

GENETIC ENHANCEMENT: DISTINCTIONS AND REGULATION

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Genetic enhancement can be defined as bringing the attributes of individuals above that which is species-typical, a manipulation that can be accomplished through somatic or germ-line means. Although not presently an active technology in medicine, genetic enhancement has the potential to shape future society by allowing directed improvements in future people and their progeny. As a result, some individuals advocate abandoning research into genetic enhancement because of the potential for social problems through the development of a technology that is both obviously beneficial and subtly harmful (Fukuyama 2). Benefits include the ability to identify and treat individuals at risk for serious diseases, while harms include distortions in social or political structure. This polarized view, however, which postulates strictly positive and negative uses of enhancement, ignores the often-vague distinction between enhancements and treatments such as vaccinations. Additionally, the knowledge and power relations that co-exist alongside the fear of self-serving uses of enhancement create and perpetuate the negative connotations of genetic enhancement. In truth, though, the lenses of Francis Fukuyama's "Biotechnology and the Threat of a Posthuman Future" and Deborah Lupton's "Theoretical Perspectives on Medicine and Society" reveal that the possibility of genetic enhancement itself is not innately good or bad, but rather it is the potential social applications that mar the science. Therefore, enhancement techniques should be monitored to ensure that the technology is not used for self-serving purposes, but instead is employed only for the treatment of disease; moreover, the initial power to do so rests in the hands of the medical and genetics community where regulation should involve use of the doctor-patient relationship to restrict access. Ultimately, genetic enhancement is a complex issue that requires careful reflection, especially considering the often unclear distinction between treatment and enhancement.

Despite individual viewpoints on the issue of enhancement, there is a general agreement that the treatment versus enhancement distinction depends on the field of medicine and its definition of disease. For individuals like Walter Glannon, author of *Genes and Future People: Philosophical Issues in Human Genetics* and a staunch opponent of genetic enhancement, the difference between enhancement and therapy is clear and definite: "Gene therapy . . . is an intervention aimed at treating disease and restoring physical and mental

functions and capacities to an adequate baseline” while genetic enhancement “is an intervention aimed at improving functions and capacities that are already adequate” (94). Based on these definitions of treatment (i.e., gene therapy) and enhancement, the use of genetic techniques to augment otherwise normal functioning falls outside the bounds of medicine, which is involved in “maintaining or restoring mental and physical functions at or to normal levels” (94). These black-and-white definitions reinforce a polarized disparity of good and bad uses of biotechnology—with treatment as “good” and enhancement as “bad.” Therefore, as Fukuyama observes, making use of “institutions that can discriminate between good and bad uses of biotechnology and that can effectively enforce these rules both nationally and internationally” satisfies regulatory requirements (3). However, the definitions and distinctions fall apart when the role of medicine goes beyond maintenance and norms and enters prevention. Juengst, in his article “Can Prevention be Distinguished from Enhancement in Genetic Medicine,” also acknowledges this and recognizes that the treatment and enhancement distinction “dissolves in the case of using human gene transfer techniques to *prevent* disease when such interventions involve the enhancement of the body’s health maintenance capacities” (126). Thus, the difference fades in certain instances where genetic technology enhances a body’s functioning in order to protect against or prevent the occurrence of disease.

Such is the case in vaccination, where the immune system inherited by each individual is bolstered by exposure to weakened agents of disease. In doing so, an individual acquires preemptive immune improvement in an attempt at prevention (Juengst 133). Moreover, as a logical extension, the President’s Council on Bioethics cites the possibility that “[f]urther in the future, genes that confer resistance to particular pathogens (perhaps anthrax or smallpox) might be added . . . to protect a population from attacks with biological weapons” (“Staff Background Paper” 4). Vaccination and genetic manipulations in these instances *improve* an individual’s functioning—specifically, they give ways to enhance the immune system. Therefore, since it is possible to view this treatment intervention as enhancement, should it be classified as a “bad” use of technology and thereby regulated? Some might argue “it is misleading to call this intervention ‘enhancement’ . . . it would neither be therapy nor enhancement but instead a form of maintenance” (Glannon 95). As maintenance, vaccination would fall within the realm of medicine. Maintenance, however, implies allowing the body’s natural defenses to combat a

previous exposure to disease. This is clearly not the case in vaccination where the body is given a novel defense against a previously unknown or unexposed disease. Hence, this point of view is innately flawed, not only because it fails to refute vaccination as a case in which the distinction does not exist, but also because it denies prevention both as a form of treatment and as an important aspect of medicine. Vaccinations and other forms of genetic therapy, as treatments that entail improvement of an otherwise adequate system, are both commonly accepted means of preventative medicine *and* forms of enhancement. The reluctance of individuals like Glannon to classify interventions such as strengthening the immune system as enhancement supports a negative connotation and motivates the aversion that many individuals have to the concept of genetic alterations. Nevertheless, because of the sometimes-overlapping values of treatment and enhancement, the bounds of medicine cannot be the sole basis for labeling enhancement as harmful and thereby enforcing regulation. Although establishing a “regulatory framework to separate legitimate and illegitimate uses” (Fukuyama 6) provides a logical means to moderate therapeutic applications of genetic medicine, there is not necessarily always a clear-cut difference between the two. Perhaps more importantly, the distinction is misplaced.

The real distinction that needs to be defined and regulated is not the difference between treatment and enhancement, which can be one in the same, but rather the difference between enhancement that is treatment and enhancement that is self-serving. It is the latter to which many object and should be wary of. Unlike enhancement, which seeks to treat disease or deficiency, self-serving enhancement seeks the technology to bestow genetic benefits for selfish social interests. After all, as Fukuyama warns, “as we discover not just correlation, but actual molecular pathways between genes and traits like intelligence, aggression, sexual identity. . . and the like, it will inevitably occur to people that they can make use of the knowledge for particular social ends” (6). Thus, self-serving enhancement interests are not divergent from treatment of a disorder; instead, an individual attempts to acquire enhancement to improve social, political, or economic status. For instance, unlike the case of vaccination, the possibility exists that some genetic therapies will be used in the improvement of biological functions unrelated to disease. An excellent example is the “introduction of the gene for IGF-1 into muscle cells with resulting great increases in muscle health, strength, and efficiency . . . Strong interest in using muscle enhancing gene techniques is expected to come from athletes, the elderly, and young people interested in

increasing their physical attractiveness" ("Staff Background Paper" 3). Clearly any of these uses of genetic technology would be overtly detectable, illegitimate enhancement since, rather than the treatment of a disorder like muscular dystrophy, the applications would extend to use by those who do not need it to gain adequate functioning. The use of genetic enhancement in this instance falls outside of the domain of medicine. For such cases, an appropriate course of action would be to enact legislation to prohibit application of self-serving enhancement.

Self-serving enhancement is also significant because it illuminates another major concern about genetic enhancement—the potential social applications of the technology. Enhancement is a problem to the extent that it complicates our existing social structures since, much as in the case of medical power, a diffuse knowledge organizes society (as Lupton might acknowledge). Social structure in this country is contingent upon "power, not as a unitary entity, but a strategic relation which is diffuse and invisible" (Lupton 128). In this social-constructionist sense, a system of social order and expectations saturates present medicine and culture; this "invisible power" permeates an individual's perception of genetic enhancement and, furthermore, creates aversion to it. In other words, the "system" of enhancement allocation gives more privilege to the wealthy (or the wealthy privilege themselves using the system), and because of this considerable and built-in differential of power, access and distribution issues result. As Glannon argues,

The main moral concern about genetic enhancement of physical and mental traits is that it would give some people an unfair advantage over others with respect to competitive goods like beauty, sociability, and intelligence. . . . Enhancement would be unfair because only those who could afford the technology would have access to it, and many people are financially worse off than others through no fault of their own. (97)

Therefore, the end result of genetic enhancement might be the use of the technology exclusively by the wealthy to beget enhanced progeny. This fear likely exists in those who oppose genetic enhancement—the fear that use of enhancement science will further stratify social structure. According to the film *Gattaca*, use of genes to improve humans will be manifested in the creation of a master race, one that excludes inferior or "normal humans" who were not scientifically programmed (that is, who were products of natural procreation) from society. Wariness concerning the implicit entanglements of science and social roles is

not entirely unreasonable since self-serving enhancement would derive from, as well as reproduce, existing social parameters.

These concerns of opponents of enhancement, however, come from current social constructions predicated on the premise of the wealthy possessing all power, knowledge, and economic means. Thus it is the current social distinctions that influence the imprecise, negative view of enhancement. In particular, according to Glenn McGee in *The Perfect Baby: Parenthood in the New World of Cloning and Genetics*, what these individuals ignore is that somatic and germ-line enhancements and their uses “[do] not uniquely influence the future . . . [their] power is not prefigurative or determinative” (McGee 114). Therefore, although it is possible that wealthy people might be privileged with greater access to genetic technologies, that possibility does not make it an absolute truth. Furthermore, even though these fears constitute valid concerns, they assume an inability to detect and regulate self-serving and therefore illegitimate enhancements from legitimate ones; however, we are neither blind nor powerless toward these distinctions.

The main question to ponder then becomes whether genetic therapies “can be developed for therapeutic uses without increasing the possibility of future application for human genetic enhancement” for selfish purposes (“Staff Background Paper” 4). A logical preliminary answer and basis for regulation would be to maintain medical focus on the treatment of individuals afflicted by disease and disease alone, even if that treatment entails enhancement (i.e. vaccination). This issue, however, calls into question the definition of disease, since it is entirely possible that in the future people might question whether diminished physical capacity or short stature can be considered disease. Juengst offers a potential answer: “[w]here the human problems anticipated by an intervention cannot be tied together into a diagnosable disease entity, with its recognizable constellation of subjective symptoms, physical signs and causes, it should not be adopted as a proper part of medical practice” (139). Thus, genetic enhancement should not be used to foster “social hopes.” Unless there is a legitimate deficiency or quality that necessitates use of the technology, there is an obligation by the doctor or physician, as well as society, to refuse access.

Another basis for regulation derives from current medical knowledge constructions as explained by Lupton: “power relations in the medical encounter [are] ‘everywhere,’ enforced as much by the individuals unconscious self surveillance as by the authority figures” (129).

Therefore, just as the social “system” potentially gives more access to gene technology to the wealthy, the medical system potentially allocates a more substantial role in medical discourse to the doctor, thereby allowing doctor-sponsored patient restrictions (or restricted access). Although the patient retains a substantial role the medical encounter, the present medical system may empower doctors to ensure enhancement techniques are obtained only by those whose condition merits them. For instance, in terms of present germ-line therapies, such as *in vitro* fertilization and prenatal genetic diagnosis (IVF/PGD), techniques are employed *only* if there was “prior birth of a child with a genetic disease, prior spontaneous abortions, or abortions after a prenatal diagnosis of a genetic disease” (“Staff Background Paper” 6). Existing medical parameters in this case not only confine the technology within disease bounds, they also exhibit doctor-sponsored limitations. Such interventions may give an initial stance for regulation, which in turn will help separate legitimate therapeutic uses of enhancement from illegitimate self-serving ones. Hence, to the extent that the doctor-patient relationship provides a platform from which initial access regulation may arise, the decision to dispense genetic medicine could be partly left up to the discretion of the doctor. Doctors maintain the power to apply the technology in medically-necessary cases and at the same time prohibit its use in frivolous instances, which will alleviate some concerns about genetic enhancement. This is a hefty responsibility, one not necessarily to be undertaken by individual physicians but allocated to the greater medical community involved in the production and application of genetic enhancement technologies.

Even this option may be troubling, though, since it relies on the notion that all doctors are trustworthy and can effectively distinguish between appropriate and improper uses of the technology. The perspective that medical professionals will use their power for strictly beneficial purposes may prove shortsighted. Therefore, not only do we need to be wary of self-serving uses of enhancement by patients, but we also need to be cautious concerning self-interested doctors. In particular, Maxwell Mehlman, author of *Wondergenes: Genetic Enhancement and the Future of Society*, argues that although “professional self-regulation might play a role in limiting access to genetic enhancements . . . under certain circumstances, health care professionals may be unable to resist the economic lure of the enhancement business” (137). Genetic knowledge, in this case, acts directly in the interest of the doctor, who might utilize his or her power to survey both medical and social aspects of the patient and consequently succumb to economic temptation. This is entirely possible

considering that medical knowledge is diffuse and “should be considered the product of power relations, and as such, is never neutral, but always acting in the interests of someone” (Lupton 111). Use of technologies could therefore be dependent on both the doctor’s or the patient’s personal needs and value system which could influence the use of medical power for self-interested purposes.

Additionally, assuming some rogue doctors or patients do use the system for personal gain, an important concern would be the detection of the illegitimate enhancement. As Matt Crenson, in his article “Tomorrow’s doping scandal? It could be genetic enhancement,” notes that “like the technology itself, testing for genetic modification is still in its infancy—and it may never be easy to detect” (2). This problem may not be easily overcome by mere doctor-patient restrictions, but instead requires use of other internal and external constructions that are already present in our current medical system. For instance, Mehlman suggests licensing of the technology to regulate genetic services: “Health care professionals would have to be licensed to dispense enhancement drugs or to provide enhancement services” (157). Licensing could consequently give a way to “limit sales to licensed purchasers, and impose reporting requirements so that sales could be tracked by the government” (Mehlman 157). Thus, other factors such as government legislation and international policies would also need to be present to provide a strong basis for restricted access in the distribution of the technology.

Ultimately, somatic and germ-line genetic enhancement technology, like prenatal screening and IGF-1 therapy, bestow challenges that present and future generations alike must face. Therefore, while it is important to take action, it is imperative to make sure it is the appropriate course of action. One of the first steps is to recognize that treatment and enhancement may be one in the same, as exemplified by vaccinations, and to strip away socially-motivated fear constructs and embrace the technology’s possibilities. That is not to imply that enhancement technologies are nothing but good, but rather to urge that society as a whole recognize that the science of enhancement itself is not innately bad; it is the potential social applications that create a threat. Genetic enhancement should therefore be regulated to prevent self-serving patients and self-interested doctors from abusing the technology to gain superior social, political, or economic status. An essential means to accomplish this is to partially allow scientists, genetic counselors, doctors, and other constituents of the greater medical community to restrict access within the bounds of the

doctor-patient relationship. Despite the possibility of the corruption of an individual doctor, placing the responsibility in the hands of the medical community first may provide one option to curb self-serving enhancement, but by no means should it be the only regulatory action. Restricted access should be but one source of regulation—a small step in a greater national and international scheme to minimize the dangerous social uses of current and prospective genetic technologies. In the end, as Mehlman argues (156), rather than fear genetic progress, we should channel the advantages of enhancement so that they are employed for the good of present and future generations.

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