



Genetic Testing May Not Benefit Society. Tina Albertson.

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Genetic Testing May Not Benefit Society

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From "Cons of Genetic Screening," by Tina Albertson, *Biospheres*, Winter 1995. Copyright © 1995 by Tina Albertson. Reprinted with permission.

Genetic testing enables an individual's genetic predisposition to develop a disease or condition to be detected. In the following viewpoint, Tina Albertson contends that although genetic testing is a powerful tool in preventing the onset of numerous illnesses, large-scale testing for genetic disorders may be more harmful than beneficial. For example, Albertson argues that screening the population for diseases may result in high incidences of misdiagnoses. More importantly, she warns that the goal to eliminate harmful genes may lead to eugenics, genetically altering humans for social, racial, or political purposes. Albertson is a biologist and graduate of the University of Oregon at Eugene.

As you read, consider the following questions:

1. Why is genetic control of human diseases highly complex, according to Albertson?
2. According to Albertson, how many genetic mutations that result in cystic fibrosis have been discovered?
3. In the author's view, what nonfatal conditions that can be predicted through genetic testing may lead parents to abort a fetus?

Population screening for genetic disorders, with the intent to eliminate "disease genes" from our population, will be a formidable if not impossible task. The uncertainty in the present screening process will inevitably produce a high incidence of misdiagnoses—through either the failure to detect unique mutations or the detection of false positives—and such mistakes could be devastating to individual lives. Along with these technical arguments, possibly more important to the general public are the ethical arguments against the large-scale genetic screening of the public. If genes for obesity, personality disorders, blindness, or other genes that could be titled "disease genes" are found, should genetic screening with the intent to eliminate this genetic material be legal? And when does screening for the benefit of future offspring become confused with eugenics?

Unavoidable Caveats

There are far too many, as yet unavoidable, caveats in genetic screening to do mass population screening efficiently. As scientists are finding out every day, the genetic control of human disease is much more complicated than anyone could have hoped for. It is being found that very few diseases result from single gene mutations. Most of the prominent fatal genetic disorders such as cancer and heart disease are multigenic, meaning that single mutations in many genes, in varying combinations, can cause one of these complex disorders to manifest. The severity of symptoms also depends on multiple genes, and on how these gene products interact and respond to each other and to the environment. This makes simple genetic tests insufficient to accurately diagnose whether symptoms will arise. Even in disorders that result from a single mutation in a single gene the severity of symptoms cannot be foretold by simply assessing whether the mutation exists. It has been found that some individuals who carry the most common mutation associated with extreme symptoms of cystic fibrosis only exhibit symptoms similar to asthma. This shows that genetic analysis is not adequate as a diagnostic procedure for the severity of disorders that are already genetically

defined.

It needs to be understood, as scientists are quickly learning, that genes and their products are still enigmas. Each gene is made up of thousands of base pairs that all have the potential to be mutated, and mutations can arise spontaneously all over the genome. Most of the time these mutations are silent: they do not result in dysfunctional gene products. Only when these mutations occur in certain DNA sequences that are essential for normal function of the gene product do genetic diseases occur. It is virtually impossible to design a test that will screen for all permutations that could cause a particular disease because the possible mutations are just too numerous and many are as yet unknown. Taking cystic fibrosis as an example again, 70% of afflicted patients have a particular mutation that would be correctly diagnosed using a current genetic test, another 20% would be correctly diagnosed using a second test, but the remaining 10% would be missed entirely because their mutations are rare or unique. Even those diagnosed with the present tests might be told they carry a debilitating mutation when they may never get sick in their lifetime. With each new test that detects a new mutation there will be a higher risk of misdiagnoses, and since there are now at least 360 known mutations that result in cystic fibrosis, population screening would be a costly and time-consuming process that would not achieve the intended results.

Of course, I am not arguing that genetic screening is not a valuable technique in certain instances. It has certainly been used successfully in diagnosing individual families that are at high risk for Tay-Sachs disease and cystic fibrosis. In these cases fetal screening and pre-implantation screening of embryos are used to avoid the medical and emotional hardships that accompany both of these deadly disorders that onset early in life. But who is going to determine which genetic disorders constitute enough pain and suffering to be eliminated from the population? What about diseases that appear late in life but still allow 40-60 years of productive years of life, as is the case with some cancers and Huntington's disease? Should a fetus be aborted because 60 years later it might die of cancer and in the meantime propagate that same genetic material? Another concern deals with afflictions such as blindness, deafness, or albinism that by some people may be considered diseases. These disorders are not fatal, and rarely even cause pain to the afflicted, but some parents may believe that their child should be spared the emotional hardships that may accompany such genetic conditions. As a result, they may abort a fetus or not allow implantation of these embryos. Is this ethical? I believe these issues must be resolved now, before it turns into a problem of eugenics. Eugenics, with the help of genetic screening, could become a very real and perverse problem in a few years. The line must be drawn between what is legal and right, and what is selfish and wrong. Deadly diseases can be avoided in some cases using this amazing new technology, but this new technology has the potential to be misused. Genetic screening must be used sparingly and at all costs avoid becoming a commercial service that can be exploited.

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