Introduction

In honor of the publication of *From Chance to Choice: Genetics and Justice*, the University of San Diego School of Law held a two day symposium on the book. The essays in this collection emerge from that symposium. Some of the essays respond to the authors' arguments as a whole or to specific aspects of these arguments. Other essays push beyond the limits of the book, suggesting problems not raised by the authors or otherwise challenging the book's presupposition that genetic interventions will transform our society.

First, Arti K. Rai, Assistant Professor at the University of Pennsylvania Law School, responds to chapters 3 and 4. In these chapters, the authors argue that distributing genetic interventions in a manner that restores individuals to normal functioning will preserve equality of opportunity and thus will adequately address the distributive justice dilemmas raised by such interventions. Moreover, according to the authors, the conditions that prevent such normal functioning are generally limited to inequalities that could be considered diseases. Thus, according to the authors, a treatment versus enhancement distinction is a plausible mechanism for allocating genetic intervention resources.

In *Genetic Interventions: (Yet) Another Challenge to Allocating Health Care*, Rai suggests that the treatment versus enhancement approach is both underinclusive and overinclusive. The authors' approach is overinclusive, reasons Professor Rai, because it does not adequately limit the services society needs to provide all individuals; that is to say, it fails to account for the scarcity dilemma. By the same token, the exclusion of interventions for conditions that are not diseases is underinclusive; enhancements that might further equality of opportunity are excluded simply because they are not treatments for recognized diseases. The authors anticipate that the concept of disease will change over time and ultimately use the disease concept to encompass all correctable genetic conditions that adversely impact equality. This implies, according to Rai, that the distinction between

treatment and enhancement is purely semantic. Loyalty to the distinction should be abandoned and the underlying issue of equality should be the focus of concern. After critiquing the method of resource allocation set forth by the authors, Professor Rai sets forth several alternative suggestions, noting the possible drawbacks of each.

Like Professor Rai, Professor Mark A. Hall of the Wake Forest University School of Law and School of Medicine is concerned with the authors' proposed distinction between treatments and enhancements. In *Genetic Enhancement, Distributive Justice, and the Goals of Medicine*, Professor Hall focuses on chapter 4 of the book. Hall identifies this chapter, which distinguishes between treatment of disease and enhancement of genetic traits, as the one in which the authors appear to have the greatest ideological disagreement. Professor Hall notes that many of the moral and ethical issues surrounding the field of genetics tend to revolve around the treatment versus enhancement distinction.

Professor Hall notes that what is currently normal may not always be considered so. In examining the concept of distributive justice, which focuses on achieving balance by closing gaps in equality, Hall argues that a compromise must be made between holding certain people back in violation of their liberties and exceeding what is practical in order to elevate those in need. Hall concludes 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 example, Hall identifies a shift in the later part of the twentieth century from the treatment and prevention of disease to increased attention on a more wholistic concept of health and well-being. This change in focus has resulted in an evolving concept of what is medically necessary for health insurance to cover. Likewise, genetic engineering has a tremendous potential to change our view of what is normal and what are the proper goals of medicine. Professor Hall concludes that the normal species functioning model may be the best current guide, but its application by the authors fails to consider the very real possibility that the goals of medicine may change dramatically.

In addition to challenging our assumptions regarding distributive justice, genetics puts new pressures on individual and institutional choice. *From Chance to Choice: Genetics and Justice* introduces ethical principles designed to guide individuals and institutions through genetics issues. The authors took a middle road between the extreme paths of the public health model, designed to improve the genetic health of society, and the personal services model, which emphasizes individual choice. In *Punishing Reproductive Choices in the Name of Liberal Genetics*, Alexander Morgan Capron, Professor of Equity, Professor of Medicine, and Co-Director of the Pacific Center for Health Policy and Ethics at the

University of Southern California, praises the authors for carefully structuring their arguments and thoroughly exploring the implications of different concepts of justice for genetic interventions. Capron is ultimately unpersuaded, however, by the authors' conclusions because of the way in which their moral reasoning applies to social policies.

To critique the authors' ethical principles, Capron evaluates their discussion in chapter 6 about reproductive freedom and its application to genetic testing, counseling, and manipulation. Reproductive freedom cannot be attached to an individual, according to Capron. Because this freedom involves the decision about whether to procreate at all, the act must encompass a reproducing couple. This lack of individual autonomy further complicates issues of reproductive freedom and decisions regarding genetic modification. Capron casts doubt on the authors' conclusion that parents are morally wrong in not taking steps to prevent overwhelming burdens to their children caused by genetic conditions. Capron's analysis questions whether the authors have stepped in an ironic quagmire by attempting to prevent the eugenic abuses of the past.

Janet Radcliffe Richards, Reader in Bioethics at University College London, examines the claim of the radical disability movement, discussed in chapter 7, that genetic technology must not be used to prevent or cure disability because this would imply that disabled people were of less worth than the able. The authors of *From Chance to Choice: Genetics and Justice* concede a great many of the radical campaigners' arguments, but claim that nevertheless the use of technology to cure or prevent disability can be justified without any denial of equal worth to the disabled.

Radcliffe Richards agrees with the authors' conclusion that genetic techniques should be used to prevent disability but, in *How Not to End Disability*, argues that their justification is inadequate. First, they do not sufficiently meet the radical argument that to try to prevent the existence of these people is to imply that they are of unequal worth, because they overlook an ambiguity in the idea of equal worth. Radcliffe Richards explains that the authors are right to claim that their view allows the disabled equal *intrinsic* worth, but detailed consideration of the radical ideas shows that the movement's distinctive concerns are with the lesser *instrumental* value of disabled people. The authors' claim does not meet this concern, and in fact their case *depends* on regarding disabled people as of lesser value in this and similar ways. Nevertheless, Radcliffe Richards argues, the radical disability movement's case still cannot be

made out, because the authors concede too much in allowing the radical claim that disability is largely a social construction. In fact, Radcliffe Richards argues, no amount of social reorganization can turn disabilities into abilities, or vice versa, and therefore by far the best way to end the disadvantages of disabled people is to prevent or cure disability itself, by whatever technological means are available.

In his critique, Richard J. Arneson, Professor of Philosophy at University of California San Diego, takes a more global and theoretical approach to the authors' thesis. In *Is Moral Theory Perplexed by New Genetic Technology?*, he claims that the authors exaggerated the extent to which the moral issues posed by advances in genetic knowledge are new and understated the resources of current moral theories to resolve these issues in an intuitively satisfactory manner. According to Arneson, this underestimation of current theory results from neglect of the consequentalist family of views (these assert that one morally ought always to do whatever will produce the best outcome). In this connection Arneson finds prioritarianism to be especially promising. Prioritarianism identifies the morally right action or policy with the one that maximizes a function of human well-being that prefers greater to lesser aggregate well-being but also gives priority to obtaining gains in well-being for the worse off. Arneson contrasts the prioritarian approach to the question, what is owed to the severely disabled, with the authors' discussion of what they claimed to be the new problem of the morality of inclusion. Arneson also compares the prioritarian approach to health care justice with the approach embraced by the authors—the Rawlsian fair equality of opportunity doctrine extended to include health care. The tentative conclusion reached is that the degree of moral perplexity induced by advances in genetic knowledge is less than the authors proposed.

Rebecca Dresser, Professor of Law and Ethics in Medicine at Washington University in St. Louis, seeks to further address two topics that were not fully addressed by the authors of *From Chance to Choice: Genetics and Justice.* In *The Ethics of Genetic Intervention: Human Research and Blurred Species Boundaries*, Dresser focuses primarily on ethical issues associated with researching genetic interventions and the effects of interspecies genetic studies that may blur the moral lines shaping our view of what is ethical genetic manipulation.

Dresser comments that genetic manipulation and germ line intervention in embryos will require parents to allow their children to undergo extended experimentation. Initial testing will likely be limited to extreme cases where children face poor quality of life and where conventional treatment techniques offer little hope for recovery or have risk factors equal to, or greater than, genetic manipulation. Accurate

analysis of the effectiveness of any procedure would require randomized clinical testing in order to separate the results of genetic intervention from environmental issues. Doing so could involve blind testing, requiring parents to undergo in vitro procedures, possibly receiving no genetic intervention as part of a control group. These complicated decisions are compounded by the fact that scientists do not currently have a standard of safety by which to evaluate potential clinical interventions.

Dresser also believes that the authors failed to confront the broader implications of genetic intervention for our perspective of distributive justice. While the authors focused on the concept of justice only as it applies to humans, Dresser indicates that the ability to alter the genetic makeup of an organism allows scientists to blur traditional species lines and raises accordant ethical concerns. How do we apply justice toward a blurred species? If we add cognitive abilities to the great apes, at what point do they become eligible for human-like treatment? Given our current definition of disease as "adverse departures from normal species functioning," how do we apply a concept of normality to a transgenetic species? Many questions remain unanswered, Dresser suggests.

Robert A. Bohrer, Professor of Law at California Western School of Law, invokes a theoretical approach similar to that used by the authors to address an issue that may arise as we gain a greater understanding of the human genome: employer discrimination based on genetic profiling for jobs involving toxic workplaces. In *A Rawlsian Approach to Solving the Problem of Genetic Discrimination in Toxic Workplaces*, Bohrer applies concepts from John Rawls's *A Theory of Justice* and examines workplace discrimination apart from existing laws, like the Americans with Disabilities Act. He presents a hypothetical situation: the risk of glioblastoma, a fatal form of brain cancer, increases drastically for persons with a certain genetic susceptibility when exposed to small amounts of benzene. An employer could save a considerable amount of money by not reducing the level of toxins in the workplace given that a majority of workers are not threatened by the present level—only a small percentage of potential employees would be likely to contract the fatal cancer.

Bohrer argues for the implementation of a Rawlsian pay-to-exclude system, when the appropriate ground rules are in place. Employers could require genetic profiling for a given susceptibility and could refuse to hire candidates with a high risk factor. Doing so would be beneficial

to the employee (not being placed in harm's way) as well as to the employer. However, Rawlsian analysis also dictates that employers pay into a central fund based on their realized savings from using genetic testing so that individuals denied employment could be compensated for their exclusion. This pay-to-exclude system would prevent employers from using tests to exclude in cases where the cost of exposure is low, would reduce the use of tests with questionable value, and would encourage employers to reduce exposure to rare toxins.

Rawls's theory is best applied when behind a veil of ignorance. Bohrer believes that the Human Genome Project is a prime example for such an analysis because we still know very little about the issues that will become known. By setting ground rules now, we have the ability to form the basis for ethical limits that are beneficial to society at large.

Michael H. Shapiro, Professor of Law at the University of Southern California, authors the last piece of the collection. Rather than critiquing the discussion in *From Chance to Choice: Genetics and Justice*, he expands upon the subject matter and offers additional insight on a host of moral, legal, and policy issues relating to human genetics. In *Does Technological Enhancement of Human Traits Threaten Human Equality and Democracy?*, Professor Shapiro explores the technical aspects of human genetics and relates these issues to legal and moral theories. He delves into the concept of equality and questions whether measuring equality is an appropriate means of evaluating moral and social justice. A brief discussion follows regarding the way that merit attribute enhancement might change the structure of our democratic institutions to conform to the type of plural voting system envisioned by John Stuart Mill. Potential constitutional issues are noted in addition to the possibility that the moral and policy issues surrounding human genetics will ultimately be debated within the legal system.

Shapiro proposes that several issues raised by the authors should be further analyzed. First, he believes the concepts of merit and desert should be further probed. Shapiro also believes a deeper concept of justice should be examined, including its links to equality and to the way in which all our basic values, including fairness, autonomy, and utility, bear on each other. Finally, he favors a more thorough examination of the potential withering of noncontingent bonds of duty and affection between persons. Professor Shapiro ultimately concludes that the most difficult aspect in determining how genetics will impact our value system is the ambiguity in the system itself. Advances in technology may undermine the assumptions that form the foundations of our current value system.

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