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Gene Therapy or Genetic Enhancement: Does It Make a Difference?

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Asked whether genetically altering an embryo to improve the musical talent of the child-to-be is a treatment goal of medicine and, as such, should be reimbursed by health plans, most people immediately answer, “no.” But suppose the human embryo (or parental gametes) could be genetically altered so that the resulting child’s immune system resisted common cold and flu viruses. Would that be medical treatment? Technically, no. Should the immune system alteration—whatever it is called—be offered to everyone? Should health plans pay for it? Some would answer, “yes,” and some, “no.”

The point is, it’s easy to recognize that extreme cases of enhancement fall outside the goals of medical treatment; not so easy to decide borderline cases like that of immune system fortification. And like so many of the questions genetic information and technology are raising, the therapy-enhancement question is neither a new one nor one that is limited to the domain of genetics. The same fuzziness has long existed between treatment and enhancement in plastic surgery and psychiatry, to name just two specialties. Developments in psychopharmacology such as personality, performance, and attention enhancers sorely test category boundaries.

Therapy

A widely accepted working definition of medical “therapy” comes from Norman Daniels’ formulation of the standard medical model. In the standard medical model, “therapy” is an intervention designed to maintain or restore bodily organization and functioning to states that are typical for one’s species, age, and sex. According to Daniels, society has a duty to provide “treatment” only for medical need defined as departure from normal organization and functioning.

Enhancement

Enhancement, on the other hand, is alteration to improve upon normal organization, appearance, health, and functioning. Taking of anabolic steroids, undergoing certain forms of rhinoplasty, and altering one’s gametes to imbue one’s offspring with greater than average musical talent represent attempts at enhancement.

Prevention

Perhaps the immune system example with which this article began fits best into the category of prevention—like immunization itself. Prevention has sanction as a medical intervention because it helps achieve the medical goals of maintaining

health and obviating a later need for treatment. It is important to remember in germline genetic intervention, however, that what is being prevented is not a mere disease or symptom, not even merely the existence of a species-normal immune system (which might be prevented, for example, by gamma globulin injections, vitamin C or achinecia). What is being prevented is the existence of a human being who has a normal immune system, a human being with a certain genotype. Preventing certain genotypes from coming into existence does not fall within the traditional medical goals of prevention. The concept of genetic prevention calls for new thinking.

Remediation

There is a 4th possibility along the gene therapy-genetic enhancement continuum. Suppose an embryo's genome revealed that the child-to-be would have lower than species-normal cognitive ability or violently aggressive behavior. Molecular science knows little about the genetic components of cognitive ability and behavior at this time, but suppose, in future, genetic engineering could bring aggression or cognitive ability within normal limits. The intervention would not help maintain or restore physical health and functioning; it would not prevent illness, and would not enhance ability beyond levels that are species-normal. LeRoy Walters and Julie Gage Palmer have categorized this hypothetical intervention in cognitive ability and character traits as remediation.

Does It Matter Whether Genetic Intervention Is Therapy, Prevention, Remediation, or Enhancement?

What does it matter whether a genetic intervention is called therapy, prevention, remediation, or enhancement? First, there is the obvious matter of equal access to the intervention. How an intervention is categorized largely determines how accessible it is to all who wish to use it. Looking into the future of germline genetic interventions, those that are labeled therapy, prevention, or remediation stand a far better chance of being available to people who cannot pay for them out-of-pocket. If an intervention is categorized as an enhancement, it will probably not be thought to satisfy the therapeutic goals of medicine and, hence, will not be a reimbursable service. Under such conditions, termed "genobility" by 2 bioethicists, the rich will not only have more money than the rest of us, they'll be taller, smarter, and better looking, too.

There is an individual therapy-enhancement matter that each physician will decide for himself and herself, and the question is not limited to genetics. Each individual physician must interpret the goals of medicine and the appropriate use of his or her education and skills in fulfilling those goals. A physician may decide not to use her skill and professional status to prescribe ritalin for normal, healthy college students; another physician, not to manipulate embryos to produce super stars in athletics or the entertainment field. Either of these physician may, on the other hand, decide to prescribe growth hormone for a young boy who does not have growth hormone deficiency, but whose parents are both short and whose adult height will place him well below normal range for his sex.

Many factors enter into the decision. Is there meaning in striving to make the most of what nature or God has given us? Do we cheat ourselves or others when we attempt to short-circuit the normal course of learning, say, or the discipline needed to excel in sport or in music? Do parents do a better job of parenting a made-to-order child? Is that what parenting is about? Is there possible harm in curtailing diversity? in systematically preventing certain genotypes from coming into existence? To what extent do we, as physicians, help people by giving them what they ask for when what they ask for is unrelated to physical, mental, or emotional health?

Some may shrug their shoulders at such weighty questions and say, “What difference does it make whether I provide services that stretch professional or ethical boundaries? If I don’t do it someone else will.” But therein lies the ethical boundary that must not be crossed: the boundary that separates exercise of professional judgment and integrity from shirking of responsibility. Every physician has entered into a covenant with society to apply his or her skills and judgment in the patient’s best interest. The bright ethical line in the debate over therapy versus enhancement separates acting in the patient’s best interest from abdicating the responsibility to determine, with the patient, what constitutes “best interest” in a given case. If the physician and patient disagree, the physician must act as professional ethics and the profession’s covenant with society direct.

The specific issues are philosophical questions about which thinking people disagree. They underlie simple actions (Do I write that script?) and monumental ones (Do I participate in altering the genome of a child-to-be?). Professional judgment and integrity form the ethical framework for deliberating them.

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