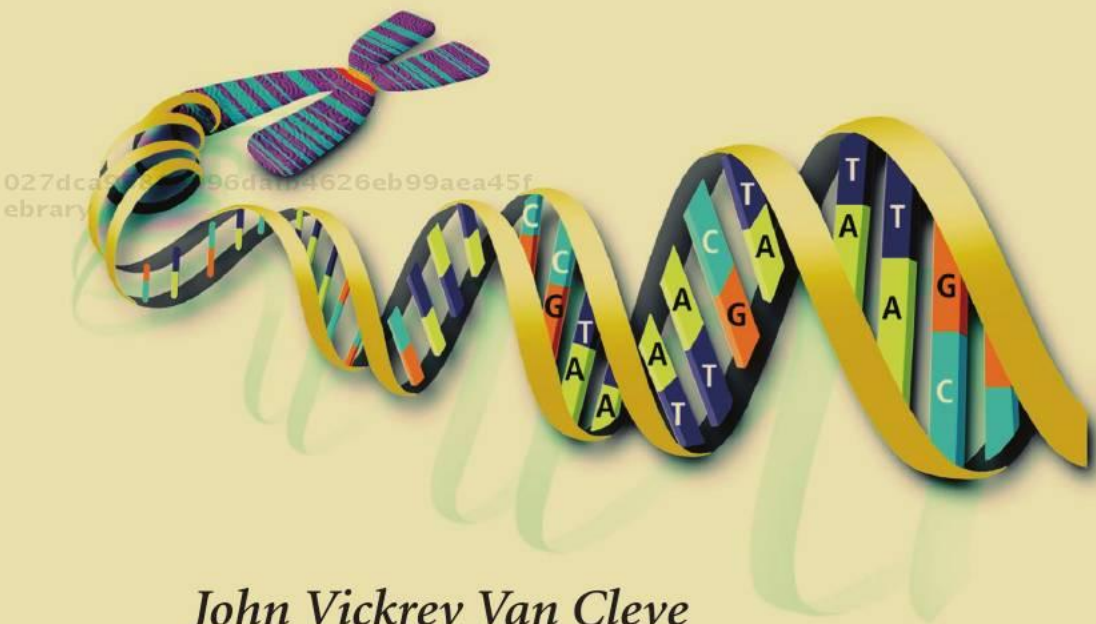


Genetics, Disability, and Deafness

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John Vickrey Van Cleve
Editor

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INTRODUCTION

Disability theorists have argued since the late-twentieth century that disability is a social construct and that cultural and political decisions, rather than biological characteristics, restrict their full and complete participation in society. Historian and activist Paul Longmore, for example, has written that “for the overwhelming majority [of disabled persons] prejudice is a far greater problem than any impairment; discrimination is a bigger obstacle than disability.”¹ Deaf people also have tried to shift the focus of public discussion from their personal physical attributes to society’s response to them. They have argued that deafness is not fundamentally different from ethnicity and should be viewed from the same perspective. The use of accessible language, either a signed language or a spoken language in written form, they continue, renders deafness an interesting human variation, one that should be cherished, respected, even preserved.² In these views, the “problems” encountered by people who are deaf or disabled are variable, socially constructed, and not inherent in their biological being.

The attitude of the general, nondisabled public is different. In the popular imagination, disability “promises an unmistakable and non-contingent correspondence between biology and the self,” as one author has noted.³ The even more radical view that biology is destiny is gaining adherents in the United States, fueled in part by the claims of evolutionary psychologists, who view individual realization and social interaction within a framework of supposed evolutionary selection of biologically determined behavioral traits.⁴ Louis Menand notes in the

first essay in this volume that even such behavioral attributes as anxiety or a taste for novelty recently have been ascribed to the effects of immutable genes rather than to complex human interactions within a specific cultural context. Current social arrangements, cultural habits, and public resource allocations are seen as timeless and essential to national well-being. In this popular view, then, improvement in the conditions of people with disabilities or deafness must come from rehabilitative technology, such as cochlear implants, or from changes in the genes that produce human variability.

The Human Genome Project and other large scientific projects have contributed to the popular interest in genetics and their influence on human variability, behavior, and development. Generally, attempts to find genetic “cures” for disabilities, or other conditions that some people believe are nonconforming or negative in their effects on human potential, are applauded as progressive wonders of the modern age. Yet their realization in practice has been complex and raises troubling questions, such as when, under which conditions—or whether at all—it is ethical to use in vitro fertilization to select an embryo with particular, desired genes, or to use prenatal diagnoses and abortion to deselect for other, undesirable, biological characteristics.

This volume, drawn from conference papers delivered at Gallaudet University in 2003, addresses these issues by bringing together essays from science and humanism, history and the present, to show the many ways that disability, deafness, and the new genetics can interact and what their interaction means for society. These questions are timely, as prenatal diagnosis of the most frequent form of genetic deafness, for example, is now easily accomplished. Indeed, in her study, “Deaf and Hearing Adults’ Attitudes toward Genetic Testing for Deafness,” Anna Middleton notes widely reported examples of couples attempting to use genetic knowledge and technology both to select for and against a gene that causes deafness.

The historical sections show how deafness and genetics have been linked in the past and how deaf people have addressed eugenic concerns, but they are also cautionary. The line between scientifically neutral genetics and politically motivated eugenics is neither easily drawn nor easily identified. John Schuchman’s essay on deaf people in Nazi Germany recounts what can happen when the state sponsors eugenics programs. Moreover, scientifically validated linkages between human behavior

and genes open the doors to genetic manipulation based on blatantly cultural preferences—such as gender, skin color, and height—which are neither consistent across cultures or time nor provably conducive to human well-being.

Several arguments reappear in many of these essays and tie them together into a meaningful whole. One is that “The true good is the different, not the same,” as Menand writes in “The Science of Human Nature and the Human Nature of Science.” In other words, most authors share the belief that human diversity is a valuable attribute, and they are skeptical of attempts to eliminate it through changes in the human genome. The complexity of even this general observation, however, can be seen in Mark Willis’s finely crafted discussion of his reaction to his own genetic makeup, “Not This Pig: Dignity, Imagination, and Informed Consent.” On the one hand, Willis sees his hereditary heart problems as a disease. He is a willing participant in studies to find ways to identify and eliminate the genetic abnormality that leads to the premature heart problems he confronts. On the other hand, he writes, “I do not experience vision loss as a disease. It is a different way of perceiving the world, and it is rich with its own sensory skills and sweet satisfactions.” Thus, he refuses to be involved, to give his “informed consent,” for genetic studies of the particular kind of blindness he has experienced.

The variability of disability—in physical expression, in cultural meaning, and as lived experience—leads to the most important argument to recur in nearly every essay: Choice and democratic values should control social approaches to disability and to the uses of genetic science and technology. The scientists, particularly Walter Nance, the most well-known student of deafness and heredity, tend to emphasize the role of personal choice and the importance of science in offering individuals knowledge from which they can fashion their own decisions about genetics and disability or deafness. Nance writes that “as long as decisions about issues such as marital choices or whether or not to use specific genetic technologies are made by fully competent, fully informed individuals, I’m willing to live with the consequences.” Michael Bérubé, by contrast, focuses more on public choices and public policy, arguing that “disability is always and everywhere a public issue.” Despite the different focus on where choice should be applied in considerations of genetics and disability, however, both the scientists and the humanists

writing for this volume would agree with Bérubé's concluding essay when he argues that disability should be considered "democratically." They also would agree, as emphasized by authors of the essays in the section titled "The Uses of Genetic Knowledge," that any "democratic deliberation" about disability requires "the voices of people with disabilities" to be involved.

These essays are offered, then, as a way to provide context and meaning to a public discussion of difference—its past, how it should be dealt with in the future, and what the role of genetic counseling and genetic manipulation might be as society thinks about disability and deafness and the public and private choices that need to be made in this age of genomics.

ACKNOWLEDGMENTS

Academic conferences require planning, creativity, attention to detail, and money. We were fortunate to have all these in abundance to put on "Genetics, Disability, and Deafness" under the auspices of the Gallaudet University Press Institute in the spring of 2003. I want to thank the other members of the conference planning committee—David Armstrong, Cathy Arnos, Derek Braun, Wendy Grande, Michael Karchmer, and Dan Wallace—for their commitment of time, creativity and good company. Some financial support was provided by the Dean of the Graduate School and Professional Studies at Gallaudet University, Tom Allen, and the members of the Gallaudet University Schaefer Professorship Committee. Paul Kelly, the Gallaudet University Vice President for Administration and Finance, provides the overall financial support necessary for the Gallaudet University Press Institute's operations and for the underwriting of the conferences it sponsors. Without his commitment, this conference could not have taken place. Finally, although I have thanked her once, Wendy Grande deserves special recognition for her unfailing efforts to ensure that the conference logistics were managed flawlessly, the presenters' needs were met, and the attendees derived maximum benefit from the conference.

NOTES

1. Paul Longmore, *Why I Burned My Book and Other Essays on Disability* (Philadelphia: Temple University Press, 2003), p. 130.

2. The classic statement of this position is a book by Carol Padden and Tom Humphries, *Deaf in America: Voices from a Culture* (Cambridge: Harvard University Press, 1988).

3. Natalie A. Dykstra, "Trying to Idle': Work and Disability in the *Diary of Alice James*," in *The New Disability History: American Perspectives*, ed. Paul K. Longmore and Lauri Umansky (New York: New York University Press, 2001), p. 109.

4. See, for instance, Steven Pinker, *The Blank Slate: The Modern Denial of Human Nature* (New York: Viking, 2002).

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PART 1

SCIENCE, CULTURE, AND HUMAN VARIATION

INTRODUCTION

Louis Menand and Nora Groce, the authors of the first two essays in this book, are both well known—Menand for *The Metaphysical Club* and Groce for *Everyone Here Spoke Sign Language: Hereditary Deafness on Martha's Vineyard*.¹ Despite profound differences in their approaches to matters of genetics, culture, and human variation, Menand and Groce suggest a similar need for skepticism and critical thinking in the consideration of human differences and genetics. By implication, both also question the emphasis that American society places on biological solutions—changing human genes—to a range of social problems supposedly caused by human differences. This critique has two major aspects: First, variation is itself a social good, that is, striving to achieve a physical or cultural “norm” for everyone is a mistake; second, cultural,

social, or political measures are the appropriate ways to enhance the lives of people with conditions labeled as disabilities.

Menand's Pulitzer Prize-winning *The Metaphysical Club* focuses on a group of American pragmatists and their intellectual milieu during the late-nineteenth and early-twentieth centuries. This was the heyday of eugenics' practices and popularity in the United States. Darwin's theory of evolution had spawned speculation about linkages between genetic characteristics and human behavior; states were beginning to pass laws providing for the sterilization of "genetic inferiors"; new immigration policies overtly favored supposedly superior genetic stocks of some nations over others; Alexander Graham Bell raised the fear of the growth of a "deaf variety of the human race"; and the Nazis had not yet discredited eugenics through their program of sterilizations, forced abortions, and murders of persons with alleged genetic defects.

Menand uses some of the material from this text and the period he knows well to develop his arguments in the essay, "The Science of Human Nature and the Human Nature of Science." Therein Menand states flatly, "There is a great battle going on in our intellectual culture today . . . between people who believe that science opens new possibilities for human life and people who worry that it closes them." Menand is in the second camp, concerned that a focus on the genome limits human potential. The people who advance genetic explanations of behavior, he writes, "speak as though genes are some sort of irreducible reality, as though they are a power behind human affairs that cannot be abrogated or countervailed against." He uses both contemporary and historical arguments, tracing the thinking of individuals such as William James, Horace Kallen, and Alain Locke to challenge biological determinism and argue that human intelligence has "released us from the prison of biology."

Groce's *Everyone Here Spoke Sign Language* is a classic in comparative anthropology, arguing that a society's reaction to deafness, and by implication other characteristics or disabilities, is variable, depending on cultural considerations. Groce has studied disability in many different

cultures, and in her essay, “The Cultural Context of Disability,” she reviews the ways that cultures have defined and interpreted disability and creates an interpretive framework for discussing the relationship between culture and disability. She makes two core arguments. The first is that the lives of individuals with disabilities “will in large measure be determined not by the fact that they have a disability but by the way the society in which they live conceptualizes what it means to be ‘disabled.’” The second is that society’s reaction to disability is culturally dependent; that is, societies do not, in fact, all conceptualize all disabilities the same way. In other words, society and culture can be constructed in such a way that people with a variety of physical and mental attributes can lead fulfilling and useful lives.

NOTE

1. Louis Menand, *The Metaphysical Club: A Story of Ideas in America* (New York: Farrar, Straus and Giroux, 2001); Nora Groce, *Everyone Here Spoke Sign Language: Hereditary Deafness on Martha’s Vineyard* (Cambridge, Mass.: Harvard University Press, 1985).

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