Senate Subcommittee on Government Research Hearings on the human impact of advance in biological science

I am grateful for this opportunity to complete the testimony I started three weeks ago. I was mainly concerned that the proposed commission might have too sweeping a mandate. I suggested that its main functions be 1) educational -to alert the public to the realistic probabilities of changes in the pattern of life likely to emerge from present-day scientific discovery, and 2) exploratory, to investigate the process by which social decision is and should be reached on subjects vital to the human future. I have been charged with being opposed to inquiry, with professionalism, with the belief that experts can make decisions that might affect the deepest public interests. Far from it! I favor the inquiry, but believe it should be a continuing process, and I am especially gratified at the present hearings, and the interest they help to focus on central problems of biology and medicine.

I am opposed to premature closure of inquiry.

The danger I foresee is that a committee charged with recommending guidelines on ethical issues after one year's study might forestall the debate we should continue to have, that it would help to lock us in to contemporary values just at the time we are beginning to learn the way to a liberal, or at least a pluralistic approach to many vital questions. Our attitudes are in a state of constant evolution commensurate with the constantly expanding level of education of the electorate.

Suppose such a commission had been in operation ten or twenty years ago, and had been charged with setting prescriptive guidelines. Would it have helped or hurt the growing enlightenment of the American people about birth control or abortion? Or would it have locked us into the prevailing mores? Even now, is Congress the right agency to be directly involved with setting moral standards on subjects like these? Or on new problems as controversial as these appeared to be a decade or two ago?

But this is merely the negative side. There is unanimous agreement that such a commission could perform many constructive tasks.

Many areas of national policy urgently need investigation. The commission should be charged to frame the questions, not answers of a kind that will need long and balanced study by the representatives of the people. Here are some that touch on the policy responsibilities of the Congress in its relationship to medicine and health research.

- 1. The authenticity of medical care. There is abundant evidence that Americans are over-medicated. Does the medical profession police itself with the diligence needed to ensure that practitioners maintain their professional skill, so that they can make wise judgments about the use of new drugs? How much variance is there is these skills? How can the lay individual make the intelligent free choice of physician that is the hallmark of our system of practice -- that is, how can a layman find and identify a good doctor?
- 2. The equitable availability of medical care. What is our social decision about the fair availability of excellent medical service in relation to the patient's ability to pay?
- 3. Access to medical devices. The artificial kidney (hemodialyser) is the prototype of many devices that will return the gift of life for a price beyond many people's means. What is our policy about the social distribution of that price? At what point will we draw the line (\$10,000 -- \$100,000 -- \$1,000,000: I stop at what it costs to kill an enemy soldier)? Is there any limits, or reasonably should there be any limit to the fraction of the national product that can be devoted to the maintenance of health or life? After we have dealt with this, we can take up Senator Mondale's concern for "who shall live or die", a question that now seems more troublesome when we dramatize individual targets, than when we contemplate the inexcusable differences in mass mortality rate by class, or by country.
- 4. Availability of medical innovations. We fuss about the price of drugs; but the most costly one is the drug not yet developed but needed by a patient. Do we have the ideal system for the discovery, authentication and distribution of

drugs? If the needs of the Asian war take precedence today, to we at least have plans for an industrial reconversion for health technology tomorrow?

- 5. Safety and efficacy of virus vaccines. Since vaccination for many viruses is or soon will be practically compulsory, the government has a maximum commitment to the safety, efficacy and purity of these products. Why do we fail to use the scientific information already available to meet that commitment?
- 6. Biological warfare. Research in this area, and particularly the large-scale test and deployment of contagious, anti-human or anti-food weapons is a threat to the survival of the species. Are we doing all we can to contain that global threat? How can we discuss the ethics of experimentation that might be hazardous to single subjects, and not control secret experiments designed to annihilate whole populations? If we cannot unilaterally give up some research in this area, why do we make no effort at international regulation of it?

7. The impact of medical advance on the structure of the population.

We may eventually have to give serious thought to genetic and developmental engineering, and their impace on the pupulation. But an exaggerated emphasis on fine details obscures much larger changes already being implemented. Medical progress over the next 10 or 20 years is almost certain to open up the possibility of forestalling death for every man to ages like 80 or 90. What are the social implications of this kind of shift in the age of the "average human", a far more formidable shift in aggregate than any other we are likely to engender? How do we cope with this possibility of mastering death, where it is not accompanied by vigorous health and youthful intelligence?

8. <u>Medical experimantation and the rights of patients and subjects.</u>

The respect we have for the rights of individuals eptomizes our attitudes towards life, and therebygains an importance out of proportion to the number of people actually involved.

Since this is already a subject of the deepest concern to many public and professional groups, and is under active discussion, there is little merit to giving the commission a unique charge to formulate the binding answers. It should however investigate whether the right questions are being asked, and whether reasonable processes are in motion to achieve wise policies.

9. The "market" in organs. As organ transplantation progresses from an experimental to a useful, life-saving procedure, legislation governing the provision and distribution of valuable organs will surely have to be drafted. Again, a one-year commission will be more useful as a body to frame the relevant questions than to make conclusive recommendations.

Public information on the facts is an essential base for wise policy, as Judge Bazelon has pointed out. The public conscience often needs only the facts to produce the right answers.

I am gratified that Congress has the foresight to start to grapple with these problems, especially the processes by which we can find the most humane solutions.