Disability Studies Quarterly
Summer 2001, Volume 21, No. 3
pages 166-179 <www.cds.hawaii.edu>

Disability and the Genome:
Resisting the Standardized Genomic Text

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"If appropriate go-ahead signals come, the first resulting gene-bettered children will in no sense threaten human civilization."
- James D. Watson, "All for the Good"

"The Human Genome Project has engendered genohype, from early pronouncements that our destiny is in our genes to recent declarations that new discoveries will minimize or prevent the appearance of disease phenotypes altogether."
- Neil A. Holtzman, "Are Genetic Tests Adequately Regulated?"

"The underlying epistemology, history, and theory of a field cannot be separated from its rhetoric."
- Charles Bazerman, "Shaping Written Knowledge: The Genre and Activity of the Experimental Article in Science"

Writing for *Time* magazine's special issue on "The Biotech Century," James D. Watson, the co-discoverer of the structure of DNA, asked in "All for the Good: Why Genetic Engineering Must Soldier On" that both the public and the scientific community remain vigilant in their resolve to pursue technologies derived from the sequencing of the human genome. Watson assured his readers that they have nothing to fear from "gene-bettered children" and that such "genetic manipulations" will not be done frivolously but in order to "change a death sentence into a life verdict." Watson concluded by writing that if "we" fail, "let it be because our science is not yet up to the job, not because we don't have the courage to make less random the sometimes most unfair courses of human evolution" (91).

Genomics may (or may not) result in such long-promised advancements as gene therapy, pharmacogenomics, and other forms of genetic medicine. The purpose of this article is not to

question the efficacy or the wisdom of the ongoing revolution in biotechnology. Rather, my concern here is with disability and how people with disabilities are negatively, if unintentionally, affected by some of the rhetorical strategies employed by the genomics industry. If we accept, as I think we should, the argument made by Charles Bazerman and others that "language accomplishes the work of science" (291), then genomic discourse raises serious social concerns.[1] Specifically, I argue in this article that genomic discourse, reflecting the dominant cultural construction of disability as defect or deficit, presents disability as textual error to be edited and/or erased by genetic engineers. This construction tends to essentialize disability and serves to reinforce the cultural stigma attached to people who have disabilities. Finally, I argue that the concept of embodiment, as articulated by N. Katherine Hayles, might replace the authoritative, standardized text proposed by genomics and foster a deeper understanding - and acceptance - of difference.

Organized efforts to sequence the human genome and decode the genetic text began around 1990 and rapidly picked up support (and funding) with talk of life's "final frontier" and the often repeated assertion that our "destiny" is in our genes. Evelyn Fox Keller, Richard Doyle, Celeste M. Condit, and Lily E. Kay all have written extensively about the widespread use of genetic metaphors.[2] Donna J. Haraway has referred to the sequencing of the human genome as an "act of canonization," the production of a "standard reference work ... through which human diversity and its pathologies could be tamed in the exhaustive code kept by a national or international genetic bureau of standards" (215).

Disability as Textual Error

The sequencing of human DNA has evolved into a two-way "race" between the public Human Genome Project and Celera Genomics, a private biotechnology company located in Rockville, Maryland. A genome refers to the complete DNA code of a particular organism or species. DNA molecules are found in the nucleus of every cell, carried on chemical structures known as chromosomes. Sequencing the human genome involves identifying its roughly three billion pairs of nucleotide bases and then storing this information in computer databases. Mapping involves location analysis meant to establish linkage. In one sense linkage refers to the location of a particular gene in relation to other genes, but it can also mean correlation with a phenotype (i.e. a gene "linked" to Parkinson's). Biotechnology and pharmaceutical companies hope to make billions of dollars as the function of more and more genes is established and feasible treatment options for harmful mutations within them are developed.

Genomes are sequenced by high-speed robotic sequencing machines. The resulting information is transformed into an alphabetical pattern of symbols for DNA subunits called nucleotide bases (C, T, A, G)[3] which are stored as digital information in computer databases.

Digitalization/alphabetization of the genetic body-text has

fostered the much used analogy of DNA as molecular language, where the "letters" are bases, the "words" are genes, and the "book" is the complete genome.[4] Scientists, science writers, and science journalists frequently use this analogy to (ostensibly) explain genomics to lay audiences. In this analogy genetics becomes textuality, and the human genome becomes the "Book of Life." Both scientific and mass media publications borrow the terminology of textual translation, editing, and computer science as a way of discussing the mechanism by which DNA participates in the production of the proteins involved in all biological activities. For example, consider these recent headlines from *Science*: "Faithful Translations" (10 Sept. 1999) and "Dirty Transcripts from Clean DNA" (2 April 1999).[5]

However, the metaphors (and narratives) used in scientific discourse do much more than explain: they accomplish significant cultural work shaping social attitudes and public policy.[6] Implicit in the genetic/textual analogy is the fiction of the standardized body-text. The logic here suggests that any deviation from this authoritative genetic script results in a flawed and thus corrupted text. One recent example of this usage is "Repairing the Genome's Spelling Mistakes" by science writer Trisha Gura in *Science*.[7] The article begins: "On the computer, correcting spelling errors takes nothing but a quick keystroke or two. Now, researchers are trying to harness the cell's own spell-check program - its DNA repair machinery - to tackle a much more difficult problem: fixing errors in the flawed genes that cause such hereditary diseases as sickle cell anemia and cystic fibrosis" (316). Thus disease and disability are cast as textual irregularity and those in the biomedical community become editors who attempt to amend, delete, and correct the defective texts of diseased/disabled bodies.

However, the concept of a single, authoritative text poses as many problems for genome sequencers as it does for other textual editors.[8] To begin with, the Human Genome Project and Celera Genomics are both constructing a hypothetical DNA sequence by assembling DNA fragments into a complete genome. Like all composites, this common or "consensus" DNA sequence will be a fiction. Moreover, the DNA fragments now being sequenced come in increasing numbers from certain, nonrepresentative groups of human subjects. In actuality, there is no prototypical genetic script by which to measure or evaluate all others.

Genomic discourse reveals biotechnology's impossible attempt to normalize the chaotic text of genetics. "Thus the deceptively simple answer to the question `Who wrote the book of life?' is, of course, the scientists," argues Lily E. Kay. "They think they are reading the book of life, but in fact they have been writing it all along" (629). No two human genomes are or can ever be alike: all have mutations, deletions, and other genetic variations. Not only is genetic variation the norm; these variations are never fixed, but always in the process of becoming. Thus, in the final analysis, arguments that posit a correct genetic script are ultimately teleological: they imply an

evolutionary "final intention."

I am not suggesting that deleterious, potentially lethal genetic mutations do not occur; clearly they do. Rather, my intention here is to question the construction of "normal" versus "abnormal" genomes and the implications of that fiction for people who are thereby designated as pathological. If genomics does indeed have the potential to revolutionize biology and medicine, it also has the potential to permanently stigmatize people with disease and/or disability as the "Genetic Other."

"Genohype" sometimes obscures the fact that cultural meanings are automatically coded into words like "genes" and "inherited traits." Indeed, such terms, when proliferated by the mass media, lead to the popular assumption that genetics represents the fundamental essence, the inescapable fate of a person. This ideological baggage, Celeste M. Condit argues, "encourage[s] an asocial biological determinism and discriminatory attitudes with regard to both class and disability" (178).

Here it might be helpful to take a closer look at the all-powerful gene. First, it is important to remember that genes are not physical but conceptual, referring to functional segments of DNA. Biomedical discourse categorizes the 90 percent of human DNA that is nonfunctional (or function unknown) as "junk" DNA.[9] The DNA segments designated as genes are functional in that they participate in the production of the proteins involved in all biological activities.

Often scientists, as well as science writers and journalists, will construct a hierarchical model of this process with the gene at the top and the many other factors involved at the bottom. The active verbs most often used to describe what genes do clearly reveal this bias: genes are said to "control," to "program," to "determine," to "encode," proteins. Consider this typical example from "Gene Therapy's Focus Shifts From Rare Illnesses" by *New York Times* science journalist Andrew Pollack: "The idea is simple and eloquent. Many inherited diseases are caused by a faulty gene, which makes the body unable to produce some essential protein or enzyme." Or consider this variation that relies on the familiar but awkward trope of "genes gone bad" by Emma Ross of the Associated Press: "Genes can promote or cause disease when they don't work properly. Some illnesses linked to genes gone bad include cancer, arthritis, diabetes, high blood pressure, Alzheimer's and multiple sclerosis" (A11).

Rhetorically, this hierarchical model of protein production serves the biomedical community in specific ways. For example, making public relations, as well as lobbying and fundraising, easier because scientists can point to a single gene as the culprit in the production of a certain protein linked to diabetes or breast cancer. With adequate funding, so the suggestion goes, biomedical editors can rewrite this and other flawed genes that "cause" disease and disability so as to produce a genetically altered - and approved - text. However, this marketing strategy ignores the fact that genes only participate in the formation of

these proteins. Other factors involved in the transcription process include ribosomes, messenger RNA (mRNA), transfer RNA (tRNA), and amino acids, as well as both social and environmental factors.[10]

Making the situation even more complicated is the fact that some traits are polygenic (that is, they involve multiple genes). "We must remember that genetic functions are embedded in complex networks of biological reactions and social and economic relationships" (12), write Ruth Hubbard and Elijah Wald in *Exploding the Gene Myth*. A more accurate verb to describe the function of genes would be "mediate." Genes do not act alone but participate in an integrated network of biological, environmental, and social systems. Though more accurate, the integrated network model of DNA transcription poses public relations problems to science writers and journalists eager to employ pat phrases like "genes gone bad" to simplify and sensationalize complex information; and to scientists just as eager to promote genetic engineering, the promise of remediation.

The Standardized Genomic Text

The stated purpose, the very promise of genome sequencing and mapping, is to "correct" errors in the genetic body-text that result in disease and disability. New technologies in genetic engineering, gene therapy, and genetic-based drugs have been promised for years, so far without tangible results. The "blockbuster medicines," the "cornucopia of new medicines," announced by biomedical researchers and echoed by the national media have not materialized.[11] In fact, as of early 2001, new concerns over genetic engineering had surfaced after six deaths in gene therapy experiments over a nineteen-month period went unreported to the National Institutes of Health.[12] Still, the lack of tangible results has not dampened interest in the genetic market place nor the growth and prosperity of the biomedical and pharmaceutical industries.

The concept of a standardized genomic text implies a view of disability that illuminates the social constructionist argument central to Disability Studies. Disability Studies resists the medical model of disability as disease or trauma and the "natural" view of it as deficit or defect. Instead, Disability Studies considers disability as socially constituted by the interaction of individuals with their environments when particular conditions, either physical or mental, become social impediments. How people with disability are - and historically have been - represented, situated, marginalized, educated, and employed, for example, yields a recognition that what it means to be disabled. Indeed the very conditions of disability are crucially determined by the social orders in which individuals live.

Genomic discourse reinforces the social stigma attached to disability by constructing it as abnormal, pathological, and in need of genetic "correction." However, "normal" as a category is not obvious or given. "...normality has to be constructed in

discourse" (194) Jonathan Potter reminds us in *Representing Reality: Discourse, Rhetoric, and Social Construction*.[13] What counts as normal is "indexical" (that is, occasioned, dependent on its context of use). Everyone experiences disease regularly and routinely. How then is disease "abnormal"? Likewise, everyone who lives long enough will experience disability. Disease and disability are common, ordinary, and yes, even "normal" aspects of life.

Before continuing, I should add that I am not arguing against genetic research or medical technology. Indeed, it would be absurd for those of us in the disability community to take such an extreme position since many of us who have experienced disability are alive today because of medical technology. Once again, my concern here is that genomics, as the field is currently constituted and presented to the public, reduces people with disease and disability to the level of "spelling mistakes," typographical errors that need to be eliminated by genetic editors and engineers.

Consider the following examples of genomic discourse. The first is from *Science* where Esmail D. Zanjani and W. French Anderson write in "Prospects for in Utero Human Gene Therapy":

> For the neurologic diseases (such as Tay-Sachs, Niemann-Pick, Lesch-Nyhan, Sandhoff, Leigh, many leukodystrophies, generalized gangliosidosis) that appear to produce irreversible damage during gestation, treatment before birth (perhaps early in pregnancy) may be required to allow the birth of a normal baby (2084).

The second, also from *Science*, was written by science writer Trisha Gura. Her "Gene Defect Linked to Rett Syndrome" is a report on the gene "at fault in Rett Syndrome, which afflicts at least one in 10,000 girls." "Exactly how the defect leads to the neurological decline of the afflicted girls has yet to be deciphered" (27), Gura admits. However, her use of the word "afflicted," with its biblical implications of divine punishment for sin, suggests that those who have Rett Syndrome are somehow deserving of their condition.[14]

Without a doubt, this rhetoric has proven effective in terms of public relations and fundraising.[15] What makes this rhetoric so successful, and so self-serving, is that it both identifies a problem (the genetically defective) and proposes a solution (genetic engineering). Notice, however, that this rhetorical strategy constructs a social problem and then offers an individualistic, technocratic, and extraordinarily expensive solution that few people, even in affluent nations, could ever afford.

Moreover, the public relations and fundraising success of this rhetorical campaign comes at the expense of people who happen to have a disability. Scientists in the biomedical community actively participate in the creation of the "specter" of abnormality which they then exploit for public relations

purposes. This "specter," which preys on the public's fear of disability, presents disability as both a personal tragedy and a public burden that costs taxpayers excessively. One sees the "disability-as-burden" rhetoric used repeatedly in scientific discourse and public relations materials. Consider a recent example from *The New England Journal of Medicine*, taken from a review article on "Neural-Tube Defects." The authors, all associated with the National Center for Environmental Health at the Centers for Disease Control and Prevention, review current strategies to prevent neural-tube defects like spina bifida. In a section entitled "The Burden of Disease," the authors write:

> In addition to the emotional cost of spina bifida, the estimated monetary cost is staggering. In the United States alone, the total cost of spina bifida over a lifetime (the direct costs of medical, developmental, and educational services and the indirect costs associated with morbidity and mortality, in 1992 dollars) for affected infants born in 1988 was almost $500 million, or $294,000 for each infant (1511).[16]

The rhetorical effect of this passage is to suggest the "better-off-dead" logic that the disability community so strongly opposes.[17] Determinations of the quality of life, and of which lives are cost-effective and thus not a "public burden," are obviously fraught with problems. Moreover, such determinations are reminiscent of an older and deservedly notorious form of genetic technology: eugenics.[18]

In *Unnatural Selection: The Promise and the Power of Human Gene Research*, Lois Wingerson relates the story of a 15-year-old high school student with spina bifida who, as part of a school biology project, conducted a survey on the internet that asked the following question: "If we had the technology to eliminate disabilities from the population, would that be good public policy to do so?" The responses, though mixed, clearly reflected the positions of the respondents in relation to disability. In all, only 23 percent of respondents answered yes, compared to 40 percent who answered no (the rest were undecided). However, among respondents who had no experience with or connection to disability, the responses were almost evenly divided: 33 percent yes, to 28 percent no. Parents of children with disabilities were more united: 62 percent would not take public-policy steps to eliminate disabilities. The student, whose name was Blaine, admitted that his respondents were not a scientifically valid population sample, but concluded:

> I wonder if people are saying that they think the world would be a better place without me .... I wonder if people just think the lives of people with disabilities are so full of misery and suffering that they think we would be better off dead .... Most of the time I am very happy and I like my life very much .... My mom says she can't imagine the world

> without me .... and she is convinced that everyone who has a chance to know me thinks that the world is a far better place because I'm in it. Maybe she thinks this because she's my mom, but she may be right. People do seem to like me, and I think I'm a pretty good person. I don't think I'd want to change" (55).[19]

I cite this lengthy anecdote, not to argue against research that might someday prevent at least some spina bifidas, but rather to point out the obvious: all rhetorical positions are embodied. It comes as no great surprise that a research scientist who specializes in (and is funded for) investigating neural-tube defects and a 15-year-old who was born with spina bifida would have divergent views on the value of a life lived with spina bifida. Sweeping generalizations about the "emotional" or "monetary" cost of a particular disease or disability do not acknowledge the situatedness of such rhetorical positions and are thus highly problematic. The "disability-as-burden" rhetoric itself does enormous damage, both psychological and in terms of the material conditions of lives, because it casts people who happen to have physical or mental impediments as social parasites, a waste of emotional and material resources.[20]

The demonization that results from this rhetoric is not only damaging but - I would argue - illogical. Consider the above-mentioned article on "Neural-Tube Defects" for example. The authors, in fact, admit that neural-tube defects have been recognized since antiquity and are quite common occurring in 1 of every 1,000 pregnancies (1509). That is, neural-tube defects are, and have been since antiquity, a regularly occurring, "normal" part of human variation.

Disability, Variation, and Embodiment

Genomics has enormous potential to advance the understanding of human variation. We need to remember that genetics IS variation and that variation is healthy and essential for the survival of a species. If genomics, both the science and the industry, were to more effectively emphasize the "normality" of variation, the fact that human variation is a continuous spectrum, then surely there would be a better understanding and acceptance of disability - and other manifestations of difference - in the public arena.[21]

Celeste M. Condit suggests in *The Meanings of the Gene: Public Debates About Human Heredity* that genetic engineering may eventually de-essentialize disability since theoretically "problem" genetic traits would become secondary, not fundamental, and could be altered without changing the essence of a person. This might in fact happen in the distant future if gene therapy and/or genetic medicine prove effective in recoding human DNA and if these technologies become widely available and affordable to more than a wealthy elite. However, the only genetic engineering technologies available currently or in the foreseeable future involve genetic selection - that is, the selection of embryos

and/or fetuses with desired traits and the erasure of those with undesired traits.

Moreover, in order for genomics not to essentialize disabled bodies its discourse would need to avoid reflecting the dominant cultural construction of disability. Rhetoric that stresses aberration over variation, rhetoric that promises "gene-bettered children," reflects this cultural construction and embodies a Darwinian-driven logic that identifies certain kinds of human variation as unfit, defective, and in need of correction. These cultural constructions make acceptance and accommodation of disability very difficult.

One way out of this impasse is suggested by N. Katherine Hayles in *How We Became Posthuman: Virtual Bodies in Cybernetics, Literature, and Informatics*. Hayles proposes the idea of embodiment, including embodied information (as opposed to abstract, disembodied information). Hayles argues that embodiment differs from the concept of the body which is "always normative to some set of criteria" while "embodiment is contextual, enmeshed within the specifics of place, time, physiology, and culture." Relative to the body, Hayles argues, "embodiment is other and elsewhere, at once excessive and deficient in its infinite variations, particularities, and abnormalities" (196). Moreover, embodiment "mediates" between technology and discourse by creating new experimental frameworks" (205).

The concept of embodiment might replace the authoritative, standardized text proposed by genomics. Embodiment allows for the chaos, the randomness of human variation, what Hayles calls the "crisis of mutation, the recognition that pattern is always already penetrated by randomness" (215). This concept could result in a greater acceptance of embodied difference and a commitment to accommodation as opposed to erasure.

Endnotes

1. See especially Charles Bazerman, *Shaping Written Knowledge: The Genre and Activity of the Experimental Article in Science*; Alan P. Gross, *The Rhetoric of Science*; and John S. Nelson, Allan Megill, and Donald McCloskey, *The Rhetoric of the Human Sciences*.

2. See Evelyn Fox Keller's *Refiguring life: Metaphors of Twentieth-Century Biology*, Celeste M. Condit's *The Meanings of the Gene: Public Debates About Human Heredity*, Richard Doyle's *On Beyond Living: Rhetorical Transformations of the Life Sciences*, and Lily E. Kay's "Who Wrote the Book of Life? Information and the Transformation of Molecular Biology, 1945-1955."

3. The letters represent the four bases in DNA: Cytosine, Thymine, Adenine, and Guanine.

4. A similar analogy casts the human genome as "blueprint." For example, Barbara R. Jasny and Pamela J. Hines write in "Genome Prospecting" that: "Much as an architect's blueprint forms the plan of a building, genomic sequence supplies the

directions from which a living organism is constructed."

5. Likewise, original research articles published in *Science* make use of the same textual-editing language. For example, the authors of "A Molecular Pathway Revealing a Genetic Basis for Human Cardiac and Craniofacial Defects" in the 19 February 1999 issue claim to have discovered a gene that, when absent, triggers a common congenital heart defect associated with DiGeorge syndrome, second only to Down syndrome in causing malformations of the heart. Ninety percent of people with DiGeorge syndrome are missing three megabases of DNA from Chromosome 22, designated by the authors as a "DiGeorge deletion site" (1093). The first two sentences of the authors' abstract demonstrates the genetic-body-as-text model:

> Microdeletions of chromosome 22q11 are the most common genetic defects associated with cardiac and craniofacial anomalies in humans. A screen for mouse genes dependent on dHAND, a transcriptions factor implicated in neural crest development, identified Ufd1, which maps to human 22q11 and encodes a protein involved in degradation of ubiquinated proteins (1158).

6. Dorothy Nelkin writes in *Selling Science: How the Press Covers Science and Technology* that "Metaphors in science journalism cluster and reinforce one another, creating consistent, coherent, and therefore more powerful images which often have strategic policy implications" (81). See also Greg Myers, *Writing Biology: Texts in the Social Construction of Scientific Knowledge*; and Kary L. Moss, ed., *Man-Made Medicine: Women's Health, Public Policy, and Reform*.

7. Or consider this example from *New York Times* science journalist Andrew Pollack, who in "Gene Therapy's Focus Shifts from Rare Illnesses" writes this sentence: "Rather than inject entire genes, the company's technology will just `correct the typos' in the patient's own genes."

8. In literary-textual criticism the concept of a single, authoritative text is outdated and deeply problematic. See Jerome McGann's *The Textual Condition and A Critique of Modern Textual Criticism*. See also George P. Landow's *Hypertext 2.0: The Convergence of Contemporary Critical Theory and Technology*.

9. By most estimates, there are some 30,000 to 50,000 genes in the human genome.

10. Ribosomes are tiny particles in the cell that bind to messenger RNA, which carries the genetic information needed for protein synthesis, as well as to transfer RNA, the kind of molecule that supplies the ribosome with amino acids, the building blocks of proteins. For more information, see Elizabeth Pennisi, "The Race to the Ribosome Structure."

11. These quotes are from "Drugs Based on Genes Enter Human Trials" by *Wall Street Journal* staff reporter Robert Langreth. The *Wall Street Journal* reports regularly on developments in the pharmaceutical and biomedical industries which are becoming

increasingly important sectors of the American economy.

12. Indeed, the Biotechnology Industry Organization's Recombinant DNA Advisory Committee resisted making this information public arguing that details of gene therapy experiments, even adverse "events," are "by definition, trade secrets and considered commercial information." See "Gene Therapy Firms Resist Publicity" by *Washington Post* staff writer Rick Weiss.

13. See also Lennard J. Davis' "Constructing Normalcy: The Bell Curve, the Novel, and the Invention of the Disabled Body in the Nineteenth Century" in *The Disability Studies Reader*. Davis traces the evolution of the norm from a concept built on the binary logic of normal versus abnormal to an ideology of human perfectibility as measured and created by statistics, eugenics, the bell curve, and intelligence tests. See also Davis' *Enforcing Normalcy: Disability, Deafness, and the Body*, as well as Jonathan Potter's *Representing Reality: Discourse, Rhetoric, and Social Construction*.

14. For a discussion of how medical rhetoric constructs people with disease and/or disability as deserving of their conditions, see Chapter 2, "Medical Discourse and Subjectivity," of G. Thomas Couser's *Recovering Bodies: Illness, Disability, and Life Writing*. Also see Scott L. Montgomery's "Illness and Image in Holistic Discourse: How Alternative Is `Alternative'?"

15. For example, in 1996, the last year for which I have complete figures, the National Institutes of Health allocated $200 million to the Human Genome Project while providing only $1,410,925 for AIDS research, $381,880 for breast cancer research, $111,479 for schizophrenia research, and a mere $82,800 for M.S. research. The numbers come from Ari Patrinos, et. al., "New Goals for the U.S. Human Genome Project: 1998-2003, and from Cary P. Gross, et. al., "The Relation Between Funding by the National Institutes of Health and the Burden of Disease."

16. This figure hardly seems "staggering" when compared to the $200-$300 million allocated by the National Institutes of Health to the Human Genome Project each year and the total cost of genome sequencing, which runs in the billions of dollars.

17. For the disability community's position on the "better-off-dead" logic, see The Ragged Edge on-line at <www.ragged-edge-mag.com/index.shtml#edge>. See also <http://www.adapt.org> as well as Mouth Magazine.

18. For a discussion and historical overview of the eugenics movement in the United States and Europe see *Exploding the Gene Myth* by Ruth Hubbard and Elijah Wald, and *Inventing the Feeble Mind: A History of Mental Retardation in the United States* by J. W. Trent.

19. Wingerson adds: "Blaine spends his days in a wheelchair, cannot make most people understand what he says aloud, and had undergone surgery eleven times by the time he conducted the survey."

20. According to *Closing the Gaps: 1998, The National Organization on Disability / Harris Survey of Americans with*

Disabilities, over two-thirds of all Americans with disabilities are both unemployed and living at or below the poverty line.

21. Similarly, recent DNA studies have shown, rather conclusively, that genetic diversity is a continuum with no clear breaks delineating racial groups. According to Yale University geneticist Kenneth Kidd, "there's no such thing as race in [modern] homo sapiens." Instead, there is "a virtual continuum of genetic variation" around the world. See "DNA Studies Challenge the Meaning of Race" by Eliot Marshall in *Science* (281.5389: 654-55).

References

Bazerman, Charles. *Shaping Written Knowledge: The Genre and Activity of the Experimental Article in Science*. Madison: U of Wisconsin P, 1988.

Botto, Lorenzo D., Cynthia A. Moore, Muin J. Khoury, and J. David Erickson. "Neural-Tube Defects." *The New England Journal of Medicine* 341.20 (1999): 1509-1519.

Collins, Francis S., and Ari Patrinos, Elke Jordan, Aravinda Chakravarti, Raymond Gesteland, LeRoy Walters, et. al. "New Goals for the U.S. Human Genome Project: 1998-2003." *Science* 282.5389 (1998): 682-689.

Condit, Celeste M. "The Character of `History' in Rhetoric and Cultural Studies: Recoding Genetics." *At the Intersection: Cultural Studies and Rhetorical Studies*. Ed. Thomas Rosteck. N.Y.: Guilford, 1999. 168-185.

_____. *The Meanings of the Gene: Public Debates About Human Heredity*. Madison: U of Wisconsin P, 1999.

Couser, G. Thomas. *Recovering Bodies: Illness, Disability, and Life Writing*. Madison: U of Wisconsin P, 1997.

Davis, Lennard J. *The Disability Studies Reader*. New York: Routledge, 1997.

_____. *Enforcing Normalcy: Disability, Deafness, and the Body*. New York: Verso, 1995.

Doyle, Richard. *On Beyond Living: Rhetorical Transformations of the Life Sciences*. Stanford: Stanford UP, 1997.

Gross, Alan P. *The Rhetoric of Science*. Cambridge: Harvard UP, 1990.

Gura, Trisha. "Repairing the Genome's Spelling Mistakes." *Science* 285.5426 (1999): 316-318.

_____. "Gene Defect Linked to Rett Syndrome." *Science* 286.5437 (1999): 27.

Haraway, Donna J. *Simians, Cyborgs, and Women: The Reinvention of Nature*. New York: Routledge, 1991.

Hayles, N. Katherine. *How We Became Posthuman: Virtual Bodies in Cybernetics, Literature, and Informatics*. Chicago: U of Chicago P, 1999.

Holtzman, Neil A. "Are Genetic Tests Adequately Regulated?" *Science* 286.5439 (1999): 409.

Hubbard, Ruth, and Elijah Wald. *Exploding the Gene Myth*.

Boston: Beacon, 1997.

Jasny, Barbara R. and Pamela J. Hines. "Genome Prospecting." *Science* 286.5439 (1999): 443.

Kay, Lily E. "Who Wrote the Book of Life? Information and the Transformation of Molecular Biology, 1945-55." *Science in Context* 8.4 (1995): 609-634.

Keller, Evelyn Fox. *Refiguring Life: Metaphors of Twentieth-Century Biology*. New York: Columbia UP, 1995.

Langreth, Robert. "Drugs Based on Genes Enter Human Trials." *The Wall Street Journal*, 26 March 1999, B1+.

Landow, George P. *Hypertext 2.0: The Convergence of Contemporary Critical Theory and Technology*. Baltimore: Johns Hopkins UP, 1997.

Linton, Simi. *Claiming Disability: Knowledge and Identity*. New York: New York UP, 1998.

Marshall, Eliot. "DNA Studies Challenge the Meaning of Race." *Science* 281.5389 (1998): 654-55.

McGann, Jerome. *The Textual Condition*. Princeton: Princeton UP, 1991.

_____. *A Critique of Modern Textual Criticism*. Chicago: U of Chicago P, 1983.

Montgomery, Scott L. "Illness and Image in Holistic Discourse: How Alternative Is `Alternative'?" *Cultural Critique* 25 (1993): 65-89.

Moss, Kary L, ed. *Man-Made Medicine: Women's Health, Public Policy, and Reform*. Durham: Duke UP, 1996.

Myers, Greg. *Writing Biology: Texts in the Social Construction of Scientific Knowledge*. Madison: U of Wisconsin P, 1990.

National Organization on Disability. *Closing the Gaps: 1998, The National Organization on Disability / Harris Survey of Americans with Disabilities*. Washington, D.C.: N.O.D., 1998.

Nelkin, Dorothy. *Selling Science: How the Press Covers Science and Technology*. New York: Freeman, 1987.

Nelson, John S., Allan Megill, and Donald N. McCloskey. *The Rhetoric of the Human Sciences*. Madison: U of Wisconsin P, 1987.

Pennisi, Elizabeth. "The Race to the Ribosome Structure." *Science* 285.5436 (1999): 2048-2051.

Pollack, Andrew. "Gene Therapy's Focus Shifts From Rare Illnesses." *New York Times on the Web* 4 August 1998. <http://www.nytimes.com>

Potter, Jonathan. *Representing Reality: Discourse, Rhetoric and Social Construction*. London: Sage, 1996.

Ross, Emma. "Scientists near goal: DNA code of chromosome." *The Cincinnati Enquirer* 22 Oct. 1999: A11.

Thomson, Rosemarie Garland. *Extraordinary Bodies: Figuring Disability in American Culture and Literature*. New York: Columbia UP, 1997.

Trent, J. W. *Inventing the Feeble Mind: A History of Mental Retardation in the United States*. Berkeley: U of California P, 1994.

Watson, James D. "All for the Good." *Time* 11 January 1999:

91.
Weiss, Rick. "Gene Therapy Firms Resist Publicity." *Washington Post*, 11 December 1999, A2.
Wingerson, Lois. *Unnatural Selection: The Promise and the Power of Human Gene Research*. N.Y.: Bantam, 1998.
Yamagishi, Hiroyuki, Vidu Garg, Rumiko Matsuoka, Tiffani Thomas, and Deepak Srivastava. "A Molecular Pathway Revealing a Genetic Basis for Human Cardiac and Craniofacial Defects." *Science* 283.5405 (1999): 1158-1161.
Zanjani, Esmail D. and W. French Anderson. "Prospects for in Utero Human Gene Therapy." *Science* 285.5436 (1999): 2084-2088.

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