

## Ethics in biomedicine: A call for action

Fifty or a hundred years from now historians might look back on the 20th century and say that wisdom was lacking in man's application of science to man—the way it is now said that today's pollution problems are a result of previous misuses of technology. It was in the hope of helping avert such a circumstance and reducing the likelihood of scientific catastrophe that the Kennedy Foundation symposium (SN: 10/23/71, p. 275) focused debate on ethical problems in biomedicine.

The impact of the symposium is already being felt. Public outrage at the symposium's case study of a Mongoloid infant at Johns Hopkins University hospital being allowed to die because its parents would not permit surgery to correct an intestinal blockage was immediate. Last week, in the first few days following the symposium, letters and phone calls were received at Johns Hopkins protesting the handling of the case. The reaction has prompted the hospital to initiate formation of an ethical review board for such cases and to start a registry of possible foster parents for such unwanted defective infants. Robert E. Cooke, pediatrician-in-chief at Johns Hopkins, said last week, "Medical textbooks and practice in most hospitals will probably change because of the publicity this case received."

Even broader and possibly more far-reaching effects of the symposium may result from a call to action drawn up and issued last week by 21 participants in the conference.

Advances in biological, genetic and medical science present choices that can have an irreversible effect on man's future. The statement calls for development of processes to help society make those decisions in as responsible a manner as possible. Starting with public education, it says, "greater assistance should be given to the media in the gathering of facts, viewpoints, new developments and future consequences of decisions taken in the life sciences." Also, primary and secondary science courses should introduce children to the social implications of science as early and as thoroughly as possible. On the college and university level, the statement calls for more emphasis on ethical issues. It suggests special provisions be made for students to gain actual experience in a clinical setting, so that the complexities of

daily decisions will be impressed upon them.

The statement requests Congress to allocate funds for research on the social and ethical consequences of scientific decision and legislators to develop effective means of open communication between the public and scientific experts. The signatories recommend the examination of present legal structures to ascertain whether, under the conditions established by new technologies, some persons (infants, the sick, the retarded, the elderly) have rights that stand in need of defense, and by what means.

As a first means of implementing these steps, Cooke said the call to action will be sent to all college and university presidents. Andre Helligers, professor of obstetrics and gynecology and director of the newly established Kennedy Institute for Human Reproduction and Bioethics at Georgetown University in Washington, said his guess is that "operations like the one at Georgetown will become institutionalized and more wide spread." Action should be forthcoming, he said, because the Kennedy symposium brought the problem out into the open.

*Other questions raised at the symposium:*

### What are the rights of the retarded?

The rights of the retarded are often negated by people who claim that the protection of the retarded is their chief aim. To illustrate, George Tarjan of the University of California School of Medicine at Los Angeles cited examples of infringements upon the sexual rights of the retarded. Tarjan worked in California at a time when sterilization of the retarded was a routine procedure, and he was a leader in having the practice abandoned in that state. It had been assumed that retardates were incapable of regulating their physical impulses, that they would commit sexual atrocities, that they would indulge in sex immorally and indiscriminately. But Tarjan's observations show that "the extramarital conception rate of our women patients would have given pride to any college president or high school principal."

Tarjan explained that parents of the mentally retarded often have misconceptions about the sexuality of their retarded children, and they have a general tendency to be over-

protective. They do this by institutionalization or by sterilization. "I consider it unfortunate," he says, "that an adolescent girl may be placed in a custodial situation mostly as the result of either the conscious wishes or the unconscious fears of her parents." And he asks "whether parents should be permitted to deprive their children permanently of the opportunity of reproducing merely on the basis of their own concerns or fears." If the parents are not qualified, then does society as a whole have the right to act on behalf of the retarded? For example, can society designate selected arbiters and authorize them to provide an informed consent? Could these guardians rationally decide what is right and just for a 16-year-old girl on the basis of the symptoms that are readily available at the time, but which may disappear.

### Should babies be fabricated?

Is it right to help infertile couples have children when there are too many children being born anyway? Is it right to experiment with a "possible" human being? Anne McLaren of the University of Edinburgh in Scotland believes it is. Artificial insemination is already used on a large scale and egg transfer may become a routine gynecological procedure. But, she warns, "I am worried by the possibility that the desire to be first in the field will bias the judgment of those in a position to carry out egg transfers in women, leading to premature applications."

Paul Ramsey, professor of Christian ethics at Princeton, feels that manipulation of a person into being is unethical. It is too dangerous for the woman and for the possible child. And he argues that researchers who work in human experimentation are not allowed to ask volunteers (in this case the egg) to face possibly suicidal risks or to place themselves at risk of serious deformity.

Robert G. Edwards of Cambridge University agrees that problems exist but he says he will continue with his work along these lines (SN: 3/1/69, p. 209). Elizabeth M. Boggs, past president of the National Association for Retarded Children, emphasized that proper decisions cannot be made without sufficient knowledge. She says research must be allowed to go on, even in the face of uncomfortable choices.

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