

A Wanted Child

A NEW RECOMMENDATION CALLS FOR PRENATAL DOWN SYNDROME SCREENING FOR ALL PREGNANT WOMEN - THE CHANGE HAS ONE MOTHER TOUCHED BY AUTISM REFLECTING ON HER CHOICE.

By SUSAN SENATOR | April 8, 2007

It is part of being human to wonder how our lives could have been different, if only this or that had not happened. As the mother of a fairly severely autistic 17-year-old, I have certainly wondered what my life would have been like without him.

Nat has not been an easy child to raise. At 3, he seemed completely withdrawn, in his own world, mesmerized by twirling string and water droplets. At 7, he stopped sleeping the night, waking up at 2 a.m. or thereabouts with loud, maniacal laughter. At 10, he was expelled from a special education program in a nearby town because he had become aggressive and unpredictable.

Knowing what I have gone through, people sometimes say to me, "Oh, he's lucky to have you." These well-meaning folks probably don't realize how I hear this: that there is something essentially unlovable about Nat. What they don't understand is that difficult does not equal unlovable.

So when I learned that the American College of Obstetricians and Gynecologists in January had changed its recommendations for prenatal screening for Down syndrome from pregnant women 35 and older to all pregnant women, I found myself worrying about how many otherwise "lucky" children would now never see the light of day. And what might I – an abortion-rights supporter for so long – have done had there been such a screening for autism, before I knew Nat? Now I shudder to think of it. But given that so much of what you hear in the media involves stories of struggle or horrors like the stabbing at Lincoln-Sudbury Regional High School, rather than any of the positive potential of autistic people, autism may be forever tied to tragedy. I fear what many people might do with information from an autism screening, if it existed.

Certainly many people choose not to abort a fetus with a known disability and instead prepare themselves for this child's needs. Former Harvard academic Martha Beck wrote about her choice not to terminate her fetus with Down syndrome in the book *Expecting Adam: A True Story of Birth, Rebirth, and Everyday Magic*. People like Beck are not saints. However, they do seem to possess a certain basic humility – an understanding that life is not always what we expected it to be.

Not getting the life we signed on for is something that privileged, educated, technologically savvy Americans are ill-prepared for. It is intolerable, even incomprehensible, that we have to deal with something we do not want, from our appearances to our jobs to our child's future. With enough money and time, you can change many things. You don't like your body? Get some surgery. You want your kid to go Ivy League? Send him to prep school. And if your pregnancy screens show disability, you don't have to suffer. And, you tell yourself, neither will this child.

When you give birth to a child with a disability, you learn – breathlessly and relentlessly – how life can be beyond your control. Things become even more complicated as the children grow into adults. Little can compare with the difficulty of living with a very autistic pubescent boy. Yet my husband and I managed. We taught Nat about privacy, and he even came up with his own term for masturbation: "making privacy"; we were so proud of him for that. Then there were the other achievements, attempted again and again, such as when he finally made a real friend, at the age of 15, or recently learned how to play on a basketball team.

Today, Nat presents a very different profile from his difficult childhood one, that of a young man who can control his impulses, attend school, and hold a job. Nat is not Harvard-bound. But he is a sweet soul and a real part of the family. Though difficult to understand, talk to, or even be around, he has taught us many times over how to be happy with even tiny triumphs. If not for Nat, I might have never learned just how hard life can be and how strong I really am.

I guess you could say I am lucky to have him.

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