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## WIDENING CIRCLES

*Rachel Adams*

The resident who stitched me up looked improbably young. I watched his head bobbing between my thighs. Everything was numb enough to block the pain, but still I could feel him handling the most private recesses of my body. I can't remember much about his face, but I know he wore a surgical cap made of colorful print fabric and that his hair was buzzed close to his head, military style.

He finished what he was doing and stepped back to survey his work. Concluding that it was good enough, he told me that the stitches would fall out within a few weeks and left the room.

He must have known, but he didn't show it. He didn't say anything about it to me, and I never saw him again. I guess he thought that his job was done once the baby was delivered. Breaking the news would be left to someone else.

In the stillness that followed, I felt a tremendous sense of calm. A nurse kept moving my new baby to different positions, trying to get him to latch on to my breast. His mouth opened and closed weakly. No sound came out. The room was completely quiet and filled with watery winter sunlight.

A pediatrician from Neonatal Intensive Care arrived. She introduced herself to my husband Jon and me, and told us she was going to examine our baby. She spread him on a heated table and turned her back. A few minutes later, she wrapped him up and handed him to me.

"I was called here because your baby has features consistent with Down syndrome," she said. "He's pink and he looks healthy, but we're going to have to run some tests to make sure his heart is functioning properly."

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The world should have stopped.

"I know this is a lot to take in. Do you have any questions for me?"

Of course I had questions. *How could this be happening? Couldn't you give me just a few more minutes to believe that my baby is perfect? Why did you have to snatch away my fantasy that anything is possible so quickly?*

I shook my head.

"I'll be back later when you've had time to digest this. We can talk more then," she said kindly. She placed our baby in a wheeled cart and pushed him out of the room.

After she left, the room was still quiet and sunny. I still felt calm. I was enveloped in a numbing blanket of hormones. But somewhere beneath the surface, I knew that fear, grief, and rage were roiling.

Jon and I sat in silence. There was nothing to say. I couldn't cry, thanks to the hormones. But I had already begun to mourn the death of the son I thought I was going to have, and the family I imagined we would be. I remember feeling utterly alone, my entire world compressed into the hospital bed. Who among our accomplished, overeducated friends, with their perfectly healthy, perfectly normal children, would understand our grief? Who else, in this city filled with strivers and go-getters and overachievers, would be reckless enough to forgo an amniocentesis at the age of thirty-eight? Where would we find a community to welcome this fragile, unexpected baby?

My mind raced back over the choices that had brought us to this point. When the time came to make decisions about prenatal testing, ours were on the unorthodox side. For most ambitious, professional women of my age, amniocentesis is a requisite stage of pregnancy, a reassuring guarantee of good health and normalcy. Having devoted a good many years to the study of disability, I had different ideas about the knowledge those tests can yield. I knew that no test could guarantee a perfect baby, or even a perfectly healthy one. And I knew that whatever information the genetic analysis revealed, it couldn't predict the person my child would become. When the results of blood work and ultrasound revealed almost no chance that our fetus had Down syndrome or any other genetic disorder, we declined an amnio. We very much wanted this baby, the tests suggested that he was very likely to be healthy, and we didn't want to risk losing the pregnancy. Besides, we reasoned, given all of the things that could go wrong with a child, Down syndrome wasn't even near the top of our list of undesirables.

Things looked very different from the NICU, as I watched my new baby through the plastic walls of his incubator, where he lay in tangle of tubes and wires. It was one thing to profess my appreciation for difference, quite another

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to contemplate bringing it home and making it a part of my life. My research had made me painfully aware of the discrimination faced by people with disabilities in the United States. I knew that my baby—with his extra twenty-first chromosome—had been born into a world that has little tolerance for his kind of imperfection. Later, I would learn that as many as 90 percent of all women choose to abort a fetus diagnosed with Down syndrome. Henry was less than an hour old, and already I was worried about where he would go to school, if he would ever have friends, and whether I was capable of giving him the care he needed.

The hospital offered no answers. Over the next week, Henry was examined by countless doctors. All were attentive and thorough. They answered our questions and explained their concerns about his heart, his muscle weakness, and his problems with feeding. We discussed the treatment he might need over the next weeks and months. Our conversations were always about symptoms. Nobody asked what we were feeling or how we were coping with the unanticipated prospect of raising a child with a disability. Nobody offered to direct us toward people who had shared our experiences. When I asked the hospital's social worker if there was a support group that I could contact, she seemed at a loss. It was as if Henry were the only baby with Down syndrome ever to be born on her watch.

I spent that first long night after Henry's birth alone at the hospital. Lying awake at home, Jon reread Michael Bérubé's *Life As We Know It*, about the first three years in the life of his son Jamie, who has Down syndrome. The crazy thing is that I know Michael Bérubé, who teaches American literature at Penn State University. Our paths had crossed a number of times at conferences, and I once invited him to give a talk for a lecture series I run at Columbia. *Life as We Know It* was the first book I ever reviewed, back when I was a graduate student who never imagined having children of my own. My interest in the field of Disability Studies was purely academic, and I thought Michael Bérubé got it better than just about anyone else.

As soon as I was back on e-mail, and before I told any of our friends in New York about Henry, I sent a message to Michael:

*Dear Michael,*

*My husband, Jon, and I have been rereading your beautiful book, which suddenly has a new meaning for us. Last Monday morning our second son, Henry, was born. Twenty minutes later we were told he had "features consistent with Down syndrome." And over the next few days this careful phrasing evolved into a more*

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*definitive diagnosis, although we still haven't received genetic confirmation. I think you can understand the shock of such news and the effort to manage the jarring disjunction between the particularity of your own beautiful baby and the category that others are already using to define him. In contrast to many of the books and articles we've already read, we've found your stories about life with Jamie to be so heartening and your perspective on what it means to have a disabled child so thoughtful and sensitive. I hope that we can find the kind of wonder and inspiration in Henry's arrival into our family that you have found in Jamie, and that he will teach us to see the world in new ways, as Jamie clearly has done for you. At any rate, you have been in my thoughts so much in the last days that I wanted to write and share our news with you.*

*Very sincerely yours,*

*Rachel*

I will always treasure the message he sent in response.

*Dear Rachel,*

*Wow. My goodness. Well, let's just say I wasn't expecting this e-mail. But first things first—a hearty welcome to Henry! May he always find the world as warm as his parents' arms. And congratulations to his wonderful parents! Of course, I know the parental shock well, though back in 1991 my information was so outdated that I thought Jamie's life expectancy would be about twenty-one or so—and now, of course, I couldn't bear the thought of having him with us for only five more years.*

*You're probably inundated with books and articles and advice, and worries about what the next couple of years—or next couple of decades—will bring. I don't want to wish away those worries; they're real worries, as you know, and the most immediate thing is Henry's health. I hope he's thriving and happy—and that all your doctors and medical personnel understand the concept of "healthy baby with Down syndrome." But over the next few months or so, you'll probably find that the truism is true: babies with Down syndrome are babies first. Henry may reach those grasping-crawling-talking-walking developmental milestones at his own pace, but he'll surely take the same delight in music and play and stimulation that his older brother does, and he'll surely be every bit as beautiful as he is now.*

*Most of all, I share your hope that you find in Henry's arrival the kind of joy we've experienced with Jamie. About our chaotic human lives one can make no*

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*promises, but here's the latest from him: just last month, Jamie proposed that he and I go to New York, because (as he pointed out) we haven't visited the city all year. And because he's now sixteen, I decided to stretch him a little. We dined Friday night at the Plataforma Churrascaria on 49th, played games at ESPN Zone til midnight, slept til 9, got up, hit the Metropolitan Museum at 11 on Saturday (he's on an early modern-baroque binge, and bought a coffee-table book of Caravaggio's greatest hits), went to the Lion King, grabbed a pastrami sandwich for dinner and a 2 train to BAM for some surrealist Japanese dance. Sunday morning it was salsa at Carnegie Hall. He was kinda bored from time to time at the surrealist dance, but then, plenty of other people were too. (Unlike the people who got up and left, Jamie just flipped through his Caravaggio book during the dead spots.) His only disappointment that evening was that we didn't take the Q train over the Manhattan Bridge. The rest of the weekend he spent rubbing his hands together in glee. I know this may seem a bit impertinent when you're dealing with a newborn, but Rachel, when Jamie was a little neonate, nothing made me feel more reassured than the testimonies of older parents with older children, who could tell me from experience that life—in its somewhat altered form—would indeed go on. So I hope this helps. What I'm saying is that you never know. The next few years might be a strain at times, but you're in the greatest city in the world at the best time in history for children with Down syndrome. I know you're inundated with advice, but entre nous, I'd say start the salsa concerts early.*

*Seriously, our hearts and thoughts are with you and Jon. We know very well how weird and disorienting this time can be. (May I forward your letter to Janet?) If you need to get in touch with us for any reason, please feel free to call.*

*And best wishes to all your family from all of ours,*

*Michael*

Michael understood the importance—and difficulty—of separating our baby from his diagnosis. The story he told about Jamie was far from impertinent. What it said to us was: your life is not over. You may not believe it now, but you will be happy again. Like other children, your child will bring you joy and frustration. And he has the same potential for happiness as any other child. I've gone back to his note many times in the years since Henry was born. I remember my despair, and how moved I was by Michael's encouragement and understanding. Every time I read it, I hope that one day I'll write something so meaningful to another new parent caught in the throes of disappointment and fear.

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Michael's message reminded me that I wasn't alone in the decisions I had made or the emotional turmoil I was feeling. My world, which had contracted to the lonely, impersonal space of a hospital bed, started to expand. Gradually, I found that being a mother to Henry didn't isolate me from other people, as I had feared. Instead, he became my bridge to an entirely different city than the one I had been living in for the past ten years. From there, he led me to a global network of people with Down syndrome, their families, and supporters. Although I've written on the subject of globalization, it was only as I learned to be Henry's parent that I came to understand, in a palpable way, what it means to belong to an interconnected world.

I started small. A few days after I got home from the hospital, I called our local chapter of the National Down Syndrome Society. The woman who answered the phone congratulated me on my new baby. This was a refreshing change from the doctors, who talked of our son only in terms of possible medical complications. She gave me the numbers of several families who had volunteered to serve as contacts for new parents. It turns out that when it comes to Down syndrome—as in so many other things—New Yorkers like to go it alone. Unlike nearly every other major city in the country, Manhattan has no organized parents' group. At first I was dismayed. I felt awkward about calling complete strangers. But when I finally got brave enough to pick up the phone, the women who answered were more than ready to talk. Over time I realized that there was a sizable community of sorts. Most of our contact takes place via e-mail, but occasionally we meet at informal gatherings, fund-raisers, or lectures and seminars.

It also turns out that New York City is a great place to be a child with a disability. The Individuals with Disabilities Education Act (IDEA) guarantees Early Intervention services to all children diagnosed with developmental delays. Research has shown EI to be particularly effective for children with Down syndrome, whose prospects for development improve dramatically with early and consistent therapy. Because we live in New York State, which has one of the best EI programs in the country, Henry is entitled to treatment by a team of skilled therapists, who come to our apartment free of charge. I discovered that my city is home to an army of these therapists, almost all of them women, who spend their days traveling from home to home, lugging backpacks full of paperwork and equipment to treat their clients. For years I must have passed them on the sidewalk and shared seats with them on the bus, but Henry made them visible to me. Through these therapists, I've glimpsed a world beyond my own. They've taught me about innovative treatments coming from England and Israel. Our

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occupational therapist was learning to build equipment from cardboard, using techniques she hoped to export to Africa.

After imagining myself so completely alone, I was surprised to find that two boys with Down syndrome already lived on my street. And there were other families in my neighborhood. I wondered why I hadn't seen them before. Or maybe I had seen them, and then quickly looked away. Before I had Henry, children with Down syndrome represented a misfortune that had nothing to do with me. People with disabilities will tell you how common it is to feel like they're invisible. For the able-bodied, it's easy not to see the wheelchairs and the walkers and the crutches and the white canes, the people who limp, and those who are shorter or taller than average. Because of my academic interests, I've known this for a long time. But I still didn't *see*. Once your eyes are opened, a whole different world comes into view, one that most of us will join some day.

Our circle soon grew beyond our own small corner of Manhattan. Others families in our group come from all five boroughs, New Jersey, and Connecticut. The Internet plays a crucial role in connecting our scattered community. Like so many other dispersed communities in our globalized moment, technology holds us together. There was the mother who wrote to me in the middle of the night about how she sometimes hated the twin with Down syndrome, who was constantly spitting up and whose right ear folded over like a cabbage leaf. Another woman shared slideshows of her adult brother with those of us who wonder what our kids will be able to do when they grow up. Another used Facebook to send updates from the hospital where she and her son were living while he was being treated for leukemia. And there were all the useful discussions about where to buy glasses and orthotics, and who was willing to give swimming lessons to a kid with DS. I like to think that all of the Internet discussion boards, blogs, and Web sites might make it easier for prospective parents to choose to have a baby with Down syndrome. On my international listserv, families in Scotland and England connect with families in North Dakota and Pennsylvania. We are overjoyed for a mother in Los Angeles, whose daughter survived chemotherapy and kept her blood counts up for five months. Together we share indignation over the woman with Down syndrome who is asked to leave her college ceramics class because she needs extra assistance.

Of course it was all about the mothers. How could it be otherwise when women still do most of the child care in most parts of the world, whether or not they're fully employed outside the home? And when the child is disabled, women overwhelmingly shoulder the burden of any extra emotional and physical care. I wasn't surprised to find that mothers were the ones contributing to

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our e-mail list, going to fund-raisers, lectures, and information sessions, and organizing the social events. We're the ones who keep in touch and share resources. And we're the ones who enjoy the friendship and support that comes from belonging to our makeshift community.

When I finally met some of these women in person I was struck by how different we all are. There are mothers from Latin America, the Caribbean, Canada, England, South Africa, Holland, and India. We have widely varied economic resources, families, and career paths. We tell very different stories about how we came to have our babies. Many did so despite the disapproval of their doctors and other medical professionals responsible for their care. Some had religious beliefs that prohibited abortion. Others were like me, surprised by the diagnosis after their babies were born. Still others had received a "positive diagnosis" and just decided to continue their pregnancies, Down syndrome or no.

Some of us have a lot in common. One night I had dinner with a group that included two women who had known each other since their schooldays in Mexico City. By sheer coincidence, both had moved to the same neighborhood on the Upper East Side. And each had given birth to a child with Down syndrome. There's at least one other humanities professor in our group, and another woman with a PhD in Anthropology. There are also stay-at-home moms, teachers, lawyers, insurance agents, and a doula. Whatever our differences, we're united by the uncommon paths we've taken in a society where many regard the birth of a child with Down syndrome as a preventable mistake. We're drawn together by concern for the well-being of our children and our struggles with a world that is often resistant or hostile to giving them what they need to thrive.

Henry has introduced me to this other, more heterogeneous New York. But I'm constantly reminded that our world doesn't end at the borders of this city, or even the United States. Down syndrome has nothing to do with culture, region, or nation. It has no common demographic and is distributed across ethnic and socioeconomic groups. Although older women are more likely to give birth to babies with Down syndrome, it can happen to anyone.

Throughout much of history, inadequate medical care meant that many babies born with Down syndrome would not live past infancy. Sometimes they were allowed to die, even when care was available. And those who did were thought to be incapable of education. In the United States, parents were routinely advised to send them to institutions, where they languished without affection or stimulation.

Today there is ample evidence that, given proper resources and support, people with Down syndrome are capable of accomplishing a great deal. I keep a

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scrapbook that I know Henry will appreciate when he gets older. On the first page is a signed publicity photo of Chris Burke, the musician and actor who starred on the hit TV show *Life Goes On*. There are stories about the champion swimmer Karen Gaffney, who crossed the English Channel in the summer of 2001; the celebrated fiber artist Judith Scott; and the musician Sujeet Desai, who has performed around the world. In addition to these notable Americans, I also want him to know about people with Down syndrome in other parts of the world. I hope he'll feel inspired to learn that the tapestries of Canadian artist Jane Cameron hang in many different countries. And that Pasqual Duquenne of Belgium, Pablo Pineda of Spain, and Paula Sage of Scotland have all won international film acting awards.

World Down Syndrome Day is March 21, a date that represents the tripling of the twenty-first chromosome that causes the condition. The twenty-five countries listed on the World Down Syndrome Day Web site span the globe, including Canada, Mexico, Japan, Singapore, Brazil, Saudi Arabia, Switzerland, Turkey, Kenya, and New Zealand. In 2010 they commemorated the occasion with lectures and symposia, fund-raising walks, performances, and parades. The fact that people with Down syndrome are celebrated in so many parts of the world represents a drastic change from past generations. It is a supreme irony that this greater acceptance of people with intellectual disabilities coincides with the development of ever more precise tests for detection and, presumably, elimination of "defective" fetuses. The impulse to search and destroy is pervasive throughout the Western world, and beyond.

Sometimes these contradictions come to a head. In 2008 I was dismayed by reports from Baghdad that two women with Down syndrome were strapped to remote-control bombs that detonated, killing at least 73 people and wounding 150. Although the women's diagnoses were later called into question, the disregard for the lives of people with Down syndrome that the story conveys is all too real. The Internet, which has been such a vital resource for sharing information and building community, also makes it easier than ever to spread hatred and prejudice. In early 2010, an Italian Facebook group called for children with Down syndrome to be used in target practice. It circulated a picture of a baby girl with the word "imbecile" written across her forehead. That same month, a Russian blogger wrote a widely circulated article titled "Finish it off so it doesn't suffer" that called for the euthanasia of disabled newborns.

This isn't to say that prejudice exists only abroad. Of course, there's plenty of homegrown bigotry to be found in the United States, beginning with the casual use of the offensive word "retard" in the halls of the White House, and in films

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like Ben Stiller's 2009 *Tropic Thunder*. The influential Princeton philosopher Peter Singer advocates killing infants with severe disabilities, and he has argued that individuals with some forms of cognitive disability are undeserving of moral consideration. In March 2010, the U.S. National Down Syndrome Congress had to dismantle a Web site featuring its "More Alike Than Different" campaign after vandals defaced several of the photos with cruel slurs. And when I was quoted at length for a story in *The Daily Beast*, one reader commented that I'm an irresponsible person. "We should make a social contract type deal on this topic," he wrote.

Every single parent who knows they have a fetus with an extreme and expensive developmental disability such as Down syndrome is more than free to have the baby. The trade is that they should be responsible for the full cost of raising the child. That means no 70k from their school district for special classes, no aide, no special dispensations from the government, none of that. They made their bed, they lie in it. I bet you anything if we stopped socializing the cost of these choices, people would make different ones. It's easy to say "I want a child no matter how much it costs to treat him after he's born" when it's not your money.

His words remind me that there are still many people out there who think a child like Henry shouldn't be born, or that his life is expendable. I hope that someday, he'll be able to tell them how wrong they are. In the meantime, I consider it my job to represent his interests as best I can.

Just before Henry turned three, I saw *Yo Tambien*, a Spanish film about Daniel, a man with Down syndrome, who falls in love with Laura, a nondisabled co-worker. It's a sensitive portrayal of the difficulties they encounter as his desire for adult intimacy conflicts with her desire for a nonromantic friendship. When their relationship reaches a crisis, Laura is forced to probe the sources of her resistance, confronting her own prejudice as well as her genuine love for Daniel. A parallel plot tells the story of a man and a woman with Down syndrome who attend the arts program where Daniel is employed. In their case, both desire the same thing—a mature relationship, sex included—but they have to contend with parents and caregivers who want to keep them in a perpetual state of childhood.

A number of things about the film reflect its foreignness. On the positive side, it portrays a society far more committed to making opportunities for meaningful work and artistic expression available to people with intellectual disabilities than my own. But I'm more skeptical about its suggestion that Down syndrome is

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something that can be mitigated or overcome through sheer force of will. When asked how he became so successful, Daniel explains that his mother pushed him to achieve where other parents would have accepted less from their children. The notion that Down syndrome can be conquered with a properly strict education is foreign to me. In an ideal world, I'd like to see each child receive the resources to develop to her fullest potential, but I'm also aware that children with Down syndrome—like all children—are greatly varied in terms of ability. It sends an unrealistic and potentially harmful message that each, with the right training, would be equally capable of the academic and professional success Daniel has achieved. A child who accomplishes less should not be seen as a sign of personal or parental failure.

Other subjects broached by *Yo Tambien* are more universal. The themes of thwarted quest for intimacy and the challenges of adult sexuality among people with intellectual disabilities must resonate in any number of cultural contexts, since they reflect basic human needs and desires. Although my Henry is still a baby in many ways, I know that at some point in the future we'll need to contend with the questions about sex and relationships raised by the film. It left me thinking hard about the difficulty and importance of assuring that people with Down syndrome have opportunities to learn about mature, safe, and respectful forms of sexual expression. We'll need to walk a fine line between respecting Henry's privacy and independence, and making sure that he doesn't harm himself, or anyone else. These are intimate challenges that are global in nature. They must be shared by parents of children with intellectual disabilities in all cultures and regions of the world, although I have no doubt that we approach them with widely varied beliefs and attitudes.

The day after I saw *Yo Tambien* I took Henry to the park. As soon as he got out of the stroller, he made a beeline for a group of bigger kids clustered around a fountain. They were loud and joyful and a little bit rough, engaging in exactly the kind of play he finds irresistible. I ran over, worried he might be knocked down. I noticed that somebody had already dumped water on his shirt and somebody else had grabbed his favorite pouring cup. Henry didn't seem to mind. In fact, he was having the time of his life, screaming with delight as he made his way directly into the center of the action. I felt the urge to hover, to make sure he got his turn at the water and that he didn't get hurt. But then I forced myself to step back, leaving him to look out for himself.

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