

Ethical issues in biomedicine: Choices on everyone's conscience



The house lights went down and the screen lit up. The birth of a child had been put on film again. But this was not a normal birth. What, under most circumstances, can be a highly emotional experience was made more so when a nurse diagnosed the premature baby boy as a Mongoloid (Down's syndrome). Further tests by the Johns Hopkins University doctors revealed an added complication—duodenal atresia—intestinal blockage that would prevent the child from taking food by mouth. A condition that can be easily corrected by an operation of quite nominal risk.

The physicians in this true-life case history kept the defective child alive intravenously and went ahead with plans for the surgery until informed that parental permission for the operation was not forthcoming. The parents had decided it would not be fair to inflict the burden of a retarded child on themselves and their other children. The staff at the Baltimore hospital was powerless. Legal, moral and ethical considerations prevented them from either saving the child's life or hastening its death. The infant was set aside and allowed to starve to death for 11 more days.

This film and the questions it posed opened a day-long symposium on human rights, retardation and research sponsored last weekend in Washington by the Joseph P. Kennedy Jr. Foundation and called Choices on our Conscience.

Not too many years ago there would have been no such choices. The inter-

Urgent social, moral and legal issues are being increasingly raised by new capabilities in the life and behavioral sciences, and those doing the research, as well as others, are unanimous that the public must be brought into the discussion. This article, by behavioral sciences editor Robert J. Trotter, highlights the examination of some of these issues at a special symposium last weekend. Further reports on the symposium and on another meeting last week on ethics of genetic counseling will appear in succeeding issues of SCIENCE NEWS.

nal blockage would have gone undetected and there would have been no possibility of saving the child's life. Today's medical technology, however, is making it more and more impossible to put the blame on nature. "Society is going to have to play God," says Michael Harrington, social critic and author of *The Other American*. And man must take the responsibility that goes with his newfound powers.

The Johns Hopkins case, with its specific questions, was taken under consideration by a panel of variously qualified experts. Paul A. Freund of Harvard Law School suggested that in the best interests of the child and society, the case should have been brought before a court. Legal specialists at Johns Hopkins, however, had advised the hospital that in this particular case the courts would probably have backed the parent's decision. And Robert E. Cooke, pediatrician-in-chief in charge of the case, stated that most

judges and courts do not have the medical knowledge necessary to make intelligent decisions in these cases.

James Gustafson, professor of ethics at Yale; William Curran, professor of legal medicine at Harvard; John Fletcher, director of the Inter-Met Theological Institute in Washington; and René Fox of the department of psychiatry at the University of Pennsylvania all agreed that they would have made a different decision. And they concluded that some sort of disinterested body (outside of the present legal system) should have decided the case. Psychologist Sydney Callahan even suggested that there be "child defenders" to represent infants in such cases. Cooke, representing the doctors and nurses who had to sit by and watch the child starve to death, agreed and ended the session by saying that "we as scientists must ask for ways to get advice."

Increasingly, for the past five years, scientists have been asking for this kind of advice but consistent answers have not always been given. The Mongoloid case graphically presented the need for consistent advice, and 80 intellectuals (scientists, lawyers, ethicists, theologians, psychologists and psychiatrists) were called together by the Kennedy Foundation to discuss their various points of view—in the hope that eventually consensus can be reached and wise and moral decisions be given.

To discuss related questions, seven panels were set up to debate specific issues. One panel, for example, examined the problems presented by the

modification of human behavior.

Using examples from prisons and mental institutions, Harvard psychologist B. F. Skinner described his behavior control methods. These methods have been used to induce prisoners to learn and work toward rehabilitation and to teach retardates to behave in socially acceptable ways. The end result is desirable, but are the means? Ethical questions arise because the persons are not always aware of the controls imposed on them and they can not always consent to these controls.

José M. R. Delgado of Yale has also developed methods of behavior control. His methods are physical rather than purely behavioral. Psychoactive drugs, psychosurgery and direct chemical or electrical stimulation of the brain are among the techniques. And stimulation of the brain is Delgado's speciality. In one case, electrical excitation of the second temporal convolution elicited an eight-fold increase in friendly manifestations and in the verbal output of the patient. These results and other research introduce questions that require more experimentation. "But the results obtained

in animals and humans show that we have the necessary tools for investigation of the neuronal basis of emotional and behavioral reactions, and also that we can influence psychic functions by direct stimulation of the brain," says Delgado.

These controls, together with Skinner's operant conditioning, represent powerful tools for shaping human behavior. But who is to decide what shape behavior is to take? Who is to decide what is normal? These questions were asked by other members of the panel. "The history of man is marked by attempts of one group to impose its values on another," said Jerome Kegan, professor of psychology at Harvard. "The Spaniards tried to make the Mayan Indians Catholic, the Americans tried to make the Vietnamese democratic. . . . Uninvited intervention into the personal space of another is one of man's cardinal traits." But electrical stimulation and behavioral conditioning add to the list of potential manipulations. Therefore, we must "search for a set of rules—or moral prescriptions—that might inform us as to which of these intrusions are likely to be beneficial."

Roger L. Shinn, professor of Christian Ethics at Union Theological Seminary in New York City, put the question differently. "How much conformity is necessary for social life?" He points out that man must voluntarily accept many facts of life that control his behavior for his own good (highway speed limits, airplane seat belts, etc.) and this "makes it all the more important that we maintain freedom, initiative, and spontaneity somewhere near the heart of self. . . . A sensitive ethic for our time will beware of activities that are subversive of human purpose."

Warnings of the panel, emphasizing the importance of man's freedom, were accompanied by a general agreement that behavior control already exists in many ways and that it is often beneficial. And research along these lines will continue. But even Delgado proposed that some institution must adopt "a strategy for mental planning."

"There will be many questions raised today, and probably not many answers," said Sen. Edward M. Kennedy (D-Mass.). But at least the questions were asked. Engineers and physicists developed the atom bomb. Are they to decide where and when to use it? Medical researchers have developed procedures for prolonging life. Are they qualified to decide when to use and when to withhold these procedures? Amniocentesis can tell expectant parents that their child will be genetically defective. Who is to make the decision to terminate the pregnancy? Western civilization has been developing an ethical code for the past 4,000 years. Is this code equipped to answer today's questions? □

Transfer of bacterial genes to human cells

It is possible to make genetic changes in a mammalian or human cell by using a bacterial virus to introduce a specific gene, report scientists at the National Institute of Mental Health.

Carl R. Merrill of NIMH, Mark R. Geier of George Washington University and John C. Petricciani of the National Institutes of Health used cells from a person with galactosemia as a model system to test for such a possibility. They chose those particular cells because galactosemia, a hereditary disease, is caused by a known genetic defect. (In the disease, the gene necessary to produce the enzyme used in breaking down galactose, the sugar found in milk, does not function.) The researchers exposed the cells to a bacterial virus known to contain the specific gene. They report in the Oct. 8 NATURE that the human cells took up and used genetic material from the bacteria. The cells began producing the previously absent enzyme and passed the ability to do so on to succeeding generations of cells.

Six years ago, taking a course on viruses, Merrill began to wonder if the bacteria he was studying could have any effect on him. He found no satisfactory answers from the literature or from fellow scientists so he looked into the problem himself, and has now found the answer. Another group at NIH is also working along the same lines. They are using different viruses and different cells and if they run into no difficulties, they will help to confirm Merrill's work.

In the beginning, however, Merrill's ideas were met with prejudice. Other scientists intuitively refused to believe that bacterial viruses could be effective in human cells. "Scientists had a dangerous gut reaction," to his hypothesis, he says, "with no real reason." But now that the experiments have been successful, he is receiving congratulations from all sides. "This is, of course, a claim little short of the revolutionary," comments NATURE.

In Merrill's view the revolutionary aspect of the advance is not in its eventual possibilities for correction of genetic deficiencies in humans but in its contribution to basic understanding of cellular mechanisms. "I personally think this will play a big role in understanding how cells work," he says. Such research should advance knowledge of how genes control cells and how suppressor mechanisms work and answer many general questions in the field of molecular biology. The next step in Merrill's work is to attempt to repeat the experiment in a whole organism.

NIPCC meetings still closed

Despite conservationist and Congressional criticism, the Commerce Department's National Industrial Pollution Control Council is still meeting behind closed doors. The NIPCC, made up of high-ranking industrialists (SN: 7/31/71, p. 82), met Oct. 14 to discuss Phase II of President Nixon's economic policy. Representatives of the National Wildlife Federation and Friends of the Earth asked to be admitted when they learned of the meeting, but were refused.

The NIPCC was created by Mr. Nixon as part of his environmental program so that he could receive the advice of industrialists on pollution control matters. Hearings before Sen. Lee Metcalf (D-Mont.) earlier this year indicated a large part of the NIPCC's function is public relations aimed at convincing the public that industry is doing something about pollution.

Chairman Russell Train of the President's Council on Environmental Quality and Commerce Secretary Maurice Stans attended the Oct. 14 meeting. □