

**Masking Eugenics as Science: A Critical Disability Studies
Perspective of New Reproductive Technologies
Commentary on Stowe et al., *Journal on Developmental
Disabilities*, 13(2), 2007**

Michael George Miceli and Jason Kenneth Steele

Due to rapid advances in reproductive technologies, the availability of emerging prenatal genetic testing now allows for the detection of genetic abnormalities, among embryos or in the expectant fetus, that would have previously gone undetected. The use of such technology has generally been presented unquestionably, with the exception of preimplantation genetic diagnosis (PGD), as part of routine prenatal care; however, it has raised a myriad of ethical, medical, and legal dilemmas for all those involved. In particular, a discussion of the ethical and social implications of new reproductive technologies for persons with intellectual and developmental disabilities has generally been absent from the literature. Stowe, Turnbull, Schrandt, and Rack in their landmark article have filled this gap by examining "the implications of genetic research and technology development for persons with disabilities in six parts: health and medical implications; evolving attitudes and perceptions; effects on autonomy and self-determination; cultivating discrimination or equality; designing lives and the public health; and the effect on the family and society" (this issue, p. 9).

One of the more prominent dilemmas facing prospective parents is the termination of an embryo or fetus based on a predetermined genetic "abnormality" or "defect." That being said, does prenatal genetic testing serve to facilitate a modern eugenic belief system by attempting to mask the underlying meaning as scientifically oriented? As Stowe et al. have pointed out, "Eugenic proponents argued that the fit of society should not shoulder the burden of the unfit and that preventing the unfit from reproducing and simultaneously encouraging reproduction of the fit would alleviate most, if not all, social ills" (this issue, p. 6). Presently, by screening for various genetic traits and employing measures that attempt to reduce the number of individuals living with a genetic abnormality, we are repeating an act that has historically devalued the lives of people living with a disability. For instance, PGD is used in combination with in vitro fertilization (IVF) techniques in an effort to, in most cases, select against a genetic anomaly – defined by some as an imperfection. By producing numerous embryos by means of IVF followed by preimplantation procedures, science invariably

discards a large portion of potentially viable human lives that would have otherwise developed into human beings living with genetic disorders. Therefore, rather than using practices that prevent the transmission of disabling traits, science has now employed a new way of optimizing an individual's genetic blueprints by selecting which embryos or fetuses are ideal for access into this world (Prusak, 2005).

Shakespeare has made a distinction between strong and weak eugenics and has argued that current genetic testing practices are weakly eugenic "as [they promote] technologies of reproductive selection via non-coercive individual choices" (1998, p. 669). A potential concern raised by the disability community is that the crude racial and class prejudices espoused by early eugenicists are now being replaced by so-called scientific evidence of genetic inequality. According to Patterson and Satz (2002), the positive aspects of living with a disability are seldom ever mentioned during the non-directive genetic counselling sessions that help guide the decision making process. Thus, by not providing the entire picture of what it means to experience disablement, true reproductive "choice" from a disability rights perspective does not exist due to the implicit coercive nature used by the genetic counselling discipline.

In addition, the use of such prenatal genetic technology has implications for all persons with disabilities, but it has specific implications for persons with intellectual and developmental disabilities. Down syndrome and fragile X syndrome are two of the most commonly screened disabilities through prenatal diagnostic testing. According to Asch, "whites and middle class people in general showed more discomfort with Down syndrome and retardation, whereas as people of color and those of lower socioeconomic status expressed more fear of physical vulnerability" (1989, p. 87). Thus, it might be inferred that individuals of higher socioeconomic status may be more likely to abort fetuses or select against embryos with intellectual disabilities, while people of lower socioeconomic status may be more likely to become concerned about fetuses with physically disabling traits. This would suggest that the characteristics by which people tend to be judged in Western capitalist economies – specifically, rationality, intelligence, and athleticism – are the attributes that Caucasian middle-class individuals see as valuable.

Arguably, peoples' decisions about genetic pre-selection are reflections of the social order; therefore, in the case of persons with genetic or chromosomal abnormalities, these individuals are often portrayed as the "victims" of the unlucky throws of random genetic dice. Furthermore,

prenatal testing may unavoidably contain eugenic principles whether or not those who implement and practice these procedures claim to embrace or refute this perspective. By using methods that, knowingly or unknowingly, alter the perceptions of prospective parents in a negative fashion, and discard or terminate potential human life based on a genetic abnormality Western biomedicine reinforces the notion that disability is not welcomed in our society. In essence, the techniques used to reduce the presence of disability may cause more harm than good; hence, "intentions toward individuals with disabilities do not always translate into benefits for them and may even result in harm (or death) to their persons or their basic rights as human beings" (this issue, p. 6) and, in this case, before they can even utter a sound. Therefore, a cautious approach to new reproductive technologies needs to be taken to ensure that the possibilities of present and future eugenic practices are not masked as science.

References

- Asch, A. (1989). Reproductive technology and disability. In S. Cohen & N. Taub (Eds.), *Reproductive laws for the 1990s*. Clifton, NJ: Humana Press.
- Patterson, A., & Satz, M. (2002). Genetic counseling and the disabled: Feminism examines the stance of those who stand at the gate. *Hypatia*, 17, 118-142.
- Prusak, B. G. (2005). Rethinking "liberal eugenics": Reflections and questions on habermas on bioethics. *The Hasting Center Report*, 35, 31-42.
- Shakespeare, T. (1998). Choices and rights: Eugenics, genetics and disability equality. *Disability & Society*, 13, 665-681.
- Stowe, M. J., Turnbull, H. R., Schrandt, S., & Rack, J. (2006). Looking to the future: Intellectual and developmental disabilities in the genetics era. *Journal on Developmental Disabilities*, 13(1), 1-64.

Correspondence

Michael George Miceli
yu254969@yorku.ca

Jason Kenneth Steele
jasonks@yorku.ca

Michael George Miceli and Jason Kenneth Steele
M.A. (Critical Disability Studies)
Graduate Program Office
Room 438, Health, Nursing and Environmental
Studies (HNES) Building
York University
4700 Keele Street
Toronto, Ontario, Canada
M3J 1P3