

From 'Passing' to 'Coming Out'

by Candice M. Lee

I confess: I've been passing.

I'm a 32-year-old woman, disabled since birth, and until recently I have been firmly in the closet.

I have been living in the nondisabled world all my life. I was part of early attempts at "mainstreaming" children with disabilities into regular classrooms. (I received special services at recess.) Once I passed adolescence, my health stabilized to the point that ongoing medical care is not required, other than regular check-up visits with various specialists. I completed college, then graduate school. I am a full time professional. I have been married eight years to a nondisabled person.

In most of the situations I encounter, I am the only person present with a disability. All the key disability rights issues — work, housing, medical care — have left me unscathed, because of my fortunate ability to work full time, to put a roof over my own head, to purchase health insurance.

And yet, here are these braces. This limp. This ostomy appliance. These stares in the supermarket. All remind me that, while I live among the nondisabled, I remain on the margins. I remain Other.

I was born with a congenital defect of the lower spine called sacral agenesis. This means that my sacrum is mostly missing — where "normal" folks have vertebrae, I have a mass of soft tissue. Resulting nerve damage means that my lower legs are undeveloped, and that I have little movement in my feet and none in my ankles. Most of the time my calves and feet are encased in custom-molded plastic braces that slip into my shoes and allow me to walk nearly normally, albeit with a noticeable limp. My bladder also was damaged, causing me to need a urostomy, a surgically created opening in my abdomen where urine flows out, and collects into a plastic bag.

When I was born, in 1971, doctors weren't so sure I'd live, or walk, or be functional. With luck, good medical care, and a determined mother, they were wrong. Only as I age have I begun to realize that I have spent all my life among the nondisabled trying to measure up.

If I am smart enough, maybe They won't notice my limp. If I am pretty enough, maybe They will accept me anyway. If I am accomplished enough, maybe They won't mind my braces.

There are rules for passing. First, I must come up with a nice, short, palatable, cocktail-party explanation of my disability to set people at ease when they ask. Nothing too scary. And then, I must never mention it again.

I must learn to change my ostomy appliance in less than five minutes standing up in the stall of a public restroom. I must work hard to keep up while walking with others. I must act like I don't mind when they leave me behind. I must arrange my doctor appointments during off hours so I don't appear to be taking too much sick time. And I must never, ever mention the rigors of life in this body. To do otherwise draws Their attention to my otherness.

And They do Their part, too. I can't tell you the number of people who say, "I just don't see you as disabled," or "I had met you three times before I noticed your braces." Most folks just can't reconcile the me they meet with the images of disability generated by the media — the only images they have.

There is no box to put me in. I am not asking for their charity or assistance. I am not defined by my disability. I'm not the angry cripple. Why, I'm not even inspirational (although, lacking any other way to categorize me, people sometimes tell me I am. It never fails to rankle.) I'm just a person, like them. Therefore, I must not be disabled. Not really.

Given all this, why am I outing myself at this late date? Because I have broken a cardinal rule, done something so subversive that I feel the shockwaves ripple around me everywhere I go. I have become pregnant. By choice.

My doctors couldn't give me a great deal of reassurance about what a pregnancy might mean for me. Not a single case study was to be found. Apparently, if anyone like me has ever been pregnant, it wasn't written up in the journals. Ultimately, my husband and I decided that pregnancy is a leap of faith for any couple — and we would take that leap.

As soon as my pregnant belly began to be obvious, balanced atop my spindly braced legs (in the words of a wry friend, "like an olive on a toothpick"), the stares from strangers increased, both in number and in hostility. They telegraph their messages clearly: "I didn't think that kind had sex!" and "Good God, is she bringing another one like her into the world?"

This kind of hostility has made me angry in a way that even the intrusive curiosity that has followed me all my life never did. I'm angry at being excluded from that group of people who can, in Their eyes, acceptably have children, all for want of a pair of perfect legs. I'm angry that, should my child have health problems, all eyes will turn to me — even among family, and even if the problems are unrelated to my own.

It is anger that kicked open the closet door, but it is impending parenthood that pushed me out. I want my child to have a mother who claims what she is, who accepts herself and expects others to do the same — not one who stands at the margins, waiting to measure up.

I like it out here.

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