

CRG PREDICTIVE TESTING: Position Paper

The array of predictive testing available to pregnant women has expanded exponentially over the 35 years since ultrasound was first made available to "high-risk" pregnant women. The most severe and fatal disabilities were not the first objects of prenatal testing. Rather, the availability of condition-associated tests and economic considerations were significant influences on the development of such methods.

Currently, no bright line guides individuals who use predictive testing to attempt to select against any specific characteristic (disability, medical condition, tendency or trait). Routinized predictive testing opens the door to the termination of embryos or fetuses with a broad range of characteristics. Variability among humans is due partly to genetic differences, but the developmental processes that form us, our life experiences, the environment, and chance all play a significant role in determining who we are. The joy that comes from the breadth of experience that such variation and diversity provide, could become much less vibrant in a few generations if we selectively target some characteristics for elimination. We would be likely to see lessening of people's acceptance of unusual characteristics, leading to the unquestioned assumption that certain ordinary variations should be "cured" or prevented, including all forms of "disability," and even gender, leading to a further devaluation of various "non-mainstream" characteristics.

In western countries, there is already considerable selection against inherited disabilities. Additionally, in some countries baby boys are

selected over baby girls. The notion that disabilities or other undesired conditions can be eliminated by means of predictive testing is based on the faulty assumption that such conditions are usually genetic. The majority of disabling conditions, however, are acquired during a person's lifetime.

Sadly, the increased demand for prenatal genetic testing is, at least partially, reflective of society's continuing failure to support those who choose to raise children with different abilities. Without adequate economic and social support systems, pregnant women (and expectant fathers) may feel pressured to forego bearing children with characteristics that fall outside the norm.

Women should retain authority over their childbearing decisions without being expected to become quality control agents for the fulfillment of societal expectations. Society can do much to provide an environment in which women are better equipped to raise disabled children; without social supports, a woman's freedom to bear children with certain conditions is illusory. Pressures by the medical profession, insurance providers or society at large for women to undergo and act on predictive testing should be opposed. Most importantly, society should be educated regarding the benefits of diversity and variability among us. Fundamentally, we must stop equating "different" with "less worthy" or "less good."

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ABOUT CRG The Council for Responsible Genetics fosters public debate on the social, ethical, and ecological implications of genetic technology. Founded in 1983, CRG is a non-profit/ non-governmental organization based in Cambridge, Massachusetts (USA). In addition to producing educational materials on various issues raised by biotechnology, CRG also publishes a bimonthly magazine, *GeneWatch*, the only national magazine that continually monitors the ethical, social, and ecological impacts of biotechnology as they apply to both humans and the environment. CRG has **position papers and question-answer sheets** on a variety of topics, including genetic discrimination, human cloning, predictive testing, genetically engineered food, the "gay gene," life patents, and germline engineering. Other resources include **The Genetic Bill of Rights**, a **Genetic Discrimination Legislation database**, and **selected books** on biotechnology and genetics. CRG also runs a **competitive internship program** for exceptional college and graduate students.

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