

What's Lost in Prenatal Testing Why Encourage Testing for Down Syndrome

By Patricia E. Bauer

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She was a fresh-faced young woman with a couple of adorable kids, whiling away an hour in the sandbox at the park near my home. So was I, or so I thought. New in town, I had come to the park in hopes of finding some friends for myself and my little ones.

Her eyes flicked over to where my daughter sat, shovel gripped in a tiny fist, and then traveled quickly away. The remark that followed was directed to the woman next to her, but her voice carried clearly across the playground. "Isn't it a shame," she said, an eyebrow cocked in Margaret's direction, "that everyone doesn't get amnio?"

It's been more than 20 years, but I saw the face of that woman again when I read about the recommendation from the American College of Obstetricians and Gynecologists (ACOG) this month that all pregnant women get prenatal screening for Down syndrome. I worry that universal screening brings us all closer to being like that woman at the sandbox -- uninformed, judgmental and unable to entertain the possibility that people with disabilities have something to offer.

The ACOG news release notes that the recommendations are based on consistent scientific evidence and will allow obstetricians and gynecologists to best meet their patients' needs. Until now, women 35 or older were automatically offered genetic testing for Down syndrome; under the new guidelines, less invasive and earlier screening options will be extended much more broadly.

What's gone undiscussed in the news coverage of the guidelines seems to be a general assumption that reasonable people would want to screen for Down syndrome. And since nothing can be done to mitigate the effects of an extra 21st chromosome in utero, the further assumption is that people would be reasonable to terminate pregnancies that are so diagnosed.

Certainly, these recommendations will have the effect of accelerating a weeding out of fetuses with Down syndrome that is well underway. There's an estimated 85 to 90 percent termination rate among prenatally diagnosed cases of Down syndrome in this country. With universal screening, the number of terminations will rise. Early screening will allow people to terminate earlier in their pregnancies when it's safer and when their medical status may be unapparent to friends and colleagues.

I understand that some people very much want this, but I have to ask: Why?

Among the reasons, I believe, is a fundamental societal misperception that the lives of people with intellectual disabilities have no value -- that less able somehow equates to less worthy. Like the woman in the park, we're assigning one trait more importance than all the others and making critical decisions based on that judgment.

In so doing, we're causing a broad social effect. We're embarking on the elimination of an entire class of people who have a history of oppression, discrimination and exclusion.

Much of what people think they know about intellectual disabilities is inaccurate and remains rooted in stigma and opinions that were formed when institutionalization was routine. In fact, this wave of terminations and recommendations comes as people with Down syndrome and other intellectual disabilities are better educated and leading longer, healthier and more productive lives than ever.

Nowhere in the fine print of the ACOG recommendations are these misconceptions or the advances of recent years recognized. Perhaps this is not surprising: OB-GYNs concern themselves primarily with mothers and well babies, not people with intellectual disabilities. But it's frightening, too, when you consider the millions of lives affected by their guidance, explicit or otherwise.

Federally funded research has found that physicians have lower expectations for people with intellectual disabilities than do other professionals. Some 81 percent of medical students polled by Special Olympics in 2005 said that they are "not getting any clinical training" about people with intellectual disabilities. The Hastings Center found that 80 percent of genetics professionals polled said they personally would terminate a pregnancy involving Down syndrome. These are the people advising pregnant women in the harried days when the clock is ticking.

Here's my fervent hope: that calls for universal prenatal screening will be joined by an equally strong call for providing comprehensive information to prospective parents, not just about the tests but also about the rich and rewarding lives that are possible with disabilities. If physicians and genetics professionals are willing to learn from people with disabilities and their families, they can disseminate the nuanced, compassionate message at the core of diversity and human rights: All people have value and dignity and are worthy of celebration.

Plastic shovels no longer captivate Margaret. She's more interested in her school roommates, her part-time job, the Red Sox and, at least recently, wrestling on TV. She knows how to hold an audience and how to bring down the house with a one-liner. And, like most of my relatives, she knows how to be

an absolute pill some of the time. Such is life.

That day in the sandbox, I went home and cried. I didn't know what to say. I didn't know whether the woman was right. Today, I know. She was wrong.

The writer is a former Post reporter and bureau chief. Her e-mail address is patriciaebauer@aol.com.