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# Heredity and Hope: The Case for Genetic Screening.

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#### Heredity and Hope: The Case for Genetic Screening.

By Ruth Schwartz Cowan. Cambridge, Mass.: Harvard University Press, 2008. Pp. 292. \$27.95.

Since Crick and Watson discovered the DNA sequence in 1953 the genetic enterprise has gained increasing momentum to include the mapping of an individual's entire genome and the construction of entire populations' genetic data collections. The hope is that overall human mortality and morbidity can be improved by unlocking the secrets of our genetic codes, which contribute to the health that we and our kin enjoy. By understanding the mechanisms and determinants of genetic inheritance, one can predict the predilection of an individual or a group to inherit diseases that have a genetic component. Essentially, this is a rationale for genetic screening and testing. Screen-ing is more often directed at the population level and may include carrier and adult screening, whereas genetic testing refers to a host of techniques focused more on the individual level such as prenatal diagnosis and newborn screening, but the terms are often used interchangeably.

Genetics both as a scientific technology and a medical system is thought by some to have a dark past, a history associated with eugenics (ironically meaning "the beautiful inheritance"), whose early proponents hoped to "improve the race" through ethically dubious practices such as involuntary sterilization and restrictions on reproduction. Yet Ruth Schwartz Cowan in her book *Heredity and Hope* persuasively argues that one should not make a "genealogical fallacy" by confusing the motives of the founding fathers of medical genetics with the motives of the early eugenicists. The former had motives that were applaudable—to alleviate human suffering; the motives of the latter were condemnable because they sought to elevate certain subsections of the human race over others. Hence, Cowan asks opponents of today's genetic screening not to make the mistake of assuming that the genetic techniques and procedures now offered to pregnant women are an extension of the eugenics movement as was practiced in the early twentieth century.

*Heredity and Hope* is separated into several parts. Cowan begins in the early twentieth century with a detailed account of the eugenics movement in the United States, Germany, and Scandinavia, where eugenicists had some influence on public policy. Then she outlines how the eugenics movement related to medical geneticists working at the same time, before moving on to discuss the history of prenatal diagnosis and adult screening, focusing on specific conditions that were developed after the 1960s: newborn screening for phenylketonuria (PKU), fetal testing for Tay-Sachs disease, carrier screening for sickle-cell anemia, and finally mandated adult screening for thalassemia in Cyprus.

The detail of Cowan's analysis and historical exposition is second to none, and rarely is such a heated and controversial topic dealt with in such

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a clear and forthright way. Although I was a little unsure about why Cowan focused on these disorders in particular, I take the point that Tay-Sachs screening was successful because it was supported at the grassroots, whereas sickle-cell anemia screening failed because of opposition from the black community. This led me to wonder if there was a further point about public support and opposition for genetic screening that was being made. Perhaps if Cowan had focused on other single-gene disorders this would have been instructive and added to her argument. Cowan also makes the point that genetic screening, particularly prenatal diagnosis, opens up choice; that is, parents can choose to have a healthy child rather than not to have a child at all. Yet we know from recent studies in the United States that some parents simply refuse to have genetic tests—they choose not to choose.

Cowan offers very good arguments that we should not object to genetic screening because of its (loose) association with eugenics. Further, her book undoubtedly fills a void by providing a much-needed historical overview of the evolution of genetics. Such a void perhaps reflects a general lack of interest, awareness, or willingness by social scientists to engage with the eugenic past. They should read this book. You should read this book. Love it or hate it; either way this book should not be ignored.

**GILL HADDOW** 

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