

Genetic Interventions: (Yet) Another Challenge to Allocating Health Care

ARTI K. RAI*

TABLE OF CONTENTS

I.	SOME BACKGROUND ON RESOURCE ALLOCATION	658
II.	OVERINCLUSIVENESS	661
III.	UNDERINCLUSIVENESS: WHY EXCLUDE ENHANCEMENTS?	662
IV.	WHERE DO WE GO FROM HERE?	664

*From Chance to Choice: Genetics and Justice*¹ is a highly compelling and thoughtful work on an important issue. Some of the best minds in bioethics, each of whom writes from a distinct perspective, have come together to produce it.² Its publication is quite timely, as we are already beginning to see a raft of biomedical interventions based on genetic and genomic research.³

* Assistant Professor, University of Pennsylvania Law School.

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

2. The authors of the book are Allen Buchanan, Dan W. Brock, Norman Daniels, and Daniel Wikler.

3. Thus far, most of the clinically viable interventions have been drug therapies and diagnostic tests based on genetics research. See generally Arti K. Rai, *The Information Revolution Reaches Pharmaceuticals: Balancing Innovation Incentives, Cost, and Access in the Post-Genomics Era*, 2001 U. ILL. L. REV. 173 (2001).

Much of the existing literature on genetic intervention addresses questions of discrimination or reproductive decisionmaking. Although this book discusses those questions,⁴ it takes as its major focus an issue that is perhaps even more vexing—the issue of how we should, from the standpoint of distributive justice, allocate genetic interventions. In other words, given the wide range of genetic interventions that may become available, how should we divide such interventions? Implicit in this problem is the reality that scarcity will prevent individuals from having access to all genetic interventions that would be of benefit to them. In this brief Essay, I take issue with some of the proposals that the authors put forward in chapters 3 and 4, specifically their argument that distributing genetic interventions—and, more generally, health care⁵—in a manner that restores individuals to normal, or “species typical,” functioning will preserve equality of opportunity and hence respond adequately to our distributive justice dilemmas.⁶

I. SOME BACKGROUND ON RESOURCE ALLOCATION

Distributive justice concerns have long pervaded health care. In the early 1980s, well before the advent of most therapies based on genetic research, a Presidential Bioethics Advisory Commission issued a series of comprehensive reports on the question of how to respond adequately to distributive justice concerns.⁷ Although the Commission’s members were divided on many issues, one theme of agreement was that all individuals should receive care that is “adequate”⁸ or meets some sort of “decent minimum.”⁹ Indeed, most commentators on health care

4. See BUCHANAN ET AL., *supra* note 1, at 27–60 (discussing discrimination); *id.* at 204–57 (discussing reproductive decisionmaking).

5. Genetic interventions are clearly part of health care more generally. They simply represent interventions that emerge from a different mode of investigation than other health care. For example, in the case of many proteins that serve as drugs, the very same protein could be manufactured either through genetic recombinant DNA techniques or through nongenetic techniques that extract and purify the naturally occurring protein. Although there is no reason—at least from the standpoint of justice—to distinguish genetics-based health care from other health care, what the authors rightly recognize is that the genetically-oriented mode of investigation is emerging as the dominant paradigm in health care research and delivery. See *id.* at 16. They also recognize that the expense and scope of genetic interventions that may become available will further increase the tension between access and cost. See *id.* at 96–97, 99.

6. *Id.* at 73–75, 109.

7. See, e.g., 1 PRESIDENT’S COMM’N FOR THE STUDY OF ETHICAL PROBLEMS IN MED. & BIOMED. & BEHAVIORAL RESEARCH, SECURING ACCESS TO HEALTH CARE: THE ETHICAL IMPLICATIONS OF DIFFERENCES IN THE AVAILABILITY OF HEALTH SERVICES (1983).

8. *Id.* at 3–6, 18–47.

9. Allan Gibbard, *The Prospective Pareto Principle and Equity of Access to Health Care*, in 2 PRESIDENT’S COMM’N FOR THE STUDY OF ETHICAL PROBLEMS IN MED.

resource allocation dilemmas tend to agree on the adequate care standard.¹⁰ The adequate care standard can be justified from the standpoint of several different ethical perspectives. In their previous works, two authors of this book, Allen Buchanan and Norman Daniels, have justified the standard in two quite different ways. In Buchanan's view, alleviating the misery caused by lack of adequate health care is an obligation of beneficence that can, and should, be enforced through collective contribution to the provision of health care.¹¹ By contrast, from Daniels's perspective, which is highly influenced by the work of John Rawls,¹² society must provide adequate health care services in order to secure for its citizens a "normal opportunity range,"¹³ and hence, fair equality of opportunity.¹⁴

While Buchanan's account justifies adequate care, it does not provide a mechanism for defining the content of such care.¹⁵ Daniels' account is more robust in that it provides not only justification but also content. Perhaps not surprisingly then, the authors adopt the equality of opportunity account¹⁶ in determining what genetic interventions society should provide to all individuals. However, as they point out, equality of opportunity is a concept that is susceptible to a number of different interpretations.¹⁷ Equality of opportunity could be seen as simply requiring the elimination of barriers to opportunity for persons of similar

& BIOMED. & BEHAVIORAL RESEARCH, SECURING ACCESS TO HEALTH CARE: THE ETHICAL IMPLICATIONS OF DIFFERENCES IN THE AVAILABILITY OF HEALTH SERVICES 153 (1983) [hereinafter 2 SECURING ACCESS]; David Gauthier, *Unequal Need: A Problem of Equity in Access to Health Care*, in 2 SECURING ACCESS, *supra*, at 179; Allen Buchanan, *The Right to a Decent Minimum of Health Care*, in 2 SECURING ACCESS, *supra*, at 207.

10. TOM L. BEAUCHAMP & JAMES F. CHILDRRESS, PRINCIPLES OF BIOMEDICAL ETHICS 356 (4th ed. 1994) (noting that the idea of an individual right to a decent minimum of health care could be a point of "compromise among libertarians, utilitarians, communitarians, and egalitarians").

11. See generally Allen E. Buchanan, *The Right to a Decent Minimum of Health Care*, 13 PHIL. & PUB. AFF. 55 (1984) (suggesting that the provision of adequate health care is a public good, to which all citizens should be required to contribute).

12. Rawls argues that individuals under a veil of ignorance as to their personal characteristics (for example, social status or natural distribution of abilities) would contract to form a society with institutions that guaranteed fair equality of opportunity. JOHN RAWLS, A THEORY OF JUSTICE 302-03 (1971).

13. NORMAN DANIELS, JUST HEALTH CARE 39-42 (1985).

14. See *id.* at 36-58.

15. In fact, Buchanan has explicitly noted that his beneficence-based approach will not yield answers as to content. He has argued that, as contrasted with rights, duties of beneficence are "not precisely delineated." Buchanan, *supra* note 11, at 77.

16. See BUCHANAN ET AL., *supra* note 1, at 63-65.

17. *Id.* at 65.

talents and abilities.¹⁸ Alternatively, it could be seen as requiring not only the elimination of barriers but also affirmative intervention to eliminate the effects of “bad luck.”¹⁹ One version of the bad luck approach, which the authors term the “social structural” view, requires redressing the bad luck that results from unjust social structures.²⁰ Another, more expansive version, which Thomas Scanlon terms the “brute luck” view,²¹ requires redressing *all* bad luck, whether its origin is social or natural.²²

The authors adopt an account of equality of opportunity that falls somewhere between the social structural and brute luck approaches.²³ The authors’ account, which Daniels has developed in detail in previous work (and which the authors argue is most congruent with the Rawlsian approach),²⁴ holds that justice requires counteracting those conditions, whether natural or social, that prevent one from being a “normal competitor” for desirable social position.²⁵ However, according to the authors, conditions that prevent such normal competition are generally limited to those inequalities that could be considered diseases.²⁶ The authors argue that the brute luck alternative, which would focus not simply on disease but on all inequalities,²⁷ would be highly inefficient because it would insist on an equalizing of the distribution of natural talents and skills.²⁸ In rejecting the brute luck approach, the authors endorse a conception of justice that focuses on treating disease²⁹ and thus support “a qualified and limited defense of the treatment/enhancement distinction.”³⁰

The problem with the authors’ account of how health care distribution should be structured to address equality of opportunity concerns is that it is both overinclusive and underinclusive. On the one hand, from the standpoint of efficiency, the authors’ account does not adequately limit the services society needs to provide all individuals. On the other hand, the account draws a distinction between disease and other conditions—and, correspondingly, between treatment and enhancement—that is, by

18. *Id.*

19. *Id.*

20. *See id.* at 66–67.

21. *Id.* at 67 (citing Thomas M. Scanlon, *A Good Start: Reply to Roemer*, BOSTON REV., No. 20(2) 1989, at 8–9).

22. *See id.* at 67–68.

23. *See id.* at 73.

24. *See id.* at 73–74.

25. *See id.* at 73–75.

26. *See id.* at 74.

27. *See id.* at 67, 75.

28. *See id.* at 75, 128.

29. *See id.* at 74.

30. *Id.* at 109.

the authors' own admission, slippery at best.³¹ Moreover, despite their significant reservations about the value of the distinction between treatment and enhancement,³² the authors use it to exclude enhancements that might well further equality of opportunity more directly than many so-called treatments.³³

II. OVERINCLUSIVENESS

Consider first the manner in which the authors' account is overinclusive. Given scarcity, the account is overinclusive even if we do not consider genetic interventions. Many of the expensive interventions that our society cannot afford for all individuals—neonatal intensive care for extremely premature newborns, organ transplantation, and intensive treatment for individuals in the last stages of life—could be seen as restoring normal functioning. Even in our current health care economy, in which genetics-based interventions are just beginning to emerge, we face a situation in which we spend far more per capita on health care than any other industrialized country and nonetheless manage to leave uninsured a large number of citizens. The issue of scarcity receives little treatment in the authors' discussion. They address scarcity only in their observation that limited resources will “require[] that we meet the most important needs first, leaving people to fend for themselves in meeting less important medical needs.”³⁴ The authors fail to elaborate on how we should go about developing the requisite hierarchy of needs. For example, is using a given sum of money to extend the life of a cancer patient by a few years more or less important than using the same sum of money to provide free vaccinations to a group of schoolchildren? Notably, in previous work, Daniels has acknowledged the inability of the normal functioning framework to serve as a tool for developing a hierarchy of needs. He has admitted that the normal functioning approach “does not tell us which opportunities to protect when scarcity prevents us from equally protecting everyone's.”³⁵

With genetics-based therapies, the scarcity dilemma is likely to

31. *See id.* at 71–72, 119.

32. *See id.* at 108, 110.

33. *See id.* at 129.

34. *Id.* at 120.

35. Norman Daniels, *Liberalism and Medical Ethics*, HASTINGS CENTER REP. Nov.–Dec. 1992, at 41, 42. In some of his work, Daniels has advocated the alternative of a procedural approach towards scarcity concerns. *See infra* note 53.

become ever more formidable. As we develop new genetics-based interventions, many previously untreatable conditions will become treatable. As a consequence, we will have the technical capacity to restore many more individuals to normal functioning for longer periods of time. However, using this technical capacity will entail large costs, particularly as the demographic distribution of the population shifts towards the older end of the spectrum.

III. UNDERINCLUSIVENESS: WHY EXCLUDE ENHANCEMENTS?

While the authors' account of adequate care is overinclusive in its failure to address scarcity issues, it is underinclusive in its exclusion of treatments for conditions that are not diseases. To be sure, the authors' general exclusion of nondisease conditions comes with many caveats. For instance, the authors admit that the distinction between what constitutes a disease and what does not is a slippery one.³⁶ They give the example of two short individuals, one who is short by virtue of a growth hormone deficiency caused by a brain tumor, and the other who is short because his parents are short.³⁷ Conventionally, the individual whose shortness was caused by the brain tumor would be considered to have a disease while the other individual would simply be considered short.³⁸ In both cases, however, height, or lack thereof, is a function of one's genes.³⁹ Thus, it could plausibly be argued that the two cases should be treated similarly for purposes of insurance coverage.⁴⁰

The authors also note that what represents a disease may change if, through genetic enhancement of normal human function, we revise upward our conception of normal function.⁴¹ For example, if most individuals were to receive a genetic enhancement that allowed them to be immune to the common cold, then lack of immunity to the common cold could come to be seen as a disease.⁴² The authors also allow that a commitment to equality of opportunity might require medical intervention to counteract natural inequalities that are not adverse departures from normal species functioning but that nonetheless seriously limit an individual's opportunities.⁴³ In fact, the authors even indicate that "we [c]ould come to reclassify as a disease any correctable genetic condition that has a significant adverse impact on equality, because we would

36. See BUCHANAN ET AL., *supra* note 1, at 71–72, 119.

37. *Id.* at 115.

38. *See id.* at 118.

39. *See id.* at 116–17.

40. *See id.*

41. *Id.* at 98–99.

42. *See id.* at 99.

43. *Id.* at 74.

come to regard it as an adverse departure from normal functioning.”⁴⁴

Despite all of these concessions, the authors persist in their claim that the scope of adequate care should be limited to diseases and treatments for those diseases.⁴⁵ But their loyalty to the category of disease is misguided. If conditions that have a “significant adverse impact on equality”⁴⁶ can be reclassified as diseases, then the distinction between disease and nondisease simply serves to detract attention from the central issue of equality. Rather than engaging in distracting semantic exercises, we should instead focus directly on equality in the first instance. We could, for example, rank all conditions directly on an “effect on equality of opportunity” metric. If a nondisease condition had a more profound effect on equality of opportunity than a disease, it would be addressed before the disease that had a less profound effect. Thus, for instance, if an individual could receive either physical therapy treatment for an old knee injury or an enhancement that would improve her below average—but nonetheless within the “nondiseased” region of the bell curve—analytical ability by ten percent,⁴⁷ the enhancement might win out over the treatment.

In defending their focus on disease, the authors argue that it is unlikely that there are a large number of conditions that do not qualify as diseases that nonetheless seriously limit equality of opportunity.⁴⁸ However, if conditions that seriously impact equality of opportunity can be reclassified as diseases, then that argument is largely true simply as a matter of definition. Thus, in the future, certain limits on cognitive ability that are currently considered normal—poor memory, limited analytical ability, and deficient mathematical ability—might well be considered diseases. The authors’ pragmatic defense of the distinction between treatment and enhancement, that it provides some limitation on medical spending, is also unpersuasive.⁴⁹ Any distinction, no matter how arbitrary, can serve to limit spending. For example, drawing an arbitrary distinction between illnesses that affect organs other than the brain and illnesses that affect the brain, and excluding coverage of the latter, would also limit spending. Yet it would not be defensible as a matter of justice.

44. *Id.* at 101.

45. *See id.* at 17, 129.

46. *Id.* at 101.

47. The usual caveats regarding our inability to intervene with such precision apply.

48. BUCHANAN ET AL., *supra* note 1, at 74.

49. *See id.* at 112–13.

IV. WHERE DO WE GO FROM HERE?

In some respects, attacking any proposed system for health care distribution is far too easy. The distributive justice issues raised by health care are sufficiently complex that all proposals will have significant drawbacks. Those who criticize, as I have done, are therefore obliged to offer suggestions that have fewer drawbacks than the objects of their attack. In what follows, I offer a few such suggestions.

As a logical matter, if we are serious about equality of opportunity, then we should be concerned not only with diseases but with *any* limitations on opportunity that could be alleviated through medical intervention. In other words, we should adopt something closer to the brute luck approach⁵⁰ than to the authors' interpretation of equality of opportunity.⁵¹ The obvious difficulty with this logically consistent approach is that it provides no resource limitation at all. As the authors rightly note, the brute luck approach is difficult to reconcile with any reasonable concern about efficiency.⁵²

An alternative approach that is frequently used to resolve distributive justice dilemmas is the democratic political process. In theory, the democratic political process provides a procedurally just way of mediating different substantive conceptions of equality. Thus we could decide to have either a politically determined definition of adequate care or a political determination of the level of subsidy individuals should receive to buy health care.⁵³ But democratic political procedures are hardly a panacea, especially if we are concerned in any way about normative standards such as equality of opportunity. For example, the political process might produce a minimum that was so unsatisfactory that a majority of the population would use their own funds to buy out of the minimum. In that case, we would have reason to be concerned that the minimum did not sufficiently protect any plausible conception of equality of opportunity. Thus, it would be important to ensure that the minimum was sufficiently high that a large percentage of people were not buying their way out.

Of course, equality of opportunity can be furthered not simply by

50. *See id.* at 67.

51. *See id.* at 73–75.

52. *See id.* at 73–77.

53. *See generally* Arti Kaur Rai, *Rationing Through Choice: A New Approach to Cost-Effectiveness Analysis in Health Care*, 72 *IND. L.J.* 1015 (1997). Indeed, some of Norman Daniels's work has advocated a political approach towards distributive justice in health care. *See* Norman Daniels & James Sabin, *Limits to Health Care: Fair Procedures, Democratic Deliberation, and the Legitimacy Problems for Insurers*, 26 *PHIL. & PUB. AFF.* 303 (1997).

ensuring a robust floor of adequate care but also by placing a ceiling on the care that individuals can buy. Indeed, the authors note that if access to certain “enhancements according to ability to pay exacerbated existing unjust inequalities, justice might require . . . that they . . . not be available at all.”⁵⁴ Flatly limiting the purchase of enhancements would, however, significantly reduce autonomy. In addition, flat limitations on certain types of highly desirable enhancements would probably not be administrable, and the likelihood of black markets and other limit-defying behavior would be high.

Although a ban on enhancements is probably not desirable, regulation could be used to dissuade individuals from pursuing certain types of enhancement. In thinking of how government policy should treat enhancement, it is important to distinguish between two different types. One type is the purely positional enhancement.⁵⁵ A good example of a purely positional enhancement is increased height. Height is valuable for an individual only in relation to the height of others. Studies have shown, for example, that taller people, particularly taller men, are perceived as more attractive than shorter people and thus tend to be more successful. But greater height produces no net gain for the society as a whole. It matters little for social progress whether the average height of the human species is four feet or ten feet.⁵⁶

In contrast with purely positional enhancements, there are some enhancements that have both positional and absolute value. These also tend to be enhancements with respect to which an enhancement race would produce positive externalities. An example of such an enhancement is intelligence. Arguably, if the human species were ten percent more intelligent, on average, than it currently is, we would all be better off. Indeed, under Rawls’s difference principle,⁵⁷ inequalities in intelligence should be accepted to the extent that these differences redound to the benefit of the least well off.⁵⁸

54. BUCHANAN ET AL., *supra* note 1, at 98.

55. *See id.* at 155.

56. *See* Peter H. Huang, *Herd Behavior in Designer Genes*, 34 WAKE FOREST L. REV. 639, 651–52 (1999) (discussing body size as a positional trait without associated positive externalities).

57. *See* BUCHANAN ET AL., *supra* note 1, at 68 (discussing the difference principle).

58. *See id.* at 128, 132. Inequalities in intelligence are likely to redound to the benefit of the least well off because greater intelligence tends to produce greater wealth. Greater wealth can redound to the benefit of the least well off either through the market, in the form of job creation, or through government regulation, in the form of wealth transfers.

To be sure, there is no bright line distinction between purely positional enhancements and enhancements that produce positive externalities. For example, it is not clear how enhancements to athletic prowess should be classified. It could be argued that athletic prowess is purely positional. Alternatively, it could be argued that athletic prowess has absolute value: an across-the-board increase in athletic prowess that yielded no positional advantage might nonetheless produce positive externalities in the form of greater pleasure to spectators or utility for the participants themselves. Discussion of any particular enhancement should therefore focus on where the enhancement falls on the spectrum between absolute value and purely positional value.

Government regulation should take a different approach to purely positional enhancements than it does to enhancements that produce positive externalities. For example, high taxes could be imposed on purely positional enhancements. By contrast, with respect to enhancements that produce positive externalities, there could be lower taxation, or perhaps even subsidization. Educational interventions might represent another approach. We could have educational campaigns dissuading individuals from seeking artificial enhancements in height or other purely positional attributes.⁵⁹ These campaigns might focus on the risks, both to human health and to the social fabric, associated with such enhancements.⁶⁰ The effect of such campaigns should not be underestimated. For example, regulatory efforts to educate consumers about the negative health effects of smoking have had an impact in reducing smoking levels.⁶¹

Finally, it bears mention that certain preventive genetic interventions have the potential to reduce rather than increase the cost of health care. For example, to the extent that somatic or germ line intervention can prevent certain diseases from occurring in the first instance, the cost of treatment for the disease can be avoided. Government policy should strongly encourage these preventive measures by including them in the basic care package received by all individuals. We could also encourage the purchase of such preventive care by eliminating public funding for the treatment of diseases that could have been alleviated, or even altogether averted, by the use of timely preventive care. Whether such measures should be forced on individuals who are reluctant to take them on their own behalf or on behalf of their current or future children poses

59. See Huang, *supra* note 56, at 655 (discussing taxation and educational approaches).

60. Of course, to the extent an enhancement created a risk substantially in excess of any conceivable benefit, regulatory agencies such as the Food and Drug Administration would be obliged under current law to ban such enhancements.

61. See, e.g., Lawrence Lessig, *The Regulation of Social Meaning*, 62 U. CHI. L. REV. 943, 1025–1034 (1995).

an interesting question.⁶² Although coercion with respect to risky or highly invasive interventions would pose too great a challenge to autonomy, other interventions might be of minimal risk and potentially of great benefit. Indeed, it is conceivable that some interventions might come to be seen as analogous to vaccinations, which for reasons of safeguarding the public health or promoting the best interests of minors, the state can currently require.

62. See BUCHANAN ET AL., *supra* note 1, at 77–78.

