York City the right to transfer 400 patients from the wards of New York City hospitals into Willowbrook so that they would have room for the poliomyelitis victims.

Mr. Professor, you should have stood at those ambulances when they were emptying out their cargo. You see pictures every once in a while of people from concentration camps suffering from extreme starvation. That is the condition in which these patients were. A skin bagful of bones. They looked like skeletons. Should we have accepted these conditions as part of the picture of mental deficiency as we did with tuberculosis in mental hospitals?

Now we come to hepatitis. Does this professor, as I said before, think that the doctors from New York Medical School were working in a vacuum? As I understood and knew in my heart, every person who came into Willowbrook State School, be he patient, employe, professional or non-professional, would contract hepatitis sooner or later. Some had the attacks mild, some had them severe. Some went to bed, most got out of bed. Some did not make it.

We used gamma globulin in their treatment. It was reasoned that if gamma globulin were valuable in the treatment of catarrhal jaundice, why could it not be used for producing immunity? We knew that it could ameliorate the affects of hepatitis. Would it not be better to confer immunity upon our newly admitted patients and staff by administration of gamma globulin together with the bacillus at once?

This was the principle. As we began to get control of the situation, we began to find out more and more as to what the sickness really was, and it was not an experiment. It was really a progression in thinking and reasoning. Where was the trouble. We had to find out exactly what the situation was. So we isolated this newly admitted group of patients, with the consent of the parents, in a sep-

arate room. It was not an experiment by this time. As immunization developed, we placed the babies into the general population and watched to see if they would contract the disease, and they did not.

Admission to Willowbrook State School was according to a list established by the commissioner of mental hygiene, in the order in which an application for admittance was received. This list was strictly and absolutely followed. When a vacancy occurred, we admitted a new patient. No one was allowed to jump that list. We wrote to the parents of these children telling them of the situation and of our research program and that if they wanted to participate, we would admit them as far as there was space. It was not forced. It was offered. If they wanted it, well and good, if they did not, well and good. It did not affect their position on the original list.

This went on for years until a few disgruntled parents wanted to jump the list for admission and began to agitate that the only way to get into Willowbrook was to be exposed to this experiment. Nonsense. This research was just something separate by itself. I found some space in a building which was unoccupied. It had been reserved for a doctors' residence. I converted it into the ward for the study of hepatitis.

The research went on without the cost of one penny to the state of New York as all of the research projects at Willowbrook went on. I did not get any money to use for research. But research went on throughout the institution. I counted once. There were 73 research projects going on at one time. Why single out this hepatitis?

Babies who played around the floors of the wards were carrying and transmitting all sorts of infection and intestinal parasites. We were working on those. We had a research project there. Why single out hepatitis? We did not have to give them infectious agents. They picked them up from one another.

Should I have allowed all this to continue? Spasticity? Cerebral palsy, so called? We had a good share of this. Why not challenge the research in cerebral palsy? We used all sorts of modalities. Finally, after having worked with electricity for years, we discovered that certain drugs would be effective. Why single out hepatitis?

I consulted with my staff as to what we should do about catarrhal jaundice and the formation of a program. Those I consulted were the resident medical staff, consulting medical staff, nurses, social workers, and yes, clergymen as well as many others. You would think that from at least one person there would come a protest if it was immoral. Not one was raised. When we submitted

the proposition to the commissioner of mental hygiene, he considered it for quite a while, with his staff. When approval came, there was still no protest. Something had to be done or else I was going to lose my patients in droves, with so called "broncho-pneumonia or kidney involvement." It was only after all of this that I invited a doctor on the staff of New York Medical College to go to work.

At any rate, the professor is beating a dead horse. Willowbrook has been destroyed. Willowbrook State School should have been designated Willowbrook State Hospital, as it operated during my administration, when we were studying and working on the prevention of mental deficiency, to prevent anybody being born mentally defective. We were also working at the same time on treatment, and we did cure some patients of their mental deficiency. This you do not know. Nobody stopped to ask me when all of the challenges were being made.

The people who were in charge at that time are either gone from the scene or deceased. I am talking of the time of the demolition of Willowbrook. Catarrhal jaundice became infectious jaundice which finally became hepatitis, after the virus of the Willowbrook strain was discovered and acknowledged all over the world. And what to do about it? Should I have allowed my patients and employes to continue to contract, in this particular instance, infectious hepatitis?

I was not working toward the benefit of mankind. I was working to improve the health of my patients and the general hospital population of which that patient was one. No. He was not an isolated entity being used solely for the purpose of the world. He was just being treated and given immunity against the disease which he would contract and which might cause his death eventually. He was going to contract and pass along hepatitis almost 100 per cent, with or without symptoms. This is one of the things we learned as we went on.

There is much more I could say, but I felt that I should come out of retirement when this challenge was made and these accusations were levelled against my loyal and faithful staff, my overworked and overburdened people on the wards who had to stand the brunt of these accusations for loyal and faithful work as though they were guilty of "immorality." accused and demoralized.

By whom? By What? What for? What is the experience of this armchair philosopher and others like him who are trying to be Monday morning quarterbacks? It has just become fashionable for misinformed and misdirected people to throw stones at Willowbrook State Hospital.