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Op-Ed

The Uncertain Rationale for Prenatal Disability Screening

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On November 10, 2005, an article in *The New England Journal of Medicine* reported the increasing accuracy of first trimester screening for Down syndrome. The introduction of first trimester tests for the condition was heralded in 1998 by the National Institute of Child Health and Human Development (NICHHD), as reducing complications for women who choose abortion. NICHHD reportedly spent $15 million on the study—presumably to fulfill its mission "to ensure that every person is born healthy and wanted." Of course, few children with trisomy 21 detected in the first trimester are likely to be born at all. NICHHD's mission is also "to ensure that women suffer no harmful effects from reproductive processes," and that goal may also have provided a rationale for funding the research—many women might see the birth of a child with Down syndrome as a "harmful effect" of their pregnancy. We suggest that *it is difficult to justify prenatal screening for disability on either of these grounds, as protecting the health of the fetus or child or as protecting women from harmful effects of reproduction*.

Prenatal diagnosis—through amniocentesis, chorionic villus sampling, or preimplantation genetic dianosis (PGD); for Down syndrome, cystic fibrosis, female gender, or blue eyes—needs to be seen for what it is, or more importantly, what it is not. It is not a medical procedure—that is, a procedure intended to protect or restore an individual's physical or mental health. Rather**,** it is typically a procedure to identify unwanted organisms. Occasionally, testing is sought to guide the management of delivery and labor. But far more often its purpose is to provide information about fetal characteristics so a woman can decide whether or not to continue her pregnancy.

To say that prenatal testing and any resulting abortion are not medical procedures is not to say that they are wrong or that a doctor is wrong to perform them. A pregnancy test for an unmarried adolescent who does not want a child is not a medical procedure either, nor is the abortion that may follow positive pregnancy test results. We may regard that test and abortion as justifiable, and regard a doctor as the appropriate agent to carry them out, without believing that they serve to protect or restore the health of an individual patient. If doctors can properly perform a non-healing intervention in aborting the unwanted fetus carried by a teenager, can they do so in enabling parents to prevent the birth of a child with Down syndrome?

The answer will depend on whether there is a distinct justification for the intervention that is not based on protecting or restoring the health of individual patients. Two rationales are often given for the use of prenatal testing, and both gain spurious strength from their conflation with stronger rationales for different practices. The first is the public health rationale of reducing the incidence of genetic disease and “defects.” This rationale elides the striking difference between prenatal testing and true medical preventive measures: for the foreseeable future, prenatal testing can prevent disease and disabilities only by preventing the existence of people who would bear them. Prevention by prenatal screening lacks the obvious justification of most public health measures: preventing medical harm to existing people. While it may be reasonable to treat the incidence of disability among existing people as, in part, a public health problem, it is problematic to treat the existence of future people with disabilities that way. A policy of prevention-by-screening appears to reflect the judgment that lives with disabilities are so burdensome to the disabled child, her family, and society that their avoidance is a health care priority—a judgment that exaggerates and misattributes many or most of the difficulties associated with disability.

We believe the principal difficulties faced by people with disabilities and their families are caused or exacerbated by discriminatory attitudes and practices that are potentially remediable by social, legal, and institutional change—in much the same way that many of the difficulties associated with being African American or female in America have been ameliorated. A policy that promotes selection against embryos and fetuses with disabling traits conveys the strong impression that the problem is the disability itself rather than the society that could do so much more to welcome and include all its members.

The second rationale offered in support of prenatal screening is the enhancement of parental autonomy. The justification for enabling a woman to decide *whether* to have a child is stronger than the justification for enabling her to decide *what kind* of child she will have. Pregnancy makes massive demands on a woman’s body; parenthood involves an enormous, open-ended commitment. To treat the difference between having a disabled and a nondisabled child as being of a similar magnitude as the difference between having and not having a child greatly exaggerates the burden of disability and ignores the source of so much of that burden.

We recognize that people with disabilities and their families face difficulties in our present society and that perhaps some of those difficulties would remain even after comprehensive social reform. But we maintain that few disabilities are so undesirable that they provide good reason for abandoning a parental project, for declining to become a parent to the child who would develop from the diagnosed fetus. Given the difficulties that a disabled child is likely to face in our present society, a prospective parent may have good reason not to *cause* disability, but that is not reason enough to *select against* a fetus with a disability. In creating families, prospective parents should aspire to an ideal of unconditional welcome; an ideal opposed to the exercise of selectivity through prenatal testing. If a child develops a disease or disability—diabetes or attention deficit disorder—loving parents incorporate the challenges posed by that condition into the project of raising and nurturing him. We do not believe that parents should reject those challenges in bringing future children into their families. (It is important to recognize that most disabilities are caused by accidents or disease, not by genetic variations.)

If, however, we accept the use of biomedical technology to give parents greater choice in the kind of children they have, we should not limit that choice to the avoidance of genetic impairment; we should facilitate testing for any conditions parents might find burdensome or desirable. And even if we are comfortable with such parental selectivity, enhancing it clearly should not enjoy the priority given to measures that protect the choice about whether to become a parent in the first place.

On the other hand, if we object to such unfettered choice as corrupting or debasing the parental role, we should not make an exception for disability. To do so is to treat disabilities as uniquely burdensome, in the face of strong contrary evidence from research on families with disabled children [1-5]. To assume that most genetically detectable disabilities impair the prospects for individual and family flourishing in a way that other potentially detectable characteristics do not is truly to stigmatize disability. While such stigmatization is understandable when it is displayed by anxious couples awaiting a life-transforming event, it should not guide the public funding of reproductive research or the formulation of reproductive policy.

Given the difficulties in justifying the public funding of research and development in prenatal screening, the money spent for that purpose might be better used for research on improving the health, functioning, and longevity of children with genetically based disabilities.

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Suggested Reading

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