

## Desperately Seeking Community

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As for many of us, my disability arrived unexpected. Three years ago I was partially paralyzed as the result of complications from surgery to remove a tumor from inside my spinal cord. I now walk - haltingly, sometimes careening off to the side - with a brace on my left foot and with a cane. Last fall, hungering to connect with other crips, I attended a disability arts conference to meet other artists with a broad range of disabilities who had traveled from all over the United States and England.

The blind and deaf people sat beside each other, worlds apart, waiting their turn to voice the injustice of existing within a hostile world. Actors railed against the inequity of being brought on location to teach "real" actors to mimic their actions. Artists who use wheelchairs wondered if they could only portray their disabilities. As I joined people with stunted torsos, spastic limbs and disconnected spinal cords, I was reassured that I was not merely my disability.

Yet my own questions nagged at random moments: What to do with my anger? How to live with the ever-present pain? Will I ever stop wanting total recovery? How not give up hope? The people around me urged one another to celebrate the duality of the body and spirit, as well as the holiness of the breath, even on a ventilator. Everyone seemed so highly functioning and well adjusted that I didn't feel comfortable asking about despair and desperation. Nevertheless, my husband Larry and I continue to grapple with ongoing depression. Before the surgery we were very clear about acceptable alternatives and drew up living wills to honor each other's choices. Even assisted suicide was discussed; here, that topic was verboden.

I studied long-term survivors to see how their frames had adapted to changing circumstances, often by becoming more and more bent. My doctors had said it could happen to me, but here was the real manifestation. I was frightened to hear of overtaxed compensating muscles waning in exhaustion after decades of unrelenting service. Diminished mobility remains a daunting nightmare.

At this gathering, I was surprised to find internalized oppression subtly separating the quads from the paras - those with power chairs from manual chairs, even walkers from canes. Early-onset or congenital disabilities seemed more legitimate than degenerative conditions. We were divided by race, class, gender and sexual orientation. One quadriplegic comic derisively parodied Siegfried and Roy for being so gay and the audience roared. My queer self was enraged at the homophobia and my walking self felt like a pretender as I left the conference.

The surgery and its aftermath have politicized me. I have become intolerant of a society that disempowers us. My anger flares whenever I am referred to in the third person, assumed to be helpless and mentally compromised, or avoided by frightened children. In public, I ignore the sympathetic smiles from nondisabled people and seek eye contact with members of my tribe.

I know now that inaccessible public buildings are inexcusable. In San Francisco, where I live, two-thirds of us are unemployed - not unemployable, not underemployed, but unemployed. This is shameful. Why can't a civil society at least try to provide equal access and opportunity?

Today as I continue to seek community, I search for hope as well. But even gallant Christopher Reeve - who once spoke of walking - now describes his life with a before and an after. What I wanted to be temporary must now be accepted as permanent. There is no choice in the matter, but I still long for the life before as I reconstruct the life ahead.

There have been gifts. I have learned much about grace through the unwavering support of my husband, friends, colleagues, family and a new clan of crips who have helped with the emo-

tional and functional challenges of living with physical disability. They offered not just their empathy, but cared enough to ask how they could help and were generous enough to mean it. To them I am grateful. In them, I find faith in a less divided, more inclusive society.