Genetic Enhancement, Distributive Justice, and the Goals of Medicine

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I. INTRODUCTION

This is an exciting book.¹ Not only is it a tour de force of all the important moral issues relating to genetics, but it is written by what can only be called a dream team of bioethicists.² For the past quarter century, these four individuals have exerted a profound influence on the creation and direction of the field of bioethics, and now this book will surely be the starting point for ethical work on genetics into much of the new century.

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1. ALLEN BUCHANAN ET AL., FROM CHANCE TO CHOICE: GENETICS AND JUSTICE (2000).

2. This team is composed of the following members: Allen Buchanan, Dan W. Brock, Norman Daniels, and Daniel Wikler.
In this brief Essay, I focus on chapter 4 of the book’s discussion of the distinction between treatment and enhancement. This distinction is at the core of many of the most challenging problems of ethics and public policy raised by genetics. This is also the place where there appears to be disagreement or ambivalence among these authors and where fault lines appear in their otherwise remarkably united front.

II. THE AUTHORS’ ARGUMENT

Because the analysis in chapter 4 is complex and subtle, I will begin with a summary outline of it so that I can more precisely identify the location and importance of the points I want to address within the chapter’s overall structure. Chapter 3 lays the groundwork with the important insight that genetics radically alters the conventional domain of distributive justice. No longer can we assume that the distribution of personal traits and characteristics is beyond the reach of distributive justice, subject only to luck or natural forces. Instead, we must contemplate the serious possibility that many of our constitutive characteristics can be chosen and engineered. This awesome ability will depend on access to genetic technologies, which has profound implications for how to think about resource allocation and redistribution and about social entitlements and duties. I largely agree with how these issues are presented and analyzed at a general, conceptual level in chapter 3.

Chapter 4 then takes the analysis to a somewhat more concrete level. It asks whether, in the imagined world of vastly expanded technological control over genetics, we should think differently about fixing genetic diseases than we do about enhancing genetic traits.

First, the authors argued, and I agree, that enhancement versus treatment is a meaningful distinction; one with considerable ambiguity in close cases but one that has and will retain practical significance, even if the line shifts or cannot be precisely drawn. In my view, the distinction is based on concepts of normality that are a fundamental aspect of human psychology, deeply and biologically imbedded in how

3. See Buchanan et al., supra note 1, at 104–55.
4. See id. at 149.
5. Id. at 63.
6. See id. at 61–103. One point of disagreement is that, in stressing a requirement of genetic intervention to correct natural or social inequalities, the authors appear to go much further than necessary toward raising troubling issues of personal autonomy. See id. at 77–79. There is no reason to even suggest or suppose that distributive justice might require forcing corrective measures on competent adults who do not want them for themselves or for their children. The requirement at issue is one imposed on society to provide access or funding.
7. See id. at 104–55.
8. See id. at 109–10.
we perceive and conceptualize patterns of variation in any realm of experience. Even if the particulars change in what we view as being normal, the underlying concept of normality and therefore of corrections versus enhancements will remain.

Second, the authors considered various objections to giving this distinction moral weight. They considered the apparent arbitrariness of drawing such a line, illustrated with examples from current practices by health insurers in deciding what to cover under the concept of “medical necessity.” The authors provided a nuanced and insightful analysis of some of the practicalities in designing and interpreting a set of health insurance benefits.

Following this, the authors addressed arguments that, even if the distinction between treatment and enhancement is sensible and practical, this distinction does not define what is ethically permissible or obligatory. In other words, it is not a faithful proxy for underlying, fundamental, moral constructs. Giving special moral status to treatment and viewing enhancement as problematic may be either underinclusive or overinclusive of how we would resolve particular moral questions from a more fundamental vantage point.

Fourth, the authors’ primary response to these imagined attacks was to invoke Norman Daniels’s well-known position that distributive justice requires society to do what is feasible to maintain the normal species functioning that is necessary for each person to have a fair range of opportunities. The distinction between treatment and enhancement does not perfectly match the normal functioning concept, but it is close enough to serve as a practical proxy or surrogate for the more fundamental principle.

Fifth, the authors considered why distributive justice does not require that genetic enhancements be used or restricted to produce a more perfectly level version of equality. They observed that seeking perfect equality of opportunity is unrealistic because of practical limitations and competing values. Liberty concerns keep us from restricting others’ abilities, opportunities, or accomplishments simply in order to achieve

9. See id. at 110–18.
10. Id. at 110–12.
11. See id. at 112–13.
12. See id. at 118–21.
perfect equality with those least advantaged—“leveling down.” In the past, biological and resource limitations greatly restricted what could be done to improve the physical and mental functioning of the disadvantaged—“leveling up.” Therefore, so far we have been forced to tolerate sizeable inequalities.

Genetics, however, creates the potential to greatly reduce the opportunity gap with powerful and inexpensive tools for altering fundamental human abilities. Therefore, the authors acknowledged that the argument for expanding health care entitlements beyond treatment of disease becomes much stronger. However, they maintained that these possible uses of genetic enhancement should be considered exceptional, case-by-case departures from the disease model and not part of the basic conceptual framework for health care entitlements.

III. MY CRITIQUE

My critique of this argument focuses on the fourth, fifth, and last points above. These points are the most critical and the ones where my disagreement is most pronounced. My approach to these issues will not have nearly the same philosophical sophistication as these authors brought to bear. Instead, I will use a more intuitive analysis, informed by my understanding of the issues in the second point, namely, how health insurance works and why it is structured the way it is.

A. Versions of Equality

The authors started their analysis with Norman Daniels’s normal species functioning position and then asked whether any significant deviation or alteration is justified by genetics. For a project this ambitious, one that considers issues at such a fundamental level and reflects on the potentially radical significance of futuristic genetic technologies, I think it is incumbent to go further back in the chain of reasoning that produced the normal functioning position. That requires us to consider the fundamental aims of distributive justice.

As a starting point for thinking about equality, I believe that most people hold the untutored instinctive view that the authors label the “brute luck” version of equality. However, this is only the starting

16. See id. at 128.
17. See id. at 129.
18. See id. at 17, 129.
20. See id. at 129.
point, not the ending position, for ethical analysis. People by and large believe that it is unfair to limit opportunities based on factors not within their control. Therefore, it is the general aim of distributive justice to correct for misfortunes produced by the natural lottery. However, after a moment’s reflection, we realize this cannot be fully accomplished because of competing practical and value based reasons, as noted above. Concerns about individual liberty prevent us from denying opportunities and accomplishments to the more fortunate simply to close the gap. Our technical and economic abilities to assist the less fortunate are inherently limited. Therefore, society adopts compromise versions of equality that seem, in the circumstances, to best accommodate these competing pulls.

How these competing forces are best resolved will differ across time and among social spheres. Sometimes we may settle on correcting only abnormal deficits, but other times we seek to improve normal abilities; or we may sometimes strive for a decent minimum standard, while in other arenas we attempt to achieve a fairly level form of equality. These versions are not determined once and for all by fundamental moral principles; they are worked out at a more pragmatic level where the solutions are subject to fairly radical revision as circumstances change.

Consider, for instance, education. We are born with a wide range of abilities and opportunities to learn and think. Society seeks to equalize these mental attributes through a highly egalitarian system of publicly funded schools that, ideally, seeks to achieve more than a decent minimum. However, achieving perfect equality and correcting abnormal deficits are not the primary goals. Traditionally, public education has sought to enhance mental skills starting from a normal range of abilities. It encourages the best and brightest to achieve the most, and, until recent decades, it did not do much to address the needs of the mentally handicapped. The last point has changed markedly, however, due to increased resources and technical abilities. We now know much more about educational techniques for learning disabilities and mental handicaps, and society is able to devote more resources to this purpose than before.

The version of equality that exists now for health care is fundamentally different. In this sphere, the principal focus is on disease,
and most resources go to those with the greatest needs. However, the goal is not to provide equal amounts of the best possible health care to everyone. Instead, we accept wide disparities in access as long as a decent minimum level of care is available through hospital emergency rooms and government sponsored clinics. These compromises are driven not only by resource limitations but also by the practical realities of health care. It is possible with food, housing, education, and other similar necessities of life to distribute the basic social minimum in more or less equal increments through vouchers or by providing the service directly. The extraordinarily diverse nature of medical needs, however, means they cannot be met through any notion of equal or similar increments of service. Therefore, the only way to meet our humanitarian commitment to a decent level of health care is to provide guaranteed access to a comprehensive range of services, which we do through social insurance programs—Medicare and Medicaid. Because health related benefits are potentially limitless, however, insurance would not be affordable without constraints on what and how much is covered. This is the principal role of the medical necessity criterion, which is interpreted in a way that emphasizes the treatment of disease.

These features of health insurance are subject to change, however, as technical abilities, available resources, and structural aspects of medicine change. If these attributes change radically, so too may our concept of health care equality. The authors entertained these possibilities, but dismissed or minimized them too readily. To demonstrate that health care equality is not inherently limited to disease, I consider further the status of enhancements in current medical and insurance practices and whether this secondary status is inevitable.

**B. Treatment of Disease Versus Enhancement of Health**

For centuries, disease has been the defining concept of the sphere of medicine. Disease determines the goals, attitudes, techniques, and justification for what medicine is and does. However, this is not an absolute or unalterable condition, and it may be undergoing radical revision. Over the second half of the twentieth century, health, rather than disease, has emerged as a competing concept of equal importance that points in a somewhat different direction. Maintaining and improving health encompasses disease but is not limited to disease. Health promotion emphasizes disease prevention as well as correction.

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24. See Buchanan et al., supra note 1, at 123.
Alternative, more holistic, views of health underscore the possibility of achieving a sense of health even in the presence of unconquerable disease. Health also introduces a more generalized notion of well-being that allows medicine to enter other arenas of life, such as diet, exercise, and various sources of stress.25

These changes have been operative not only in notions of what doctors may permissibly do but also in respect to what insurance is obligated to cover under the concept of medical necessity. My own recent physical exam is a case in point. I had not had a physical in ten years, and, entering my mid forties, I wanted a thorough going over. First, it is notable that I had nothing wrong, yet my insurance covered the full cost. Based on prior experience, I expected a battery of tests, probes, and the like, which I received; but I was surprised to learn that this was incidental to what my visit was mainly about. The visit began with a long questionnaire about my general happiness; my job; my marriage; what I eat, drink, and smoke; how well I am sleeping; and how much I exercise. Anything I marked that was potentially troubling, my doctor raised in our lengthy conversation, which occupied about two-thirds of the checkup. This conversation convinced me to join a health club and to begin exercising regularly for the first time in my life. I now have more energy, I sleep better, and I do not use alcohol as much as I once did for stress reduction.

I think we would all agree that this is a model of good doctoring and that this type of service should be included in a mandatory package of health care benefits.26 Observe, however, that this service is only tangentially addressed to disease; more immediately it is directed in large part to health benefits achieved through enhancement. The physician increased my awareness of these issues, and my exercise is enhancing my previously good health as well as forestalling future illness.

However, if health insurance and medical practice encompass health


26. Norman Daniels objects that I fail to recognize that his normal functioning concept is broader than the traditional disease focus of medicine because his formulation also encompasses prevention and public health measures that modify social determinants of health. Letter from Norman Daniels, to the Participants of the University of San Diego School of Law Symposium, Genes and the Just Society (Feb. 2002) (on file with author). However, this very progression in the scope of what medicine undertakes makes my point that the proper domain of medicine has evolved, and likely will continue to evolve, as information and technologies develop.
enhancement, why does my health plan not pay for my health club membership? Does this not indicate that the disease model still prevails? Several responses come quickly to mind. First, the evolution is only partial and incomplete. Second, some health plans do cover health club membership or membership is sometimes paid for or subsidized by employers. Third, to the extent insurers continue to resist paying for exercise, this is likely for pragmatic reasons not for reasons of principle. Countless aspects of life influence health, and so it is not feasible for insurance to pay for all, or even most, beneficial interventions that promote health. If health club membership were allowed, what about mountain biking or downhill skiing? The slipperiness of these slopes (pun intended) is the main reason for limiting insurance coverage. The fact that these limits are articulated in terms of medical necessity or connection to disease is due more to the malleability of these concepts and their historical role in this realm than to fundamental principle.

This loose understanding of insurance helps to place in proper context the examples used by the authors to defend their position. They contrasted the following: (i) two equally short boys, one with growth hormone deficiency and the other without, and (ii) two equally shy adults, one with and one without a diagnosable psychiatric condition. They correctly observed that under current insurance practices, only the people whose condition is caused by disease or injury will be covered. Nevertheless, the authors read more significance into these somewhat selective examples than is warranted.

Whether these examples are prototypical or exceptional depends on how one frames the issue and from what point of view. There is no doubt that the disease concept strongly influences insurance coverage and medical practice. The issue is whether this is subject to evolutionary change or substantial supplementation. Viewed over time, the very fact that insurance covers any psychological counseling or any use of the human growth hormone shows some evolution in our insurance based concept of medical necessity. Whether this evolution finds its equilibrium at this particular compromise or whether coverage expands or contracts is determined by the practicalities of these particular conditions and so is likely to follow different routes for each example. At present, coverage of mental therapy appears to be splitting into two paths divided between organic versus behavioral causes and treatments. The bioengineered human growth hormone is extremely expensive and in somewhat short.

27. Buchanan et al., supra note 1, at 115–18.
28. Id. at 115–16; see also id. at 111.
29. See id. at 110–11.
supply; its proper use is still controversial and the long term effects uncertain; and parents can assert very strong demands. Therefore, physicians have, in a somewhat paternalistic manner, adopted very strict and objective criteria for when it is even permissible to use the hormone, and insurers have, for the most part, simply followed this medical practice. If costs decrease or controversy over proper use abates, these restrictions will probably loosen.

Even currently, the disease concept does not exert nearly the same influence in other areas of medicine and insurance. I can easily have my doctor prescribe sleeping pills, covered by insurance, merely based on symptoms of insomnia, without regard to the underlying cause or any diagnosable disease. Many other medical conditions are treated based purely or primarily on symptoms rather than etiology. Common examples include obesity, elevated cholesterol, and high blood pressure. In the purely psychological realm, although it is controversial to prescribe Prozac™ for general mood improvement, this increasingly is being done and paid for by insurance, as it was for Valium®, using malleable mental diagnoses that are clearly unrelated to any specific psychological etiology. Some insurance covers, and some does not, in vitro fertilization for infertile couples, but the disagreement is fundamentally not about whether infertility is abnormal or whether it results from some other disease condition. Instead, coverage variations result from concerns over the cost of the procedure and whether the concentrated high demand for this coverage undermines the ability to pool and spread these costs—what economists refer to as “adverse selection.” Similar points apply to contraception and Viagra®.30 Arguments for and against covering these services may be framed in terms of disease, abnormality, and the like, for those remain the operative concepts; but the pattern of results reached does not consistently match any principled understanding of these concepts. Rather, this pattern is driven by other, more pragmatic considerations rooted in the institutional structure and economics of insurance.

In sum, health insurance covers what doctors do, up to a limit; and doctors do what is technically feasible and professionally acceptable in order to promote health and well-being. Disease has been the dominant conceptual guide to insurance because, in earlier decades, medical

practice followed the disease model. But as medical practice and concepts have evolved, so has insurance, subject to practical limitations of maintaining affordable insurance. Disease based concepts of insurance coverage contain inherent limitations that help confine insurance to more easily defined and administered boundaries. Health and wellness do not and so result in a jagged boundary, defined inconsistently from one case to the next. This is nicely illustrated by the following satirical explanation of why happiness (not its opposite) might easily be considered a psychiatric disorder: “[H]appiness meets all reasonable criteria for a psychiatric disorder. It is statistically abnormal [and] consists of a discrete cluster of symptoms . . . .”31

[H]appiness is usually characterized by a positive mood, sometimes described as “elation” or “joy,” although this may be relatively absent in the milder happy states, sometimes termed “contentment.” . . . The behavioral components of happiness . . . suggest that happy people are often carefree, impulsive, and unpredictable in their actions . . . including a high frequency of recreational interpersonal contacts and prosocial actions towards others identified as less happy . . . .

. . . There is excellent experimental evidence that happy people are irrational . . . . Happy people have been shown to exhibit various biases of judgment that prevent them from acquiring a realistic understanding of their physical and social environment . . . .

. . . Acceptance of these arguments leads to the obvious conclusion that happiness should be included in future taxonomies of mental illness . . . . I humbly suggest that the term ‘happiness’ be replaced by the more formal description major affective disorder, pleasant type, in the interests of scientific precision and in the hope of reducing any possible diagnostic ambiguities.32

C. Normal Species Functioning

Against this backdrop, how should we view the vast potential for genetic enhancement? I am not convinced that the primary guide should be whether a particular genetic technology responds to what we now conceive of as a disease or abnormality. It is too easy to think of compelling, contrary examples. Suppose, for instance, that genes could be altered to allow people to feel fully rested and refreshed with only half as much sleep, thereby extending effective waking time by four hours a day. The need for sleep is a natural biological limitation, so a disease model would not include this enhancement, yet the enhancement would have vast potential for increasing abilities, opportunities, and life experiences. These authors presumably would consider this as a possible exceptional case that justifies departure from their disease based equality framework.

32. Id. at 96–97.
But whether it should be an exception or part of the rule turns simply on how many such cases one can expect, and the authors invited us to think imaginatively. Even viewed as exceptional, resolving this and countless other possibilities requires an appeal to principles and concepts more fundamental than normal species functioning, which indicates that this concept no longer will be a reliable guide.

There are a series of additional reasons I am not convinced that it will make sense to adhere to the normal species functioning guide in an era of vastly expanded genetic enhancement. Space does not permit full development, but I will briefly outline them. First, even if the disease model remains dominant, the vast expansion of genetic technologies is almost certain to alter society’s sense of what is normal, and therefore what is a disease. Over the course of the twentieth century, the range of normalcy for many medical measures and conditions has shifted in sync with external—nonmedical—social developments, including height, weight, and the length of life. Thus, what is now considered clinically significant obesity or a shortened life span is considerably different than a century ago.33 Medicine is, thankfully, not wedded to an unalterable concept of its proper domain.

The aspect of Daniels’s prescription that is in conflict with this view is his stress on species normality.34 Were we to think simply in terms of normal functioning, then the shift in biological and social norms would encompass technologies that now are thought of as enhancements but in the future may well be viewed as directed toward biological abnormalities.35 This is especially likely after several generations of germ line enhancements. I do not see in principles of distributive justice the limitation that we consider only characteristics of the species in its natural state. Normalcy may be the proper guide but normalcy is distinct

33. See generally James O. Hill & John C. Peters, Environmental Contributions to the Obesity Epidemic, 280 SCIENCE 1371 (1998); Gary Taubes, As Obesity Rates Rise, Experts Struggle to Explain Why, 280 SCIENCE 1367 (1998). These types of objective measures are also culturally contingent even within a given time frame. For instance, the body temperature considered normal varies by as much as a degree or two among Western industrialized countries. See George J. Annas and Frances H. Miller, The Empire of Death: How Culture and Economics Affect Informed Consent in the U.S., the U.K., and Japan, 20 AM. J.L. & MED. 357, 360 (1994). Similarly, I suspect, but I do not really know for sure, that the level of cholesterol considered clinically troubling likely varies from one medical system to another.

34. See BUCHANAN ET AL., supra note 1, at 73–75, 121.

from naturalness, as the authors noted in chapter 3 of the book.\textsuperscript{36} This point is also consistent with their concern that genetic enhancement may aggravate disability discrimination.\textsuperscript{37}

Finally, even if genetic enhancements were excluded from the domain of distributive justice that applies to the sphere of medicine, we must also consider how we would regard enhancements under other spheres or, indeed, if genetics would become a new sphere of its own. Without the current technologies of modern society, we would have no concept of entitlement to transportation, and entitlement to welfare assistance would make no sense without a monetary system. Genetics can be expected to have an equally transformative impact on society. Therefore, we must consider whether, apart from medicine or any existing sphere, there will arise a sense of entitlement to genetic services. If so, surely genetic enhancements will be included in the mix because disease is a limitation imposed only in the sphere of medicine. Even if this new sphere does not arise, genetic enhancements, such as some of those the authors posit,\textsuperscript{38} might fall within the sphere of education. Observe how, over the space of only a decade, we have come to the view that using computers in the primary grades is essential to providing an adequate range of future opportunities.

\textbf{IV. CONCLUSION}

I am fully convinced by the authors’ explanation that there is a deeply pragmatic dimension to moral intuitions.\textsuperscript{39} We naturally intuit only the range of options that are feasible and for which we have experience. In the past, large scale improvement of baseline human traits was not possible and still may never be feasible or become commonplace. However, if this does come about, then surely our existing intuitions will shift concerning the moral significance of the boundary between treatment and enhancement. This does not mean that our intuitions are fickle or are a poor guide. Instead, this forces us to think about the deeper moral principles that underlie these intuitions. Doing so leads me to conclude that the goal of distributive justice should be to achieve as much equality of opportunity as is technically feasible without compromising other important social and ethical demands.

For now, and within medicine, normal species functioning serves as a reasonably reliable proxy for operationalizing this version of medical equality. But when we begin to open our minds to the full potential of

\begin{footnotesize}
\begin{enumerate}
\item  See \textit{BUCHANAN ET AL.}, \textit{supra} note 1, at 74.
\item  See \textit{id.} at 107.
\item  See \textit{id.} at 152–53.
\item  See \textit{id.} at 123.
\end{enumerate}
\end{footnotesize}
genetics, it is easy to conceive of a time when this will no longer be the case. These authors did a very good job helping us think about what these conditions may look like. My only criticism is that they struggle too hard to hold onto an older notion of the goals of medicine and so are too reluctant to let this evolution occur.