

A Different Reflection

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What happens to a child who undergoes "corrective" surgery? A nurse gives her account of growing up with cerebral palsy.

One morning in the pediatric ICU in which I was working, I sat with a group of nurses as they talked about how pointless the life of a girl with severe cerebral palsy seemed to them. They cared for Jennifer well, but felt she would be better off dead. With their words and attitudes, they mocked the quality of her life. I thought, "I am Jennifer. I feel her body in my own; I feel more in common with her than with anyone in this room. She would not mock our lives if she could speak." In that moment, for the first time in my life, I chose my whole self. I valued all of myself. I preferred to have cerebral palsy.

I was born with cerebral palsy. My earliest memories of walking include long leg braces, and I remember how uncomfortable and shaming the strap that connected my braces across my buttocks, keeping my legs in an abducted position, felt. I recall, at the age of 3 or 4, having the knees of my braces locked into a straight-leg position, and being gently and repeatedly pushed into a sandbox. This memory makes me smile, for I truly value my ability to catch myself with my arms, to fall without hurting myself.

Physically, my disability limits me very little. My gait is lurching and spastic, but as it is with most congeni-

tally disabled people,¹ my body feels comfortable and natural to me. My walk is unsteady, but my body moves in ways that create the most balance possible and gets me where I want to go with the least amount of physical exertion and mental concentration.

When I was a child, even though it took me longer than the other children to get places, the kids in my neighborhood didn't make fun of my not being able to run, to balance, or to look like them. They would ask me why I didn't walk right, and I would respond, having been coached by my mother on how to matter of factly explain C.P. This neutral sharing of information worked when I was young, but as I got older the act of explaining felt like a painful apology, as if I were asking others to make allowances for me, as if society expected me to explain myself.

At the age of 9, when I no longer wore braces, my father taught me to ride a bike. It felt like flying. It was my first experience of mobility, control, and speed. I'm sure teaching me to ride was scary for my parents, but it enabled me to keep up with my friends.

At the age of 11, I was told I was going to have surgery to lengthen my hamstrings and release my adductor muscles. As with most children, I did not participate in making the decision for surgery. I remember being angry and asking my father "Why do I have to agree to surgery?" I remember saying it was unfair to make me go through

this. At 11 my body and life felt sufficient to me. I did not want them changed.

My parents chose surgery to offer me a "better life." In their place I might have made the same choice. They saw it as their responsibility and believed that I, being a child, did not know the value of a "normal body" in society. Being 11, I did entertain the idea of a "surgical miracle," after which I would wake up and walk like everyone else. (But I was also the kind of child who occasionally reviewed her top three wishes just to make sure they were ready should a genie suddenly present himself.) I don't ever remember wishing C.P. away—it never seemed important enough.

What I understood as a result of experiencing this surgery was that I was not fully acceptable as I was. In the eyes of the world I fell short and needed to be fixed. After surgery, I went to physical therapy. Perhaps the goal of surgery was to enable me to be more mobile throughout my life, but what I was shown in therapy was how to walk "correctly."

I could have explained in a minute that I couldn't walk normally, but the doctors and physical therapists held this, and only this, out to me as a model of what I was to accomplish. They seemed to believe that cutting my muscles had restored my damaged brain cells. No one ever admitted, or even suggested, that the goal might be unat-

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tainable. They kept showing me how to walk, and I kept trying and failing. I often wanted to say, "This is ridiculous!" and stop. But the nagging thought that maybe I wasn't working hard enough—along with the surgeon's insistence that therapy was necessary—kept me there. I did not want to be held responsible for the failure to produce a "better walk," so I kept working. I was not the one defining what was possible or worthwhile. What the professionals said I could do carried more authority with me than my own awareness of my body's abilities.

The fact that there was no mention of the limits of surgery, what physical therapy could or couldn't do, or what goals mattered to me as the person involved, made physical therapy very stressful for me. I watched my body "walk wrong" in lots of mirrors. I learned to be ashamed of my walk, and my failure to walk. I came to hate watching my body move.

I went to physical therapy from the age of 11 to 17. I recall almost nothing of my high school years. (I know you don't have to have a disability for this to be true.) My one clue that I wasn't handling things well was when my mom asked if I wouldn't rather go to a private girls' school. That my parents couldn't afford it indicated how worried they were about me. I insisted on staying in public school. Much of the reason was boys. I figured if it was hard to make it in a place where boys could see me, talk to me, and get used to my walk, I would never survive in a place where boys saw me only at formal dances. I feared that if I allowed the world I was in to be constricted, I would never gain it back. So I blocked out high school, even though I stayed.

At 17, I went to college and jettisoned physical therapy. I dated some, made life-long friends and became a committed social activist. I continued on to graduate school, began a career in social work, got married, went to nursing school, and gave birth to my son. I did this without knowing other people with bodies like mine who were also doing these things.

There were other things I didn't know. I thought that people would see me first as I saw myself—as a feminist, a health care worker, a mother—and secondly as disabled. I didn't allow myself to know how defining and differentiating disability is to many people. I was also unaware that I had internalized many of our culture's attitudes toward disability. I saw disability as a deficit. I believed that my

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inability to move "correctly" made me less desirable and less valuable than other people.

I never allowed myself to see myself walk in full-length mirrors; I stood as still and straight as possible. To see myself move was to see the shame and inadequacy that our culture tells us is inherent in disability. Not only did I avoid mirrors, I persuaded myself that if I was not in a wheelchair, if my mind worked well, if I supported myself, if I married, if I gave birth to a child, then I would be like an able-bodied person. I thought I could "pass," that I could escape, through how I lived my life, the stigma attached to having a disability. Only in recent years have I understood myself differently.

After my actively choosing my disability that day in the pediatric ICU, I met Ona, my first friend with C.P. Ona and I became each other's first reflection in the world. Within moments of meeting we were overflowing with things to say to each other, laughing with each other, watching how we moved differently and alike, interrupting each other with stories and thoughts that were the same. We finished each

other's sentences—words neither of us had ever spoken out loud before. We knew each other's experiences accurately and intimately because we had lived in such similar bodies. In her book *Past Due*, Anne Finger says of her first experience in a group of women who were all post-polio, "It was as if I had been living all of my life in a foreign land, speaking a language that was not my native tongue."²

Ona and I discovered that we had each led lives to which we had never given expression. Not being integrated into the disabled community, we had never spoken about how it felt to be disabled. We had never talked about disability at all except with a few friends, therapists, or lovers who initiated conversations out of their radical caring for us. Meeting Ona, watching her work, love, and live, enabled me to see myself differently.

Until the 1970s there was no organized vocal community of people with disabilities to offer an alternative view of our lives. Unlike ethnic minorities, we are not usually born into families that reflect us. There is no readily available community offering a vibrant, living corrective to what the majority culture says about us. Society defines disability solely in negative terms, so even if a community is available, it can prove hard to move toward it, to bond around a negative. Our culture, with its pitying, embarrassed, and dismissive view of disability, denied me permission to face my body and embrace it.

There is little personal interaction between able-bodied people and those with disabilities. People with disabilities are not frequently seen in the media, in positions of leadership, or in noticeable numbers in the workplace. This absence perpetuates society's ignorance of our lives and discomfort with our differences.

The tendency of our society to equate "different" with "wrong" or "of less value" is remarkably strong. People with differences varying from being overweight to being female clergy feel the narrow constraints of what our

society is comfortable with. Members of minority groups experience it constantly. There is a subtle, nonverbal expression of hierarchical valuing I often experience in crowded hospital corridors: A person sees me walking towards them, our eyes meet, and with a blink of the same eye that takes in my body, I am discounted and dropped into

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the category of "other." No further eye contact is made. To acknowledge me has been deemed unnecessary, for to this person I do not exist.

I am writing this to acknowledge the distance that exists between able-bodied people and people with disabilities and to make an effort to bridge it. The belief that people with disabilities are of less value than other people is far more disabling than any physical limitation. Restrictions of the body are one thing; restrictions of the self are of an entirely different order.

Becoming disabled is an equal-opportunity experience; anyone may join at any time. An increased acquaintance and comfort with physical limitations and differences would have widespread positive effects within the able-bodied community. Being human, we all have to come to terms with injury, illness, and aging. Our culture does not reflect the ways in which people with disabilities experience and value our bodies and our lives. Our appreciation, strengths, pleasures, and insights do not permeate the narrow, perfectionist understanding of health and normality held by our society.

It was hard for me to trust my own feelings and experiences and to affirm my body and myself within our culture. However, through my friendship

with Ona, with her as my reflection, I found a degree of distance I could not have otherwise experienced. I could watch the way she moved as I could not watch myself. Her strength and loveliness were undiminished by a "different" body, and I could see my own beauty because I could see hers. My lurching gait and my passionate brown eyes were equally mine, equally expressive of me.

Therefore I understand that it may be difficult for able-bodied people—particularly those in health care professions—to believe that disability may be experienced as different, not less. The understanding that physical difference is a variation, not a deficit, is a critical one. It is this view that nurses can bring to their daily interactions with clients. This understanding, once internalized, will convey itself to your clients verbally and nonverbally. If you offer clients the thought that their bodies are different and equal, they will make use of this information in whatever way is best for them. This is, for all, a liberating perspective.

Perhaps those most in need of this perspective are children. It was in watching my son, David, in seeing what a seamless entity he is, how his humor and beliefs about the world are as grounded in his body as is his ability to play baseball, that I glimpsed how indistinguishable body and self may be at times. I understood that surgery had not cut into my muscles alone, but into my sense of self.

This may be how many children experience "corrective" surgery—surgery that changes how they have always been. In caring for a child before "corrective" surgery, I would affirm this child and his or her body, as it is, by praise and play. I would address the issue of change and ask what the child believes will happen in surgery. I would speak of surgical changes very specifically. For example, "You will be able to straighten your knee," but not "You will be able to walk better." I would clearly distinguish between the unique person who wakes up after surgery and remains the same and the

very limited and good part of the body that is being operated on.

It is critical that children have themselves and their bodies affirmed as they are, not in terms of how close they come to appearing normal or approximating able-bodied movements. After surgery, a child needs to be involved in setting reasonable, attainable goals for new skills, especially in physical and occupational therapy. It is the whole person, not just parts of a body, that we manipulate in therapy. The changes in self-perception and in expectations for oneself need to be addressed. The goal is a whole, grounded person in a body that works with and for that person.

Each person, each body is unique. When working with children, let them participate and take the lead in discovering how their bodies work best. Use the skills of occupational and physical therapies to supplement their knowledge and use of their bodies. Nothing could be more empowering. A child will use and depend on the skills of discovery, trust, and learning from her own body for the rest of her life. ■

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