

Down Syndrome Is a Part of Who My Daughter Is

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I remember how I felt two hours after my daughter Penny was born, when I first found out she had Down syndrome. I wracked my brain for information about this thing that had just happened to our family. All I could come up with was early death and mental retardation. The doctors didn't help much. In the hospital, we received a list of all the things that might go wrong: heart defects, leukemia, celiac disease, developmental delays.

Two years later, I'm pregnant again. Recently a colleague exclaimed, "I didn't know you were expecting!"

I grinned and patted my round belly: "Hard to miss."

"I assume you've done all the screening on this one to find out, if, you know . . ."

I tried to explain why I wasn't opting for amniocentesis, why I was uncomfortable with the prenatal testing industry in general, and why I wasn't particularly concerned about having another child with Down syndrome. She didn't seem to understand.

Penny is 27 months old. She says "no" with the gusto of any of her peers. She uses spoken and signed words to tell me what she did at school today, and the names of her friends, and what she would like for her afternoon snack. Penny loves music. She's learning her shapes and colors. She gives lots of hugs. She's also very small, and she wasn't able to walk steadily until a few months ago. She is my daughter. She is my daughter with Down syndrome.

Asking whether I am at risk for having another child with Down syndrome (statistically speaking, yes, my "risk" at age 31 being 1 in 100), is akin to asking whether I am at risk for having another child with brown hair, gorgeous green eyes, her father's hand-eye coordination, or her mother's love for books. It implies that Down syndrome is something separate from Penny, something that could be extracted if only we had the proper tools and procedures. But that extra chromosome is intrinsic to Penny's being. To take away Down syndrome is to take away Penny.

Later, I heard a report on NPR about a new ethics recommendation from the American College of Obstetricians and Gynecologists (ACOG), stating that doctors unwilling to provide abortions have an obligation to refer their patients to another physician who will provide them. The spokesperson said: "If a physician has a personal belief that deviates from evidence-based standards of care . . . they have a duty to refer patients in a timely fashion if they do not feel comfortable providing a given service."

Studies show that women who receive a prenatal diagnosis of trisomy 21 (the technical term for Down syndrome) terminate the pregnancy 85 percent of the time. Since new medical guidelines - including "evidence-based standards of care" - suggest that all women, regardless of age, be screened for trisomy 21, it is most likely that the number of prenatal diagnoses, and the number of terminated pregnancies, will increase. Evidence-based

standards of care result, more often than not, in the elimination of people like my daughter from our society.

As a result, I am somewhat skeptical about the standard of care offered to these mothers. I'm skeptical, too, when "personal beliefs" are pitted against evidence, implying that a physician unwilling to perform an abortion has defied ("deviated" from) the facts. I understand that many women face unbearably difficult choices about the health of their babies. Some choose to terminate their pregnancies because they have been given information about the near certainty of physical abnormalities and high possibility of early death. Yet many also choose to terminate based on probabilities, fear and misinformation. In the case of Down syndrome, many receive incomplete and outdated data.

The most recent ACOG parent education brochure entitled "Genetic Disorders," published in 2005, defines Down syndrome as "a genetic disorder resulting from an extra copy of the 21st chromosome in which mental retardation, abnormal features of the face, and medical problems such as heart defects occur." The brochure reads the same as the brochure published in 1995; by definition, it is not up-to-date.

One has to hope that in following "evidence-based standards of care," doctors and nurses will do better by their patients than 10-year-old boilerplate. I hope they include the fact that the life expectancy of people with Down syndrome has doubled in the past 25 years, or that the average IQ of a person with Down syndrome has doubled over the course of the 20th century, or that many physical "defects" can be corrected relatively easily because of advances in medical care. (Penny had a hole in her heart, for instance, that may well have killed her a few decades ago. Now, it didn't even warrant an overnight stay in the hospital.)

I will follow my doctor's orders and have a level 2 ultrasound. I will pray that this baby's heart, lungs, brain and limbs look healthy and whole. I will try to remember what I felt when the words *Down syndrome* first became a part of our reality. I will try to have compassion for every person who has trouble understanding the blessing Penny is to our family.

I will also hope and pray that physicians advising women who are frightened, confused and faced with life-changing decisions will offer those women a true choice, an informed choice, a choice based on the evidence that all of life is fragile and uncertain, with potential for heartbreak, and for great joy.