The Disability Rights Critique of Technologies that Eliminate Human Genetic Variation

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Introduction

The development and use of an expanding range of medical technologies that yield genetic information about embryos and fetuses has raised ethical questions about whether and how this increasingly routine set of practices discriminates against people with disabilities. A conversation in the form of academic articles and public media offers explications and critiques about the social and moral harms human gene editing and prenatal genetic testing and the selective reproduction practices it prompts bring to humanity. These purported harms range from increased social inequity—at the very least—to structural and individual violence—at the very most.

This collection suggests that conversations about these technologies have changed over time and also reflects the varied communities engaged in those conversations over time and across social locations. The collection thus focuses on the health humanities in the broadest sense. This means that the data, evidence, and knowledge it gathers come from the lives of individuals, families, and human communities who live with disabilities and illnesses, not from medical-scientific or clinical data. The stories in the final section of this collection present a range of lived experience that suggests both the potential benefits and harms genetic disabilities bring over lifespans to individual people, their families, and their communities. These stories offer narrative data about distinctive human lives that may be more textured than the predominant measurement data that scientific medicine provides about human lives.

The collection thus brings a humanistic, narrative, and phenomenological focus to the disability rights critique of technologies that aim to eliminate human genetic variation. It aims to open up perceptions about the ethics of gene editing and selection practices beyond the voices and perspectives of medical-scientific experts. As such, the collection responds to the perpetual call for broad public conversations and involvement from diverse stakeholders in decisions about the regulation, use, and development of genetic screening and intervention technologies.

The literature in this collection reflects three conversation sites about the ethics of human gene editing and prenatal genetic testing and selective reproduction:

1. disability rights, culture, and justice analyses of the harms of eliminating the human variations we think of as disabilities;
2. healthcare ethics perspectives on the possible ethical harms of genetic testing and selective termination;
3. public facing narratives about people living with a wide range of genetic disabilities in various relationships across life stages.

This collection complements the ELSIhub Collections “Current Legal Challenges to Abortion: Implications for Prenatal Genetics” and “Social Norms in Selective Reproduction: Implications for the Wide Offer of Genetic Screening Technologies.”

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