

Sharing Stories, In School and Out: An Autobiographical Forum

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I have always been fascinated by self. When I was in elementary school I read every biography I could find in the library. I still recall my excitement when one day I discovered a new biography of George Washington by an author named Carver. With great anticipation I plowed into the book, then became confused. It slowly dawned on me that I was not reading about the first U.S. President, but learning about a southern, black scientist named George Washington Carver, born in the 1860s, who invented hundreds of products from peanuts, as well as from other plants.

My disability experience, I believe, has had a lot to do with my compulsion to understand identity. As a young boy, who experienced almost indescribably painful bone crises, I did not know of anyone else who experienced my kind of pain (Brown, 2003). The only way I could imagine to explore my experience was to investigate myself.

I was well into adulthood before I met anyone else with the same disabling condition I have. Now there is a thriving listserv (The Gaucher Disease E-Mail Discussion Group) addressing Gaucher Disease (GD). From its inception, those who participated in it have shared their stories, or those of children or other family members. Few of us had any experience with others with GD until the past decade or so. We were all eager to learn about one another's personal journeys and the various paths we have trod.

In the past twenty-five years, as I have become immersed in what it means to analyze and live with a disability from a rights perspective, I have in some ways become even more eager to learn about how others have moved to their own truths about their lives. In the early 1980s, when I first became involved in the disability rights movement, I ventured to the local library and looked in the now antiquated card catalog for books about disability. The only one I recall finding from a rights perspective was Frank Bowe's *Handicapping America* (1978). Eight years later, Bowe published *Changing the Rules*, an autobiography that focused on his early years as a person learning what it was like to be deaf in a hearing world. As the recent controversy over who will succeed I. King Jordan as President at Gallaudet University¹ demonstrates, this search remains an issue close to the surface of disability rights identity.

As I became absorbed in my own desire to understand what disability culture might mean I read as many autobiographies as possible. I have both discussed and reviewed many of these tomes (Brown, 2002). Examples include well-known authors and books, such as *My Left Foot* (1954), Irish writer Christy Brown's story that became the subject of an Academy Award winning movie, and the contemporary acerbic cartoonist John Callahan's *Don't Worry, He Won't Get Far on Foot* (1989), to less popular, but just as compelling memoirs, like Cass Irvin's reflections in the 2004 *Home Bound* and Greg Smith's *On a Roll* (2005). Two recent autobiographies detail experiences with pain (Felstiner, 2005; Wall, 2005), another with acquiring a disability as a young adult (Linton, 2006), and a fourth with moving through the world in an unusual way (Kuusisto, 2006). A commonality of all these autobiographies is that they are well-written, from the poetic (by the poet Kuusisto) to the rousing (the motivational speaker and radio personality Smith) to the more reflective and quasi-scholarly (the academics

Felstiner, Wall and Linton). The reviews section of this journal includes more detailed descriptions of a number of the books discussed in this paragraph.

As more people are able to write and publish about their experiences, coupled with the exploding avenues opening to writers, we will learn more about a diversity of lives. Our goal in this forum is to share compelling stories that reflect the goals of this journal: international in scope, reflective of emerging and more experienced scholars, and unsung voices. We hope readers will find these self-explorations as fascinating as we did. A brief word about each is in order.

Perhaps the most satisfying article, to me personally, is that of Joakim Peter. I first met Jojo, as he likes to be called, when he approached me in a hospital lobby and asked about the wheelchair I used. That initial exchange led to a friendship and dialogue that continues to this day. For several years, I could not understand the kind of assistance Jojo requested. Why was it so difficult for disability advocacy to make inroads in his native Micronesian island of Chuuk? His article, "Building Familial Spaces for Transition and Work: From the Fantastic to the Normal" eloquently alleviated my confusion. Further west, in Taiwan, Heng-hao Chang grew up in a family that included a sibling with a disability. In his memoir, "Seeing Through the Veil: Auto-Ethnographic Reflections on Disability," he explores his own personal journey of understanding his family's approach to disability and puts his findings into a broader social context. Both Brian Shaughnessy and Nathan Say, residents of my island home of O'ahu, explore and reflect on their own disability experiences. Shaughnessy, an attorney, actor, and comic, describes life with a medically-caused disability in an excerpt from his recently published autobiography, *The Squeaky Wheel* (2005). Say, a young man with cerebral palsy, relates experiences with personal assistants in his poem, "Hands of Another." Finally, Zosha Stuckey collaborated with the aging Devera Gordon, over multiple months at a nursing home, to develop the essay, "Steaming, Compressed Air."

In my poem, "Tell Your Story," (1995) I wrote:

We all have so many stories to bear
Cry, laugh, sing, and despair;
How will our children learn and compare
If we're too timid to dare
To raise the flare
Share that we care

It still seems to me that it is for all the world's children, of all ages, that we continue to need to share our stories with one another.

References

- Bowe, F. (1986). *Changing the rules*. Silver Spring, MD: TJ Publishers.
- Bowe, F. (1978). *Handicapping America: Barriers to disabled people*. New York: Harper & Row.
- Brown, C. (1954). *My left foot*. London: Secker & Warburg, Ltd.

- Brown, S. E. (2002). *A celebration of diversity: An annotated bibliography about disability culture*. 2nd ed. Las Cruces, N.M.: Institute on Disability Culture.
- Brown, S. E. (2003). *Movie stars and sensuous scars: Essays on the journey from disability shame to disability pride*. New York: People with Disabilities Press, 3-22.
- Brown, S. E. (1995). "Tell your story," in *Pain, plain--and fancy rappings: Poetry from the disability culture*. Las Cruces, N.M.: Institute on Disability Culture, 6-11.
- Callahan, J. (1989). *Don't worry, he won't get far on foot: The autobiography of a dangerous man*. New York: Vintage.
- Felstiner, M. (2005). *Out of joint: A private & public story of arthritis*. Lincoln, NE: University of Nebraska Press.
- Gallaudet rejects incoming President. *Yahoo News*. Retrieved November 7, 2006, from http://news.yahoo.com/s/ap/20061029/ap_on_re_us/gallaudet_president
- The Gaucher Disease E-Mail Discussion Group. Retrieved November 7, 2006, from <http://pages.cthome.net/rosenfield/list.htm>
- Irvin, C. (2004). *Home bound: Growing up with a disability in America*. Philadelphia: Temple.
- Kuusisto, S. (2006). *Eavesdropping: A life by ear*. New York: W. W. Norton.
- Linton, S. (2006). *My body politic: A memoir*. Ann Arbor: Michigan.
- Shaughnessy, B. (2005). *The squeaky wheel: An unauthorized autobiography*. Retrieved November 7, 2006, from <http://www.squeakywheelbook.com/>
- Smith, G. (2005). *On a roll: Reflections from America's wheelchair dude with the winning attitude*. Ocean Springs, MS: On a Roll Communications.
- Wall, D. (2005). *Encounters with the invisible: Unseen illness, controversy, and Chronic Fatigue Syndrome*. Dallas: Southern Methodist University.

Endnotes

¹ Gallaudet University, located in Washington, D.C., is the world's only University designed for people who are Deaf and Hard of Hearing.