Reconciling the Concerns of Disability Communities with the Evolving Clinical Use of Reproductive Genetics

By: Joseph Friedman

In recent years genomic research programs have afforded unprecedented advances in understanding the genetic causes of developmental disabilities. Nevertheless, the proper use of such information is a matter of substantial debate; the tension relates back to differing models of defining and addressing disability. According to one view, often called the *medical model,* developmental disabilities represent incapacities that require medical treatment, and preferably a cure. The influence of this perspective is ubiquitous, as evidenced by the widespread adoption of prenatal screening for Down syndrome and over 90% termination rates for affected fetuses. A competing view, the *social model,* conceives of disability as a socially constructed label, instead of an inherent phenomenon. Self-advocates—activists who themselves have development disability diagnoses—advance this view and emphasize changing wider societal norms so that differences in ability are given the same status as other forms of human diversity. These competing frames have become all the more relevant as society a) implements non-invasive prenatal genetic testing (NIPT) for fetal chromosomal abnormalities (e.g. Down syndrome) and b) considers the prospect of prenatal testing for the risk of autism spectrum disorders (ASD).

Using ethnographic interviewing with self-advocates, clinicians, and patients, I explore Vermonters' views regarding the relative ethical status of prenatal screening for chromosomal abnormality and ASD. Although all parties agree that prenatal access to genetic information can be beneficial for individuals with disabilities, for members of the disability rights community, a genomic approach can represent yet another iteration of curist paradigms that seek to eliminate their community from society. Although some clinicians empathize with the views of self-advocates, many feel that their role as a practitioner requires them to "maintain neutrality" on the issue. Challenges to this view are discussed, and areas of improvement in clinical practice regarding disability, originating from both clinicians and self-advocates, are proposed.