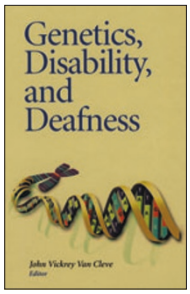
Disability or difference?



Genetics, Disability, and Deafness

John Vickrey Van Cleve, ed.

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Reviewed by Tom Shakespeare

When debates about the nature of disability and debates about the social impact of genetic research intersect, a clash of worldviews often results. For example, the year 2003 was notable both as the fiftieth anniversary of the Crick-Watson paper on DNA structure, but also as the European Year of Disabled People. The implications of the former might be that genetics, through screening and therapy, could soon reduce the impact of impairment on society by curing or reducing the number of affected individuals; the implications of the latter were that civil rights, barrier removal and social inclusion are the keys to eliminating the disability problem. These different perspectives define disability in opposite ways, and identify different solutions to the issues that disability raises for societies and individuals.

The intersection of these debates becomes most interesting, and most difficult, in regard to those impairments that are not incompatible with a good quality of life for those affected. Few are going to argue about Tay-Sachs disease or Lesch-Nyhan syndrome, for example. Deafness is the paradigmatic example of a condition that in medical terms is a pathology, but in the views of many of those affected, is simply a difference. Whereas the traditional view—as expressed by the general public, and by the medical profession—is that hearing loss is a terrible affliction that should be avoided or cured wherever possible, the view of many of those born deaf is that they are a cultural minority. An analogy is drawn with members of minority ethnic communities, who share a common language: Deaf people (who adopt a capital letter to signify this distinctiveness) share a culture based around sign language. Deaf people welcome the birth of Deaf children; they find the concept of prenatal testing for a deaf child deeply disturbing; they oppose the use of cochlear implants and other technologies to overcome this sensory loss or difference.

This fascinating collection of papers, which originated in a conference at Gallaudet University, an American university for deaf, hard-of-hearing and hearing students, explores the issues raised by genetics and deafness from a range of different perspectives.

Most of these authors counsel against biological determinism and the search for genetic solutions to complex cultural and social issues—such as deafness. Louis Menand achieves this through a sophisticated argument for the sort of pragmatism espoused by William James, by which James meant that the usefulness of an idea is the criterion for its merit, and against the varieties of reductionism popularized by evolutionary psychology. Nora Groce recapitulates the analysis from her seminal study of Martha's Vineyard, the isolated Massachusetts community where deafness became very common, and consequently sign language was ubiquitous: for her, this shows the importance of cultural constraints (or possibilities), which matter more than physical or sensory impairments. Brian Greenwald revisits the story of Alexander Graham Bell, who has become somewhat of a pariah amongst Deaf people, because of his advocacy of oral (*i.e.*, non–sign language) education. Bell himself was married to a deaf woman, and feared the emergence of a "deaf variety of the human race." For him, promoting oralism was a better option than sterilization and marriage bans to achieve the eugenic goal of reducing the incidence of hereditary deafness. Greenwald thus reclaims Bell as a protector of deaf people against American negative eugenics. Joseph Murray contributes another perspective to this story, showing how the Deaf community challenged the marriage debate by publishing evidence in 1893, drawing on 4,000 survey returns, showing that 90% of Deaf-Deaf partnerships did not produce Deaf children. This story is brought up to date in a chapter by Walter Nance, who shows how the epidemiology of deafness has changed in modern times: he concludes that the frequency of deafness caused by mutations in connexin 26 has doubled in the United States over the past 100 years because of assortative mating, and consequently suggests that Bell may ultimately have been proven right in his predictions, if not in his political conclusions.

Other chapters provide further scientific analysis of the more than 30 genes contributing to nonsyndromic deafness, together with interesting evidence about the attitudes of Deaf people in the United States and United Kingdom about prenatal diagnosis. These studies, pioneered by Anna Middleton, show that although deaf and hard-of-hearing people generally have a positive attitude toward genetics, they do not favor prenatal diagnosis. More than a quarter of culturally Deaf individuals in the US study would prefer Deaf children, although only 2.7% would consider abortion of a hearing fetus. In Middleton's study, only 6% of culturally Deaf, 11% of hard-of-hearing or deafened, and 16% of hearing respondents would be prepared to consider a termination if the fetus was deaf.

Taken as a whole, this collection presents a cautious response to the genetics challenge. Essays about the Nazis' treatment of deaf people, or analyzing the relevance of *Frankenstein* or *Gattaca*, indicate the lines along which most contributors are thinking. But the tone is always careful and reasoned, and perhaps the authors felt it important to counterbalance some of the gung-ho genetics advocacy associated with the Human Genome Project. In particular, the concluding chapter by Michael Bérubé steers a wise course between supporting abortion rights and embryonic research against the onslaught of American religious conservatives while also cautioning against geneticization. Voices missing from this book include those giving any sustained bioethical analysis, which would have added a very different set of arguments to the broad consensus represented by this selection. But these are small gripes against a book that offers thoughtful challenges to many readers of this journal, and which will be required reading for students of genetics and disability for many years to come.

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