

Human experimentation at Willowbrook

Parents had no moral right to give an OK

By ROBERT L. BENSON

Assistant professor of philosophy,
Wagner College.

We turn now to consider the second point in the Willowbrook justification for its hepatitis experiments, the various facts adduced to show that the infected children did receive benefits or at least did not suffer a net loss. We said yesterday that the rationale behind these facts seemed to lie in an attempt to assimilate the what was done at Willowbrook to the model of therapeutic experimentation.

Let us see whether such a case can be made. We will also here take the points in reverse order.

The most explicit appeal to the therapeutic model is the reference to immunity as a "therapeutic" effect of having the disease. There is some question in my mind whether this claim is indeed factual since several of the published papers mention recurrent cases of the disease. Let us assume, however, that immunity is in fact conferred in every case. Is this a benefit which can reasonably be cited in analogy to the case of therapeutic experimentation?

I am unable to see how it can be. If one is protected from the disease by the device of suffering the disease, how has he gained? What rational person would allow himself to be vaccinated in the knowledge that he would get the very disease against which he sought protection? Far better to take one's chances with nature.

There is, however, an even stronger rebuttal available. Whatever plausibility the claim of benefit may have disappears when we consider that there was available an alternative means of protection which was not contingent upon having the disease: From the beginning of the Willowbrook experiment it was known that periodic inoculation with gamma globulin carried a high degree of protection against hepatitis.

The second and third points made by the experimenters, that it was an advantage to have special care and to be isolated from other prevalent diseases, ultimately depend on the first point: That it was "inevitable" that the children would become infected under the "nati-

ral" conditions prevailing at Willowbrook anyway.

Receiving special attention while sick is not a benefit if I have a chance of avoiding the sickness entirely by not participating in the experiment. Protection from other possible diseases cannot be weighed against suffering an actual disease.

The first question to be asked is: Was infection a virtual certainty at Willowbrook given the existing conditions? Even if we forget about the existence of gamma globulin, the answer would seem to be "no." When the experiments were begun at Willowbrook, the annual attack rates of jaundice were 20 to 25 per 1,000 residents — certainly high but nowhere near high enough to "justify a judgement that infection was "inevitable."

And in the very first paper this judgement is not made. The far more cautious conclusion is drawn "that most of the patients at Willowbrook were naturally exposed to hepatitis virus" (my italics). Only a year and a half later the claim has been significantly inflated: "It was inevitable that most of the newly admitted...children would acquire the infection in the institution..." but this still does not amount to be a claim of inevitability.

Eight years later (1967) we find all modifiers dropped: "It was inevitable that susceptible children would become infected at the institution." Although grammatically ambiguous (where has the scientific precision suddenly gone), this statement leaves the impression that all susceptible children would have inevitably come down with hepatitis.

But as we have seen, this was not claimed when the experiments were first begun. It is not supported by the cited attack rates. Nor is it supported by later evidence published by the experimenters themselves: Of 210 retarded children under 10 years of age and resident at Willowbrook for a period ranging from 0-5 years, only 58 or 32 per cent showed the presence of Australia antigen, a serum antigen associated with viral hepatitis, in their blood.

It would seem then that even under the existing conditions children at Willowbrook had a decent chance at

avoiding hepatitis and, hence, that infecting them with the disease cannot be viewed as "no loss" on the grounds that "they were found to get it anyway."

But even if there had been a 100 per cent probability of contracting the disease under the conditions existing, it would still have been immoral to infect the children so long as no attempt had been made first to *change the existing conditions*, to find the cause of the endemic situation and eliminate the source of infection.

Whatever plausibility the therapeutic model has in justifying the Willowbrook experiments depends on the analogy to an epidemic situation. When Jonas Salk used experimental polio vaccine on his own children, he would have been able to justify this by pointing out that his children faced an equal hazard under the natural conditions without participating in the experiment. But contrary to the repeated statements of the defenders of the Willowbrook experiments, the existing endemic situation at the institution cannot be considered "natural," given in nature, like a polio epidemic.

Prior to 1953, hepatitis at Willowbrook was not endemic but merely sporadic in occurrence. Its prevalence was due to some social arrangements at the institution and, clearly, not even to social arrangements which were necessary in an institution of this type. But no attempt was made to eliminate the disease by more ordinary, even if more expensive, measures. One has to wonder if the researchers would have been so quick to perceive an opportunity to study the disease rather than eradicate it if the context had been a prep school dormitory or a floor of a hospital and not an institution for the retarded.

The entire weight of justification now falls on the final point, the validity of proxy consent. Since it has proved impossible to consider the experiments as a variation on the therapeutic model because the analogy to an epidemic situation fails, it becomes essential that the consent obtained be valid if the dignity and rights of the experimental subject are to be respected and he is not to be used as "a means only."

There are two major questions which arise here. First, was the consent "free and informed?" Second, is proxy consent valid for non-therapeutic experimentation on those incapable of giving their own consent?

There is real question about the freedom of the consent obtained after 1964 when Willowbrook was closed to new admissions due to overcrowding. After being informed that there was no space, parents were sent a second letter, in some cases only a week later, informing them that there were places available in the hepatitis unit if they wished to consider volunteering their children for experimentation. It would be difficult to rebut the charge that consent obtained under these conditions from parents in need of institutional care for their child was "coerced."

But there are strong reasons for rejecting proxy consent even when this consent is freely given and not obtained under duress. To allow parents to consent to experiments on their children which are not in their best interest would seem to remove children and the incompetent in general from the protection of the law governing assault and battery. It would seem to be permissible only if children were construed as the *property* of their parents and not persons who may not be used for any purposes contrary to their own welfare without their very own consent.

Emphatic statements denying to parents a *legal* right to volunteer their children for non-therapeutic experimentation abound in the literature on the law. Here is one example, written by Warren E. Burger, who has since become the chief justice of the U.S.: "No adult has the legal power to consent to experiments on an infant unless the treatment is for the benefit of the infant...It is the lamentable use in experiments of such subjects as infant children, incompetents in mental institutions...that is indefensible; and no rational social order will or should tolerate it." In other words, one could make a case for the assertion that the Willowbrook experiments were illegal even before the 1973 court ruling.

But whether illegal or not, they were certainly immoral because parents do not have a *moral* right to volunteer their children to undergo suffering and risk which is not in their interest. This follows, first, from our previous reflections on the categorical imperative. Why should the fact that a child or incompetent lacks the capacity to consent give anyone, his parents included, the right to use him as a means. Since the retarded child cannot entertain participation as his own end because he is not capable of understanding such an end and hence rationally choosing it, to subject him to such treatment is to use him purely and simply and thereby to degrade him to a mere object and deny his human dignity.

Secondly, it would seem to follow from the fundamental duty of a parent to his child: Care and protection, that such exposure of one's child is wrong. It is difficult to imagine why a parent would allow such experimentation on his child, but even if he would, he ought not. His primary obligation and responsibility is to the child and its welfare, not to the progress of science or the good of mankind.

But if proxy consent is morally invalid, why is it recognized by the World Medical Association and the AMA? I would be very interested, for one, to learn the moral reasoning on which they rest their recognition. The reasoning we have developed above, which certainly is **central to all moral thinking on the matter of human experimentation, forces us to conclude that these august bodies are simply in error.**

But with regard to the morality of the Willowbrook experiments, it is not necessary to fight this battle in this place. The reason is that the WMA and AMA attach a significant qualification to their recognition of proxy consent, and this qualification invalidates the appeal to proxy consent made by the Willowbrook experimenters.

The "Ethical Guidelines for Clinical Investigation" adopted by the AMA, for example, allow the use of minors and the mentally incompetent in nontherapeutic research only if "the nature of the investigation is such that mentally competent adults would not be suitable subjects." But this was not the case with the hepatitis study. This was not a children's disease and there were present at Willowbrook nearly 1,000 adult, competent personnel, including 600 attendants, who were just as exposed to the virus as the residents.

No attempt was made to enlist these adults in the cause of medical science; on the contrary, they were, rather, inoculated with gamma globulin before this was routinely done for the retarded population.

Of course, it would have been more dangerous to infect adults than children and it is the responsibility of a researcher to minimize hazards. But, first, the mildness of the strain and of the disease even in adults would reduce the importance of this consideration. And, second, the diminishment of danger should never be purchased at the price of switching from consenting to unconsenting persons and especially not by making use of that most helpless, weak and vulnerable member of our society: The retarded child.