Why Members of the Disability Community Oppose Prenatal Diagnosis and Selective Abortion

Prenatal tests have brought the revolution in molecular biology into the lives of ordinary people. Prenatal genetic tests promise to offer greater reproductive self-determination for families that carry genetic traits for serious disease. Originally intended to address “high-risk” pregnancies, prenatal diagnosis (PND) is becoming part of routine prenatal care. But these tests and the prospect of selective abortion raise many social and ethical concerns. Disability rights activists have begun to articulate a critical view of the practice of prenatal diagnosis with the intent to abort if the fetus appears to be destined to become a disabled person. Some people with disabilities, particularly those who are members of the disability rights community, perceive that selective abortion may be based on the assumption that any child with a disability would necessarily be a burden to the family and to society, and therefore would be better off not being born.

People with disabilities who have lived their lives creatively managing the logistics of a disability, as well as fighting disability discrimination, may regard these new genetic “options” as a way to promote selective abortion. As disability activist and lawyer Lisa Blumberg put it, “The social purpose of these tests is to reduce the incidence of live births of people with disabilities.” She describes a report which discussed, in the view of the authors, the troubling findings that some women would not have an abortion even if the fetus had “multiple, severe handicaps such as hemiplegia and incontinence.” Blumberg writes: “Nowhere do the writers ask whether preventing the existence of people with spina bifida is an appropriate goal of a program funded by state taxpayers, including taxpayers with spina bifida.” According to the disability rights paradigm, if suffering does indeed attend life with disability, then the
place to begin ameliorating that suffering is with the eradication of social discrimination—not with the eradication of people with disabilities.

Lawyer and disability activist Deborah Kaplan contends, "If persons with disabilities are perceived as individuals who encounter insurmountable difficulties in life and who place a burden on society, prenatal screening may be regarded as a logical response. However, if persons with disabilities are regarded as a definable social group who have faced great oppression and stigmatization, then prenatal screening may be regarded as yet another form of social abuse." This is the essence of the disability community's challenge to prenatal genetic testing. We believe that the current promotion and application of prenatal screening has a potent message that negatively affects people with disabilities, influences women in decision making about their own pregnancies, and reinforces the general public's stereotyped attitudes about people with disabilities.

The American public appears to have accepted the "common sense" assumption that prenatal screening and selective abortion can potentially reduce the incidence of disease and disability and thus is good. There are many misleading and mistaken views underlying this assumption: that the enjoyment of life for disabled people is necessarily less than for nondisabled people; that raising a child with a disability is a wholly undesirable thing; that selective abortion will save mothers from the burdens of raising disabled children; and that we, as a society, have the means to decide who is better off not being born. Using the literature written by people with disabilities, from the international disability community in the United States, Canada, Britain, Germany, and Japan, as well as feminist critics of PND, I will explore some of the current and historic origins of these pervasive assumptions and examine the views of people with disabilities about the message sent by prenatal diagnosis and selective abortion, as well as the impact of these technologies on the general population's attitudes about disability.

"The Medical Model" of Disability and the Need for Screening

Medical sociologist and disability activist Irving Zola explored the role that the medical system has in people's lives. Zola wrote:

[Medicine] is becoming the new repository of truth, the place where absolute and final judgments are made by supposedly morally neutral and objective experts. And these judgments are made, not in the name of virtue or legitimacy, but in the name of health.¹
The impact of the medical system’s views and influence is especially prominent in the lives of people with disabilities, as a result of the additional time many disabled persons spend interacting with medical personnel. This may be due to the need for more extensive medical service, but also to the fact that many of the services and benefits available to disabled persons are controlled by medical “gatekeepers” who certify eligibility to various social institutions, such as the Social Security Administration (for income support, if disability affects employment), the division of motor vehicles (for special parking), or the housing authority (for eligibility to accessible housing programs).

Within the medical system’s view, disability is defined as a biological problem or limitation.\textsuperscript{4} Thus, the social consequences of disability, such as high unemployment and low educational levels of people with disabilities, resulting in low socioeconomic status, are thought to be caused by physiological limitation.\textsuperscript{5} A fundamental assumption in the medical view is that greater degrees of disability (defined by medical standards as increased pathology) are associated with decreased quality of life.\textsuperscript{6} This view is often referred to in the disability community’s literature as the “medical model of disability.” Inherent in this medicalized view is the assumption that the source of any problems related to the disability is located within the individual or within the individual’s body. According to Adrienne Asch, the core of the medical model view is that “disability must be prevented, because disabled people cannot function within existing society.”\textsuperscript{7}

Tay-Sachs disease is often raised by medical professionals as justification for prenatal screening. But as a rare disease, it’s a poor basis for a paradigm. As epidemiologist Abby Lippman says, “Rare cases make bad policies.”\textsuperscript{8} Conditions receiving priority attention for prenatal screening are Down syndrome, spina bifida, cystic fibrosis, and Fragile X, whose clinical outcomes are usually mildly to moderately disabling. Individuals with these conditions can live good lives. There are severe cases but the medical system tends to underestimate the functional abilities and overestimate the “burden” of these disabled citizens.

Medical language reinforces negativity, asserts Laura Hershey, a disability advocate from Tennessee: “Terms like ‘fetal deformity’ and ‘defective fetus’ are deeply stigmatizing, carrying connotations of inadequacy and shame. Many of us have been called ‘abnormal’ by medical personnel . . . who view us permanently as ‘patients’ subject to the definitions and control of the medical profession.”\textsuperscript{9} Says Diane Coleman, another activist from Nashville, “Maybe they see us as failures on their part.”\textsuperscript{10}
The view of disability developed by people with disabilities is very different from the medical view. The "disability paradigm" was made prominent in the late 1970s. This view regards disability as a socially constructed phenomenon and is based on a view of disabled people as a minority group, much like women or persons of color targeted with social discrimination and denied full access to the mainstream life of the community. According to this perspective, once the oppression is revealed, the assumptions of the medical view (the more impaired, the less quality of life) are exposed as false.

It is important to note that authors from within the disability community have conceded that disability itself is not inherently a neutral condition but constitutes a real loss apart from the socioeconomic loss that results from oppression:

The inability to move without mechanical aid, to see, to hear, or to learn is not inherently neutral. Disability itself limits some options. ... It is not irrational to hope that children and adults will live as long as possible without health problems or diminished human capacities.

Among many socially stigmatized groups such as people of color and gay people, their "inherent characteristics" have been blamed by society for their lower socioeconomic status and/or used as justification for their social mistreatment or ostracism. The view expressed by Asch previously in this volume acknowledges that the experience of disability does not neatly reflect the experiences of these other social groups for whom negative judgments about their personal characteristic have been exposed as resulting solely from oppression. Acknowledging this does not confirm the medical model conceptualization of disability. One's options in life as a person with a disability may indeed, in some ways, be limited, but oppressive social conditions have so distorted the public's perceptions, as well as how disabled individuals themselves might internalize these perceptions, that it is difficult to assess the true impact of disability on the individual's life experience.