

Ethical Issues in Prospective Gene Therapies
(Testimony Given before
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In the written material provided for the Commission, I was particularly struck by the pieces by Tabitha Powledge and Richard Roblin as well as by much of the additional material. Rather than try to duplicate their rather exhaustive list of issues, I should like to spend my few minutes underscoring three of those areas of concern somewhat more deeply, in part because my sense is that these may well receive the greatest attention by various significant elements in the society.

The three areas of concern are: issues essentially involved in the very research into and development of gene therapies for genetic disease; issues in the socialization of the view of human disease and therapy as genetic; and issues essentially involved in the very concept of the new techniques as "therapeutic."

It is no secret that a substantial and increasingly well-organized segment of the American population opposes abortion in all but a few types of case. For those who believe that conception is the point of emergence of a human being or person who bears rights such as the right not to undeservedly be killed or harmed save by its own informed consent, any research procedure which utilizes embryos and fetuses in a manner either involving abortion or posing an increased risk of harm, will be regarded as morally unjustifiable. Such individuals judge morality of research and other deliberate human acts not in terms of expected benefits but in terms of standing obligations, such as that of human adults to protect and nurture human offspring. Persons in this group of citizens will not accept research leading to anticipated therapies for genetic disease if that research of necessity involves experimentation on electively aborted fetuses or even increased risk to fetuses that will be brought to term.

In my contribution to the Commission's reading for this meeting, I have referred to ethical issues involved in the socialization of the view that various diseases are genetic. There are factors involved concerning both the personal image of individuals who, by this typology, as identified as carriers of a genetic disease or as themselves genetically diseased, and the social perceptions that others have of them. The impact on the life of an individual suffering from a disease identified as genetic (rather than through one of its other causal factors) is complex: it involves location of the responsibility for management of the disease within the individual; it places on the individual moral and perhaps legal restrictions on reproductive rights; and it may hastily predispose both that individual's thinking and that of his or her medical consultants toward a genetic mode of therapy as preferred and appropriate. But I am after the sense of self that is involved in one who makes the judgment that he or she is genetically defective. One does not *have* a genetic disease the way one has measles or a broken leg; one *is* genetically diseased, where the genetic disease and defect is disease of and defect in oneself. Being genetically diseased is like being Caucasian or black; one might say that it is perceived as part of one's essence or identity, so that the fault is seen as lying essentially in oneself, not in the environment or diet or locus of whatever other causal factors are involved in the expression of the genotype.

There is thus a kind of coercive element potentially involved in the development of those gene therapies that promise the repair of a genetic defect, believed to be the cause of a disease, the replacement of a “bad” gene with a good one. And for those who think of their genetic structure as both their fundamental grounding in humankind and the locus of their individuality as humans, the burden of guilt associated with being genetically defective (either by themselves or those with whom they have strong peer relations) may either dispose toward a therapeutic mode which, on other grounds, is relatively inferior, or it may result in a wholesale rejection of the fact that there is a heritable dimension to the disease requiring special attention to offspring, diet, or internal chemistry. This becomes a particularly sensitive point in discussing potential gene therapies for diseases statistically associated with particular ethnic groups.

The third area of concern is that of the very conception of recombinant DNA techniques, involving “repair” of genetic defects through removal and replacement of defective segments of DNA, or addition of missing ones. Not only does one invoke a particular causal typology by speaking of gene therapy for genetic disease, the very use of the term “therapy” may be suspect. Consider: on some theological systems of belief the genetic substrate of an individual both determines its nature as a human being and, by organizing other matter in a characteristic developmental pattern, the unique individual human itself. Any alternation of that genetic substrate which materially affects the subsequent course of anatomical and physiological development may well count as not a change in the individual but as a change of the individual—a replacement of one individual developing human by another—an act morally akin to selective abortion and reconception in pursuit of a non-flawed offspring than to the therapeutic manipulation of the external or internal biochemical environment to compensate for, suppress, or prevent the unwanted phenotypic expression of a certain potential of the genotype.

There is a tendency to regard such views as fundamentally religious, in part because religious apologists such as Paul Ramsey frequently advocate them, and to infer from the doctrine of separation of church and state a duty not to presuppose them in setting state and federal policy. However, not all arguments offered for fetal personhood and for the role of the genetic substrate as a necessary condition of individual identity are religious. For example, philosopher James Nelson has recently extended the widely held causal theory of semantics in an application to the terms ‘human being’ and ‘person,’ successfully arguing that that semantic theory, plausibly developed, implies that such terms apply from the point of conception in such a manner as to establish the individual, numerical identity of the bearer. If wholly correct, this theory may require the sort of rethinking of how we categorize recombinant DNA splicing to alter genotype in the manner suggested in the previous paragraph.

Two summary points. First, I reiterate that I am not here to defend the substantive views I’ve been discussing, but rather to identify them as areas of likely concern to substantial segments of the public, and thus appropriate concerns for the Commission. Second, while I would not call for a moratorium on basic and applied recombinant DNA research until these complete issues can be studied and resolved, I believe that the Commission’s attention to these and other issues is timely and not premature despite the as yet distant onset of these particular applications of recombinant DNA technology in human genetic engineering; political and ethical debates currently raging have bearing on several of these issues and there is yet time for education of both the public and the scientist in the details of the issues involved.