

A Day in the Life

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Manuscript Received: 29 January 2014; Manuscript Accepted: 14 February 2014

AUTHOR BIO SKETCH

Rachel Adams is Professor of English and American studies at Columbia University. Her most recent book is *Raising Henry: A Memoir of Motherhood, Disability and Discovery*, published by Yale University Press in 2013. She is the author of many academic articles, and has also published essays on parenting and disability in *The New York Times*, *The Times of London*, *The Chronicle of Higher Education*, *Salon*, and *Huffington Post*.

When my son Henry lay on the floor in the middle of the school holiday fair and refused to budge, my heart sank. Although he was blocking the path to the food table, the other parents stepped over him, not seeming to mind very much. Plenty of kids were acting up, and I knew Henry was overwhelmed by the noise and chaos in the gym. His obstinacy wouldn't have bothered me so much if it weren't for the visitor observing our every interaction. Our guest was Carrie, a graduate student in genetic counseling assigned to spend the afternoon with our family as part of an experiential learning program. Seeing a day in the life of Henry, who is six and has Down syndrome, was supposed to give her insight that she could use to help prospective parents better understand the meaning of genetic disability.

Carrie isn't the first genetic counseling student we have met. Since Henry's birth, I've spent a lot of time around genetic counselors. They are curious to meet people with Down syndrome and their families, and I appreciate their willingness to listen and learn from us. I tell them they can ask me anything. Given their intended profession, they usually focus on my pregnancy, our choices about prenatal testing, and the kind of information and counseling we received. Behind their polite questions, I sense their curiosity about how a child like Henry came to be born to my husband and I, well-educated, successful parents with the best prenatal care at their disposal. When I'm asked, I tell them honestly: The truth is that although I was over 35 at the time Henry was conceived, our triple screen revealed a very low likelihood of genetic disability and we saw no reason to risk a healthy pregnancy by having an amniocentesis. We didn't learn that Henry had Down syndrome until after he was born. Because we live at a moment of increasingly routine prenatal screening, our personal decision became publicly visible.

When I meet genetic counselors like Carrie, I want them to understand what's unique about parenting a child with Down syndrome at this particular moment in history. In many ways, Henry was born at the best possible time to be a person with Down syndrome. Thanks to advances in health care and medical understanding, expectations for the quality and duration of his life have

increased dramatically over previous generations. The passage of the Individuals with Disabilities Education Act (IDEA) and the Americans with Disabilities Act (ADA) mean he has a right to education and the support he needs to live as independently as possible. People with Down syndrome are breaking barriers of all kinds as they excel in music and the arts, get elected prom kings and queens, go to college, skydive, open restaurants, and run marathons. Even if Henry doesn't become a Down syndrome over-achiever, we have good reason to hope that, as an adult, he will find meaningful work and social opportunities that would have been unthinkable in the not-so-distant past.

But when it comes to genetics, people with Down syndrome are increasingly embattled. Even as opportunities for people with disabilities expand, research to develop cheaper and safer means of prenatal genetic testing races ahead. On its website, Sequenom promotes the speed and effectiveness of its non-invasive Materni21PLUS test. Recent legal disputes with its competitors over patenting rights attest to the fact that there is money to be made off tests that will soon be administered to all pregnant women, regardless of age or any other factors that might increase the likelihood of bearing a child with a genetic disability.

Although Sequenom's product tests for a range of genetic disabilities, it is called Materni21PLUS, a name that draws particular attention to Down syndrome, or Trisomy 21. Since Down syndrome is the most common, visible, and well known of all genetic disabilities diagnosed prenatally, it is not unusual to hear these tests described as "the Down syndrome test." The consequence of this shorthand is that people who know nothing else about genetic disability have heard of Down syndrome, and tend to see it as a stand-in for all that is unwanted and disastrous in a pregnancy. Down syndrome is increasingly seen as a preventable mistake, an error of judgment or a case of science gone awry.

I've talked to genetic counseling students about how becoming Henry's parent has forced me to confront my own deeply-held commitment to women's reproductive freedom. I have always believed (and still believe) in a woman's right to have a safe and

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Conflict of interest: none.

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Article first published online in Wiley Online Library

(wileyonlinelibrary.com): 00 Month 2014

DOI 10.1002/ajmg.a.36534

legal abortion for any reason. But I object to the bias and misinformation that surrounds prenatal testing, and to the assumption that a positive diagnosis should always lead to a discussion about termination. Advocates of the new tests claim that they maximize choice, but can this really be true when women are offered inadequate or prejudicial information? Research shows that the number of women who choose to abort a fetus with Down syndrome diminishes significantly when they are given full, unbiased information about the meaning of that diagnosis. Still, in an era of routine prenatal testing, the majority of women who receive a positive diagnosis will terminate a pregnancy. This means that genetic counselors—most of them young, white women with the best of intentions and very little personal experience to draw on—find themselves on the front lines of wrenching life-and-death decisions. And children born with Down syndrome in this new era are inevitably seen as the result of highly charged decisions made by their parents.

When someone like Carrie comes around, here's my dilemma. Is my goal to give genetic counselors-in-training the fullest possible picture of raising a child with a disability? Or is my goal to be a cheerleader, promoting positive images of people with Down syndrome and proving how much they have to contribute to the world? I want Carrie to see that, like any child, Henry brings joy and frustration to our family. He fills my life with a remarkable sense of purpose at the same time that he makes it very complicated. On his best days, Henry would show a visitor that he is charismatic, affectionate, and clever. He has a great sense of humor and loves to laugh. He also loves the Muppets. His favorite "stuffies" are Fozzie Bear and a Kermit the Frog so well-loved his plush face split open and had to be patched back together. When we let him, Henry will watch *The Muppet Show* for hours at a time. He can recite entire sketches word for word and likes to ask for particular episodes by the name of the guest star. "I want Juliet Prowse!" he'll call out. Or, "Avery Schreiber tonight!" Henry loves chocolate, and his big brother Noah. Like all siblings, Henry and Noah fight and wrestle with each other, but at the end of the day there is nobody Henry admires more. He thinks every happy occasion is a birthday. When I come home from a trip, he will wrap his arms around my neck, and murmur, "Happy birthday, mom. Happy birthday." These wonderful qualities are very specific to my son. None of them has much to do with Down syndrome, nor can they be predicted by a genetic test. But seeing the best in Henry, a genetic counseling student might be vividly reminded that a diagnosis of Trisomy 21 tells only a very small part of the story about the person a fetus or new baby will become. She might learn that parenting a child with Down syndrome can bring the same happiness as parenting any other child,

and that a diagnosis of Down syndrome is not a tragedy, at least for our family.

None of Henry's good qualities were on display when he lay on the floor at the school fair, eventually requiring me to drag him out like a bag of wet cement. As I shoved him into his jacket, I wondered what the genetic counseling student would make of our struggle. Henry had been impulsive and defiant. When Noah tried to make him laugh, Henry had swatted at him irritably. When I asked him if he wanted to go home, he growled like an angry dog instead of showing off the clear speech he was developing after many years of therapy. Most of these behaviors can't be attributed to Down syndrome either. Plenty of children act out when they find themselves overwhelmed by noise and crowding. Lots of children sense when their parents desperately want them to perform and do exactly the opposite.

Of course, there are also challenges of parenting Henry that can be more directly attributed to Down syndrome. He has required extensive therapy to combat his low muscle tone and speech delays. Finding a school that could offer the extra support he needs to learn was a massive and costly ordeal. He still requires a lot of help with basic self-care like putting his shoes on, going to the bathroom, and brushing his teeth. A part of me thinks it is important for a genetic counselor-in-training to be aware of these challenges so that she can better help families determine whether they are equipped to bring a child with disabilities into the world. Surely, she would also recognize that we love our son, and that we find parenting him no less joyful or rewarding because of his disability. The problem is, I don't think I want my child to be the poster boy for what's hard about raising a child with disabilities, especially not for someone who will be counseling pregnant women deciding whether to abort an otherwise wanted fetus because it has been diagnosed with Down syndrome.

A week later, Henry's school had its annual Festival of Light holiday celebration. Henry was beaming as he stood onstage to sing along with the rest of his kindergarten class. When the song was over, he spotted his brother in the audience and ran into his arms. I wished Carrie could have seen him then. I wished her program allotted us more than a few hours together, which is hardly enough time to give a full picture of any family. Most of all, I wished not to live in a world where it's necessary to justify why people with Down syndrome should continue to be born. As we walked outside after the program, it was starting to snow. We passed a Christmas tree stand and the air smelled like pine needles. My husband and I each held one of Henry's hands and he smiled up at us, knowing he had done a good job. This was also my world, and, at that moment, I didn't wish it to be any different.