

TEXT SUPPLEMENT (Ch 3): Deafness

Who Decides What is Considered a ‘Defect’?

Very often, groups of people that society wants to ‘help’ are given little or no voice in how society will treat them or ‘help’ them. The deaf are a case in point. Some forms of deafness are inherited, yet many deaf people consider it abhorrent if genetic counseling is used to avoid having deaf children.

The following excerpt is from a speech by I. King Jordan delivered in 1990 to an international symposium on the Genetics of Hearing Impairment. Research funded by the Human Genome Project is aimed at identifying genetic causes of deafness and there is an underlying assumption, on the part of geneticists who are not deaf, that people would then want to avoid this trait. A deaf man, Jordan is president of Gallaudet University in Washington D.C., established in the 1800s to educate deaf people. He explains that he is deaf both medically and culturally. He speaks for most deaf people when he tries to explain that deafness is not a trait that he would want to eliminate.

For about 18 years, I have taught a course on the psychology of deafness. One of the first things we discuss in the class is the difference between viewing deafness as a pathology that should be cured or prevented and viewing it as a human condition to be understood. I call these two perspectives the medical and cultural points of view. Individuals from these two groups agree on audiological definitions, but disagree on the emphasis that should be given to social and rehabilitative services. I adhere to the social or cultural point of view.

What I mean by this is that I, personally, and many of the people I know well, have accepted the fact that deafness is one aspect of my individuality. I do not spend any time or energy thinking about curing my deafness or restoring my hearing, but I do spend substantial time and energy trying to improve the quality of life for all people who are deaf.

For some reason, people who hear have a very difficult time understanding this concept. If you

will permit me to digress for a moment, I will give you an example. I was interviewed by Ms. Meredith Vieira for the television show *60 Minutes*. During the interview, she asked me this question: “If there was a pill that you could take and you would wake up with normal hearing, would you take it?” I told her that her question upset me. I told her that it was something I spent virtually no time at all thinking about, and I asked her if she would ask me the same question about a ‘white’ pill if I were a black man. Then I asked if, as a woman, she would take a ‘man’ pill. Our conversation continued long after the videotaping was done, and we have had several subsequent conversations. But she never understood. She still does not. She still thinks only from her own frame of reference and imagines that not hearing would be a terrible thing. Deafness is not simply the opposite of hearing. It is much more than that, and those of us who live and work and play and lead full lives as deaf people try very hard to communicate this fact.

As you can see, this is an emotional issue for me. It is a much more emotional issue for many other deaf people. Is that relevant here? Yes, I believe it is, because the genetic study of deafness and genetic counseling have a great deal of significance for the deaf community generally. Many deaf people, particularly those who consider themselves members of the deaf community, do not consider themselves to be defective; rather, they consider themselves to be different, normal but different. In particular, this difference has a cultural or sociological basis and is expressed most saliently in the use of sign language. If deaf people are not defective or dysfunctional then, at least in their own eyes, it follows that they would be suspicious of attempts to eradicate deafness...

Genetic counseling and screening with respect to potential deafness must differ, therefore, in a fundamental way from screening for ‘birth defects.’ (I. King Jordan. ‘Ethical Issues in the Genetic Study of Deafness.’ *Annals N. Y. Acad. Sci.* 630: 236–237.)