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OP-ED

Informed Consent and Prenatal Testing: The Kennedy-Brownback Act

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For more than 2 decades, some supporters of reproductive choice have contended that the manner in which prenatal testing is typically offered to pregnant women, and positive results typically explained, does not adequately ensure informed consent [1, 2]. These critics have objected to the descriptions of testing given to women by their physicians and have challenged the type and quality of information women receive about diagnosed fetal conditions. Recent legislation provides the impetus for long-sought reforms, but, while we applaud its potential, we think it valuable to acknowledge its limitations.

Reproductive health professionals face difficult questions in providing pregnant women with accurate, relevant, and balanced information about prenatal testing for disease and disability. Among these questions are: (1) when is the best time to introduce the subject of testing; (2) what type of information about the tests do prospective parents want or need; (3) what is the proper balance between medical information and information on nonmedical aspects of life with a particular disease or disability; (4) how can the perspectives of people living with the conditions and their families best be included; and (5) how can uncertainty about the applicability of general information to a specific child and family situation be conveyed? These questions have taken on greater urgency as the number of conditions for which tests are available proliferates and their use becomes increasingly routine. In October 2008, Congress made a promising start in addressing these questions by enacting the Prenatally and Postnatally Diagnosed Conditions Awareness Act (referred as the “Kennedy-Brownback Act” or “Brownback-Kennedy Act”) with broad bipartisan support [3].

The act requires the federal government to arrange for the collection and dissemination of up-to-date, evidence-based information about the conditions subject to prenatal and early postnatal diagnosis. This information encompasses “the range of outcomes for individuals living with the diagnosed condition, including physical, developmental, educational, and psychosocial outcomes.” Such information should provide a powerful corrective to the “bad news” typically delivered to pregnant women whose fetuses are diagnosed with the tested conditions. A body of research suggests that much of the information now supplied is heavily biased, outdated, highly inaccurate, and almost always narrowly clinical [4]. The act may have an even greater impact on prenatal decision making, however, if it helps to reframe how women and their physicians view decisions about continuing or terminating a pregnancy in the face of positive test results.

Information on the range of outcomes for individuals *living with* the diagnosed condition (emphasis added) may help pregnant women and their partners see their decision as one about parenting a child who will have a disabling trait, not about preventing disability. Ideally, the information will enable them to resist the tendency to see the fetus or child merely as the bearer of a disability or disease. Receiving that information may shift attention from the accuracy of a positive test result to its significance for the lives of prospective parents. As the Boston Women's Health Book Collective notes in its 2007 chapter on prenatal testing addressed to pregnant women:

The main reason that the test won't give you as much information as you might like is that knowing your child has Down syndrome, cystic fibrosis, or spina bifida tells you little or nothing about your child's future interests, talents, appearance, or personality. The test provides only one piece of information. You will need to consider how a child's spina bifida, for example, will be a part of the child's life and yours. Imagine that one of your family activities is camping. Can you learn what you would need to know to help a child with a mobility impairment to camp with you? If your family loves reading and intellectual conversation, can you imagine raising a child who has cognitive impairments from Down syndrome and won't be able to always understand what others are talking about [5]?

If the doctor herself lacks access to developmental, educational, and psychosocial information to supplement data on medical outcomes of people with Down syndrome, cystic fibrosis, sickle cell anemia, and other conditions that can now be diagnosed, she is unlikely to be of much help in addressing these questions. Too many professionals who offer prenatal testing do not know that most people with disabilities lead complex lives that are not constantly dominated by their impairments. Even generally well-informed and conscientious physicians may not have the necessary experience or knowledge, since their exposure to individuals with the diagnosed condition is often limited to acute health crises and requests for medical services. Admittedly, the act does not require doctors to obtain or communicate information about the lives of people with the diagnosed conditions. But it ensures that they and their patients can easily acquire such information, as well as information about laws, services, and family support geared to those raising children with the hundreds of disabilities for which diagnostic testing is available.

Two recent studies suggest that the broader focus encouraged by the act may have an impact on reproductive decision making. Gottfredsdottir et al. found that the minority of prospective parents who declined prenatal-disability screening tended to be familiar with individuals who had disabilities [6]. And Kelly discovered that parents who already had a child with a congenital disability generally declined to select against future children with that condition; the largest group had no additional children; the second largest declined testing in later pregnancies; and the third largest group tested only for information, with no intent to abort based on the test results [7]. These studies suggest that prospective parents who see disability in the context of full human lives—those of the children they are raising or of their friends and

acquaintances—are less likely than other prospective parents to use prenatal testing at all or to use it to screen out children with disabilities.

For all its potential value, the act has a built-in limitation: it mandates better information only for women who have already been tested and received positive results, not for women deciding whether to obtain testing. In 1997, Press and Browner reported that women were being presented with prenatal testing as part of routine prenatal care, often calling it “just another blood test” [8]. Many were not told that the test concerned fetal health, not their own health, or that the results would not help them or their doctor manage their pregnancy or improve the health of their fetus. The option of abortion in the face of positive results was rarely mentioned. A 2009 study suggests the continuing failure of health professionals to explain the implications of prenatal testing to pregnant women: “Approximately one half of the women surveyed who underwent both ultrasound and biochemical screening did not foresee that they might ultimately be confronted with the need to make the decision about whether or not to terminate the pregnancy” [9]. This failure should trouble conscientious health professionals because it means that pregnant women are being led to obtain information they may not want to have and to make decisions they may not want to make.

Because the Kennedy-Brownback Act is not directed to women facing the threshold decision about whether to test, the information it mandates may come too late in the process to be fully effective in reframing prenatal decision making. A woman who has already been led to regard such testing as a routine part of fetal medical care may have difficulty in seeing the testing as a prelude to a decision about what kind of child she is willing to parent. She might not want to make that decision, and, if she had understood the test’s purpose before consenting to it, she might have refused to put herself in a position where she had to make it.

Women who want to test their fetuses prenatally should be able to do so, but they should only be offered testing as part of a process of exploring their goals and values for parenting and family. Reproductive autonomy requires that pregnant women have access to comprehensive information about the potential rewards and challenges of living with, or raising a child with, a disability. The kind of information they need depends on their goals and values.

We conclude, then, that the Kennedy-Brownback Act is best seen as the first stage in restructuring the prenatal-testing process. Testing should never be routine; it should only be introduced in discussing the expectations, goals, and values of the prospective parents. What do they imagine for their child, children, and themselves? Would their aspirations and dreams be thwarted or compromised by having a child with Down syndrome, spina bifida, retinoblastoma, or hemophilia? Full reproductive autonomy will only be possible when professionals can convey to prospective parents that they are free to test their fetuses or to decline testing and that it is as legitimate to become the parent of a child who will have a disability as it is to decline to do so. The act is an important first step, but only a first step, in ensuring that

pregnant women can make genuinely informed and uncoerced choices about prenatal testing.

References

1. Asch A. Prenatal diagnosis and selective abortion: a challenge to practice and policy. *Am J Public Health*. 1999;89(11):1649-1657.
2. Press N. Assessing the expressive character of prenatal testing: the choices made or the choices made available. In: Parens E, Asch A. *Prenatal Testing and Disability Rights*. Washington, DC: Georgetown University Press; 2000: 214-233.
3. Prenatally and Postnatally Diagnosed Conditions Awareness Act, PL No 110-374; 2008.
4. Lippman A, Wilfond BS. Twice-told tales: stories about genetics disorders. *Am J Hum Genet*. 1992;51(4):936-937.
5. Boston Women's Health Book Collective. *Our Bodies, Ourselves: Pregnancy and Birth*. New York, NY: Touchstone Book; 2008: 109-127.
6. Gottfredsdottir H, Bjornsdottir K, Sandall J. How do prospective parents who decline prenatal screening account for their decision? A qualitative study. *Soc Sci Med*. 2009;69(2):274-277.
7. Kelly SE. Choosing not to choose: reproductive responses of parents of children with genetic conditions or impairments. *Sociol Health Illn*. 2009;3(1):81-97.
8. Press N, Browner CH. Why women say yes to prenatal diagnosis. *Soc Sci Med*. 1997;45(7):979-989.
9. Seror V, Ville Y. Prenatal screening for Down syndrome: women's involvement in decision-making and their attitudes to screening. *Prenat Diagn*. 2009;29(2):120-128.

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