

Human experimentation at Willowbrook

'Medical progress' not sufficient excuse

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Let us begin with the last part of the justification given for the Willowbrook hepatitis experiment and work backwards. Does "benefit to mankind" justify non-therapeutic experimentation? There is no question that the Willowbrook studies (unlike many of the Nazi experiments) did promise such benefits, that they were important research carried out in accordance with sound scientific standards.

But it is equally clear that this fact by itself does nothing to justify what was done, or, at the very most, it justifies only "negatively." If an experiment does not promise such benefit, then it is certainly not justified regardless of how many other conditions of morally acceptable research it may satisfy. It is always wrong to use an experimental subject for trivial and insignificant ends; even if the subject consents, such experimentation is a misuse of the idealistic devotion from which alone such consent, if rational, can proceed.

"Benefit to mankind," then, is merely a negative criterion, a condition which must be satisfied if human experimentation is to be justified, but which even though satisfied, fails, by itself, to legitimate the experiment.

A fairly simply reasoning makes clear why this is so. If we were to concede that such humanitarian consequences are *sufficient*, and not merely necessary, to justify human experimentation, we would in effect be elevating the value of "health" or medical progress to the very pinnacle of our ethical system. We would be saying that the pursuit of this value is subject to no restrictions, is conditioned by no other and higher moral principles, that we may trample on all other values, ignore all other obligations, in the cause of advancing medical science. This end, we would be saying, justifies *any* means.

But clearly we do not believe this and we would not want to live in a society where such an order of moral priority obtained. We believe that there are higher values than the elimination of disease and that the pursuit of this end must conform to these values. Perhaps the most important among them is a value which lies close to the heart of all Western morality and expresses a commitment to "the dignity of man" and "the infinite worth of the individual."

The most famous philosophical formulation of the principle is found in Immanuel Kant's "categorical imperative:" "Act in such a way that you . . . treat humanity . . . never simply as a means, but always at the same time as an end." Of course, in countless every day dealings with our fellow man and certainly in all instances of non-therapeutic human experimentation, we treat "humanity," human beings, as a means.

Whenever we hold a conversation, make love or borrow a dollar, we are "using" another human being as a means. But that, clearly, is not what the categorical imperative forbids. Only when we treat another person as *nothing but* a means, only if we fail to respect his purposes in the interaction, only if we ignore his ends, do we run afoul of the categorical imperative by degrading man to a thing and violating his dignity.

But certainly this *is* what we do if we experiment on someone without life consent, without consulting him about his purposes, that is, if "benefit to others (mankind)" is the only justifying reason we have to offer.

It must never be forgotten that the retarded children who were infected with hepatitis were *not* part of that "mankind," whose benefit is advanced in legitimation of the experiments. They did not benefit, at least not in the sense intended by the appeal to benefits to mankind, that is, they were not protected from getting hepatitis. They only sacrificed and suffered a harmful invasion of their bodies. They were under no obligation to make such a sacrifice; they did not "owe" it to "humanity" nor did "mankind" have a right to that sacrifice.

It seems crystal clear then that their purposes were not consulted, let alone respected, their ends were completely ignored and, hence, that they were treated "as a means only." Consequently, the Willowbrook experiments, if their only justification were the appeal to benefits to humanity, would offend against the restriction embodied in the very first point set down in the AMA "Principles of Medical Ethics:" "The principle objective of the medical profession is to render service to humanity with full respect for the dignity of man."

It seems clear then that the signifi-

cance of the Willowbrook experiments, the medical benefits to mankind which could reasonably be expected to come from them, does nothing to justify them so long as the "dignity" of the experimental subject is not somehow respected.

Let us pass on, then, to consider the next to the last item in the Willowbrook justification: The mildness of the disease.

Would it not be an insane moral logic in which the fact that an evil is "mild" would count as *justifying* the infliction of it? To harm another human being is wrong unless there is a morally acceptable reason for doing so and the fact that the harm is "mild" cannot qualify as such a reason. Imagine a man hauled into court on a battery charge who presents as his only defense the fact that the lump that he produced on his victim's face was "small" or that the abrasions and contusions resulting from his attack were "mild." Would he be acquitted or sent for psychological examination?

It would seem then that, as suggested earlier, we must understand the fact of mildness to be connected in the minds of the experimenters with the principle of "no discernible risk" if its relevance to the justification of the experiments is to be intelligible. On this reading, since the disease was mild, there was "no discernible risk" to the children and hence the infliction of the disease as an experiment was justified.

But what does "risk" mean? Certainly, there was a very high risk that the children would contract hepatitis! This by itself would seem to exclude the experiments from the class of those involving no discernible risk.

But even if we are extremely generous and understand by *risk* "risk of death or permanent injury to health," it would still seem necessary to condemn the experiments. It is pointed out, for example, in support of the mildness of the virus strain prevalent at Willowbrook that no deaths had thus far occurred. But could death be ruled out entirely as a possible consequence? Was it known with certainty that no one could possibly die or was this only highly unlikely?

And what about liver damage? Did the experimenters *know* that none of the infected children would suffer permanent liver damage in spite of the fact that cirrhosis results more often from hepa-

titis than from excessive drinking? Finally, there is a real question whether some of the children might not have been made more susceptible to serious hepatitis as a result of the manner in which the experiments were carried out.

So there were risks and discernible risks in the Willowbrook experiments even if we concede, and we shouldn't, that the degree of probability that what was risked would materialize was small.

But how significant is the question of risk anyway? Is the absence of risk sufficient to justify using a person in an experiment? One could object that in an experiment, except in cases where one is using a substance expelled from the body or removed from the body with no more risk than that involved in simply living, there is always risk. Even where there is no discernible risk there is always undiscerned risk.

Recent research on the role of viral infection in chromosomal damage is instructive both with regard to Willowbrook and to the general question of our ability to "discern risk." But there is still deeper objection to the sufficiency of "no discernible risk" or even simply "no risk" as justification of human experimentation. This objection rests on the principle of respect for human dignity discussed above in the form of Kant's categorical imperative.

According to this principle, risk or no risk is a strictly secondary consideration. Primary is the self-determination of the experimental subject: The use of his body for science must be consistent with his purposes, must be the end which he wills.

The point can be illustrated nicely by a consideration of the law governing assault and battery. It is not merely a harmful attack which is defined as assault in the law but even "unconsented touching." A person is wronged not only when he is harmed (When something risky is done to him) but also when something totally harmless is done to him but done against or just without his will. Not only harmfully using someone or using someone in a way that involves risk violates his person, but also simply using him with no attendant harm or risk if he is deprived of the right to determine himself how and when this use of his body will occur.

Tomorrow: More comment on the justification.