

*To be retyped final.*

THE PEDIATRICIAN AND THE PUBLIC

by

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University of Michigan Commencement Address

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I was reflecting on what kind of message a pediatrician might bring to an audience of university graduates and their families. In asking my friends what they recalled of commencement addresses they had heard, the usual response was silence, perhaps a red face, and ultimately the confession that they not only did not remember the words, but they usually could not recall the speaker's name. The striking exceptions fell into two main groups: if the speaker was a well known politician or performer, he or she was remembered. If the speaker was the principal benefactor of the school, the name might be recalled. My conclusion from this informal poll is that I am neither a politician, a performer nor a benefactor of the University of Michigan so I can rest assured you will remember neither my name nor my words. With that new found freedom, I carry on.

The traditional Commencement message is delivered to the young by the more experienced, handing on <sup>insight and</sup> advice gained from experience. I plan to depart from that format and share with you some concerns of mine and my medical colleagues, who increasingly perceive the need for dialogue with the public.

It is immediately apparent that we have <sup>at least one</sup> ~~some~~ common interests, namely the well being of children. Some in this audience are watching their own child graduate and others have just become or inevitably will soon become parents. You share the feelings of individuals from time immemorial that children are desirable. I would submit, however, that our public posture has not always given indication of an appropriate concern for the special needs of our younger generation, ~~who will, of course, inherit our earth.~~

I would like to speak as a pediatrician, sharing with you some thoughts about areas of common interest, namely some of the social and ethical issues that arise from a new technology and a new concern for aspects of human conduct. I am thinking, of course, of the questions of fetal research, the problem of the definition of viability of an infant that became such a central issue in

the trial of Kenneth Edelin, the responsibility for good clinical research, at the same time the protection of the rights of the individual, particularly when that individual is a child and not in a position to consent to participation in <sup>Such studies,</sup> ~~clinical research.~~ I expect you share an interest in the complexities of screening for genetic disease and the responsibility one has to the individual who bears an unusual chromosome count such as "xxy" or the individual who has been demonstrated to have sickle cell trait. I have selected these topics to comment upon since they have been discussed in the lay press to a limited extent and are topics of extensive discussion in the medical schools and medical centers of this country. Increasingly physicians are recognizing the need to involve the public in considerations of sensitive issues such as these and to realize that the jurists, ethicists, the philosophers and the citizens must have some input into guidelines that we all follow as appropriate in our time.

I sometimes feel the necessity to add that guidelines are not only tentative with respect to the time in which they are written but they also have <sup>limitations</sup> bearing that may be geographically defined. For example, the extraordinary concern and expense involved in the maintenance of life of an individual born prematurely who may weigh only one to two pounds is judged an appropriate endeavor in the neonatal units of the major hospitals of this country. I doubt if it is judged an appropriate or even a possible act in a tribal community in Africa or in a village of India where children of one to two years of age may be dying of malnutrition. Thus I submit that each generation in each society may be in the process of continually questioning those actions which are appropriate or inappropriate at any given time and place.

Let's return to the list of areas of common concern. ~~Let's~~ Think for a minute about the issues that are brought into focus by the advances in fetal research. For example, it is now possible to sample the amniotic fluid early in pregnancy and ascertain <sup>not only</sup> the sex of the fetus and ~~in many instances~~ <sup>but also</sup> ascertain

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(Capitals)

the presence of certain hereditary diseases. This advance in prenatal diagnosis has depended on some sophisticated tissue culture techniques and biochemical assays which now allow us to know, for example, which infant may have Tay Sachs Disease, sickle cell anemia, thalassemia and many others. Given the information about the genetic makeup and risk of the unborn child having major illness, the option of abortion is available. The decision on the rightness or wrongness of ascertaining the likelihood of disease in the first months of pregnancy, has been a subject of debate since there is little point in ascertaining the presence of these problems if therapy is not available or abortion not an acceptable alternative. Thus the question of willingness to accept abortion as an option is central to prenatal diagnosis. In general, most individuals with these <sup>distressingly incurable</sup> familial disorders are seeking prenatal diagnosis, accepting the option of abortion, to the extent that it has become a standard approach to medical care in this country at this time.

The issue becomes somewhat more complex when the diagnosis cannot be made before the midpoint in pregnancy when the question of fetal viability becomes extremely important. The question is when is a fetus to be considered an infant with rights, with the possibility of independent postnatal life, or when is it to be considered the product of conception and the equivalent of any other tissue in the body but not endowed with any legal rights. One has to be arbitrary in this kind of situation, but the arbitrary decision ought to be based on the best available evidence and the widest agreement as to its reasonableness.

The approach used by many pediatricians and obstetricians is to ask about recent experience with respect to survival after premature birth. In general, 24 weeks of gestation or 600 grams (1 1/2 pounds) weight represents a cut-off between infinitesimal odds of survival and a remote but increasing chance of it. We have to admit that further study of extra-uterine life support systems could change these probabilities and hence require a change in legal definitions.

It is perhaps worthwhile contemplating why we are concerned with these issues at this time and why they were not of central concern to our ancestors a generation or two ago. Part of the reason is of course the advance in understanding of the care of the newborn infant. When most babies born prematurely died in the first day or two of life, it was considered of little point ~~in~~ <sup>to</sup> extending elaborate medical diagnostic and therapeutic interventions to such a hopeless group. Once it became evident that medical acts could not only save the lives of a number of these two pound infants but ensure their subsequent normality there has been a major national effort to produce regional centers for care of premature or otherwise precarious infants. Once one has labored at the crib side of such an infant, the product of a pregnancy that terminated prematurely but much wanted by parents who may not have an option to have any other child, and carried such an infant to a successful outcome, it is extremely difficult to turn around and see another infant of similar size delivered as the result of a mistimed abortion and to deprive that infant of extensive support just because he was unwanted. Surely you must understand this dilemma and surely you must realize why none of us feel content with simple solutions, nor are we happy about the pressures to write laws that will govern behavior under all of these complex situations. Legislative guidelines are one thing, legal definitions that carry a criminal penalty are something else again, to be avoided in my view.

We ~~seem to be~~ <sup>are</sup> in an era ~~where~~ <sup>whose</sup> a new technology has helped us solve some classical problems, such as the virtual elimination of poliomyelitis as the annual summer scourge of childhood in this country, the drastic lowering of neonatal mortality and morbidity and the concomitant reduction in the incidence of cerebral palsy and mental retardation, which are surely laudatory achievements. ~~On the other hand the~~ <sup>yet this</sup> continued advancement of knowledge and understanding, while it solves some problems, creates others and forces us to face some of the ethical dilemmas I have just cited. These observations are not intended to lead one to

the conclusion that we should stop the pursuit of knowledge as some of the geneticists have done with a temporary moratorium on their research, but to suggest that with new tools and new insights we as a society encourage continual assessment of their implications. For example, the problems associated with the detection of what is called the heterozygote carrier of the sickle cell gene is an illustrative example. We have learned some profound lessons about the dangers of rushing into any kind of program that involves people's genes. The complexities arose when the individuals who carried the sickle cell trait did not understand the implications of that information and felt they had a "bad gene" that might cause anemia in their child. They failed to understand that only if their mates had a similar bad gene could this disease express itself. Moreover, an appalling situation arose when some insurance companies associated the harmless presence of the sickle cell trait with the active disease, sickle cell anemia, and refused to insure some of the carriers at the usual rates. This gross misunderstanding has produced hardship, bitterness and the understandable reaction that maybe it is "inappropriate" for a society to detect the presence of an abnormality if there is no cure for it immediately available. The problem was in essence that people were given complicated and frightening information in a situation where they could do very little about it. This lesson has led members of the National Academy of Sciences to ask some searching questions: is the public interested in and prepared to accept screening for disease? The decision should surely be ~~one~~ <sup>solely by</sup> made by the individuals who are to be screened rather than <sup>1</sup> those who have the tools for doing the screening. The next question would be, will the public support facilities such as laboratories to carry out the screening, and if treatment is available are they prepared to undertake the long-term support required for effective treatment? <sup>are</sup> Another question is, would the public want to be educated about the nature and consequences of a particular program, <sup>7</sup> ~~and~~ <sup>How</sup> best does one provide information to a large group of people? All of these questions presuppose the scientific accuracy of the

methodology<sup>S</sup> to be employed and the potential availability of effective treatment.

While we can speculate on the desirability of educating a public ~~with~~ <sup>about</sup> ~~respect to~~ the availability of certain kinds of medical procedures, we have on the other hand a reasonably complicated history of an inability to persuade the public to adopt public health measures that could have a significantly favorable impact on their health. ~~I am thinking here particularly~~ <sup>Consider</sup> of the problem of

<sup>a certain</sup> low concentration of fluoride in the drinking water will reduce the incidence of dental caries in children by more than half. The epidemiologic studies have been done over the past twenty-five years, reported in the literature and are widely accepted by the dental and medical profession. On the other hand, more than half of communities in this country have opted not to fluoridate their drinking water, suggesting that the availability of fluoride in other forms, such as toothpaste, vitamin tablets, etc., ought to be a free choice made by parents on recommendation of physicians. Some argue that the compulsory nature of intake through fluoridation of public water supply abrogates in some respects the rights of the individual to a free choice. The issue here is whether the child, who is most affected by these decisions, has been considered in the overall debate. It would seem to me that if you asked a child whether he would like to reduce his chances of having caries by fifty percent, with the consequent lessening of his time in the dentist's chair, the response would be a <sup>loud and clear</sup> ~~unanimous~~

<sup>By contrast</sup> yes! We know that the freedom of choice given parents with respect to applications of fluoride or supplements has not been accepted and the high incidence of caries in children in communities without fluoridation remains in my view a public disgrace.

Thus I submit that the pediatrician has a responsibility to inform the public of what is available for the health needs of children. In some instances it would seem that the evidence for good is so overwhelming that there should be little argument about its being made compulsory for all children. I am

thinking here of immunization for diphtheria, polio, measles and the like. I would add fluoridation to that list. There are other situations where the information available may or may not be desirable and on these issues we need to maintain a thoughtful dialogue with the public as illustrated by decisions as to when to extend the option of prenatal diagnosis or when to withhold it.

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My message is that the nature of medical knowledge has ~~become such that~~ <sup>reached a stage</sup> options never before available can now be considered by the public. Ethical, economic, social and legal considerations are germane and physicians are asking for help in establishing the guidelines for medical actions. When all the country doctor had to offer was a presence and consolation, he could determine the rules and decree the probabilities of the outcome. <sup>But</sup> The country doctor of today, the deliverer of primary care as he is now labelled, can involve a massive amount of technological support that will permit not only precise diagnosis, but pose definite choices, such as to screen for disease or not, to abort or not, to recruit intensive care or withhold it.

Even with the explosion of knowledge that has been the consequence of major support for biomedical research, we are still groping for more answers, that will make therapy more definitive, and move from areas of uncertainty (which are anxiety producing) to areas of certainty that will improve our state of health. During this decade or two of transition from minimal knowledge, to ever expanding horizons, when changes are taking place with great rapidity, I would encourage dialogue and resist legislation in matters as sensitive as those I have just discussed. We need a gray zone for human behavior on issues such as these. We most certainly need as well opportunities for the pediatrician to meet the public. Thank you for this opportunity and good luck to you, your children and all children for whom you take responsibility.