

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