

THE WISCON CHRONICLES
VOL. 7

The WisCon Chronicles

VOLUME 7

Shattering Ableist Narratives

Edited by
JoSelle Vanderhooft



AQUEDUCT PRESS | SEATTLE

Aqueduct Press
PO Box 95787
Seattle WA 98145-2787
www.aqueductpress.com

The WisCon Chronicles, Vol. 7
Shattering Ableist Narratives

Copyright © 2013 by JoSelle Vanderhooft
All rights revert to authors and artists.

ISBN: 978-1-61976-042-4
9 8 7 6 5 4 3 2 1

Cover: “Image Reflected” courtesy Erin Harrop
Interior illustrations: “Wasteland” and “Woman Reading”
courtesy Erin Harrop
“Shhh” courtesy Eli Ellison

Supported by a grant from the Society for the Furtherance &
Study of Fantasy & Science Fiction [SF3].

Printed in the United States of America
by Applied Digital Imaging, Bellingham, WA

Contents

- 1 Introduction
JoSelle Vanderhooft
- I. Guest of Honor Speeches
- 6 Guest of Honor Speech: Andrea Hairston
- 15 Guest of Honor Speech: Debbie Notkin
- II. Disability and Identity
- 27 Defining Disability in a World that Fears Disability
s.e. smith
- 40 Invisible Inks: On Black SF Authors and Disability
Nisi Shawl
- III. WisCon and Access
- 47 WisCon 37 Access Policy
- 48 Welcoming Wayna, Toph, & Miles to WisCon
Sandy Olson and Jesse the K
- 56 Interviews with Jesse the K and Sandy Olson
- 66 Interview with Betsy Lundsten
- 71 I Am More Than a Dog
Andrea Chandler
- 77 The Silence
Tracy Benton
- 80 Accessibility: Signs
Jesse the K

IV. Disability and SF/F

- 83 To Go Where No Ism Has Gone Before:
Disability at the Final Frontier
s.e. smith
- 96 Dead Man Not Walking
Bobby Singer's Paralysis and Repair on *Supernatural*
Lisa M. Bradley
- 109 Gotham City Sirens: Harley and Ivy
Performing Gendered Madness
Leow Hui Min Annabeth
- 120 Deep End
Nisi Shawl
- 134 Theorizing Vulnerability in Feminist SF
Kathryn Allan
- 146 Disappearing Natives: The Colonized Body is Monstrous
Andrea Hairston
- 155 Not Turning Into Cellophane: Fighting Marginalization
Gillian Polack

V. Panel Write-Ups and Reflections

- 157 "I was born the day I began to pass"
BC Holmes
- 165 Passing Privilege Panel Notes
Ian K. Hagemann
- 166 WisCon and Being Trans
Rachel Kronick
- 171 Making WisCon Affordable
Rachel Kronick

176	Challenging the Narrative of the Undeserving Poor Beth Plutchak
189	Panel Musings: Body Acceptance— From All Sides Stef Maruch
195	The Ticking Hourglass: An Older Writer’s Dilemma Ada Milenkovic Brown
199	Do We Have to Be Strong? Disability Discussions at WisCon 36 Josh Lukin and Ann Keefer
216	The Great Divide Nancy Jane Moore
217	The Anatomy of Friendship Isabel Schechter
224	Two Moving Points: Some Notes on Friendship Elise Matthesen and Debbie Notkin
232	Contributor Biographies

Introduction

JoSelle Vanderhooft

When writing an introduction, I like to keep things short and sweet so you, the readers, can get right to what you're really here for. So I'll only keep you a moment—just long enough to give you a little context for this year's *Chronicles*.

Compared to many people, I'm a relative newcomer to WisCon—also my first-ever SF/F convention—having first attended in 2006. “Oh, you are so lucky!” So many WisConites told me when I introduced myself and let them know. “This con is going to spoil you forever!” They were right; in many ways it has. Not just because of the thought-provoking programming, the incredible people, the fabulous consuite, or the Tiptree Bake Sale, but because of its commitment to social justice, however imperfect that commitment may often be. I saw this in action upon returning the next year, when the con's Access Committee (some past and current members of which you'll hear from throughout this volume) made enormous strides in not just providing accommodations but in helping to make disability issues and ableism two more topics for discussion at the Concourse. These strides have continued ever since, with things like the arrival of the Quiet Room in 2007 (remember a WisCon without it? Do you *want* to?), better access to panels for people using wheelchairs and scooters, and a host of panels about disability. Some of which I've been fortunate enough to speak on.

“You are so lucky!” people told me at WisCon 30. But most of them probably didn't know just how lucky. You see, that WisCon marked roughly six months after I had finally sought and obtained proper treatment for the severe depression and anxiety that had

overshadowed my childhood, adolescence, and young adult life. Until then, I had tried to push through the fog of depression and the lightning bolts of anxiety without help, and while thinking that my bad grades, frequent breakdowns, and lack of friends were the fault of a flaw in my character. Oh, yeah. And having my first therapist be an abusive jerk who told me I was incurably insane and a toxic person didn't exactly convince me otherwise.

Needless to say, I arrived at WisCon 30 still very much confused about and ashamed of my brain, and, if I'm honest, still in mourning for the neurotypical person I could never be. In other words, I was suffering from years of internalized ableism and ableism thrust upon me by clueless comments, clueless professors, and a society in which people with mental illnesses are not really considered to be fully human. And while I finally had a therapist who wasn't an abusive jerk, I still had no idea what to think about myself or, really, anything anymore.

What better place to be in 2006 and 2007 than a convention that was also seriously wrestling with ableism, both externalized and internalized, both allowed to flourish because of clueless comments and clueless people?

Although I didn't realize what was happening until much later, the discussions and panels to which I was privy at WisCons 31–33 or so gave me a framework to learn who I really was and a trail of breadcrumbs to exit the black forest through which I'd been roaming for decades. Panels and discussions on social justice as it applied to disability finally gave me a framework to make sense of and talk about my experiences as a disabled person in the same way discussions about sexism and heterosexism/homophobia (two other oppressions that I experience) that received some attention in the media when I was growing up gave me tools to make sense of and talk about my experiences as a woman and a bisexual.

You could probably say that WisCon is ultimately responsible not just for my acceptance of my disability but my pride in being a

person with a disability, and for me having a more stable and fulfilling life at thirty-two than I did at twenty-five. “You’re so lucky!” they told me. But who could have known just how much WisCon would give me?

For these reasons and many more, I wanted to edit a *WisCon Chronicles* about disability to continue that conversation and, I hope, to be of benefit both to disabled people struggling with internalized and externalized ableism and to non-disabled people who, despite the best of intentions, are contributing to ableism. Although I’ve kept disability as the central focus of this book—and tried my best to cover as many facets of disability as I could in doing so—I’ve also included some pieces that focus on other oppressions, including cultural appropriation, classism, cissexism/transphobia, and sexism. After all, people with disabilities often face these and other oppressions, which can make their lives even more difficult. For example, people with disabilities in several countries are often economically disadvantaged, and poverty and ableism tend to hit people of color and women of all races harder than they do white men. In addition, sometimes responses to ableism are very similar to those of people facing other -isms; for an example of this, see the essays on “passing.”

I’m so deeply honored and grateful for the opportunity to have edited this year’s installment of *The WisCon Chronicles*. This volume would not have been possible without the generous support of SF3; Timmi and Tom Duchamp and Kath Wilham, the awesome Aqueduct Press crew; the equally awesome contributors to this volume, whose work it was my pleasure to edit; the also awesome Jesse the K, Sandy Olson, Sparkeymonster, and all past and current members of WisCon’s hardworking access committee, which should be a model for cons across the world; and the support of my dear friends and family. I would also like to thank Kim, my partner of nine years, for her love and encouragement throughout the editing process, particularly when my own disabilities made editing (or even staying awake for eight hours at a clip) a challenge.

But mostly, I would like to thank you, readers, for your continued support of and interest in the *Chronicles* and in WisCon itself. I hope you find this year's volume useful, informative, and discussion-provoking.

Publisher's Note

The artwork in this volume is from an exhibit at the University of Washington, Seattle.

Experiencing Our Worlds: A Display of Unity in a World of Diversity

This show encompasses a selection of artwork by students of the University of Washington School of Social Work who self-identify as having a disability.

March 11–May 10, 2013

Erin Harrop: "Image Reflected," cover; "Wasteland," p. 83; "Woman Reading," p. 234

Artist Statement: For the past two decades I have dealt with a chronic life-limiting illness. At times, it goes into remission, and I live my life in relative freedom. Other times it is so severe that it consumes all waking moments. To many it is an "invisible illness." I may not look ill or seem sick; I have learned to play the part well. However, it demands constant vigilance. Over the years I have struggled to accept the complicated role that this illness plays in my identity. While I try not to deny its place in my life, I must also strive to not define myself in it. Art has been a solace in the midst of this exploration, and I find myself returning to it frequently to express in images those things for which I do not have words.

Eli Ellison: "Shhh," p. 26

Artist Statement: The intention is to draw something from its shadows. A calling to the deeper and darker recesses. Stir the estuaries.

I. Guest of Honor Speeches

Guest of Honor Speech: Andrea Hairston

WisCon. I can't believe it! How'd I get here?

Thanks to all the hardworking WisCon folks for this wonderful honor!

I pour libation.

Every bright vision I have, every poetic, prophetic thought I craft, every story-song I sing, whoever I am on page, on stage, wherever I go and shine my light, I pour libation to the ancestors, to the people who didn't even know me and loved me into being. I pour libation to the humble storytellers, grand conjurers, who believed in me until I was real!

Stories are primal technology, simple machines, fundamental to all other technology as we mold our world and ourselves. Stories are conjurations, calling forth reality.

We are making it up as we go along.

I pour libation to:

Tall tales, folk tales, fables, and follies

Myths, fantasies, lies

Ballads, praise songs, sacred visions, and urban legends

Natural histories, rumors, and hoodoo spells

Epic narratives of nation

Armageddon Arias

Big Bang sagas

I pour libation to

Dreamers and Imagineers

To lonely photons

Hugging their bits of light information

Pressing on to infinity

Making space bright with the romance of life

I'm a science fiction baby. I grew up in the Iron City, Pittsburgh, PA, of the mid-twentieth century: a town of steel workers, miners, oil barons, and folks running from sharecropping to blue-collar heaven. I was fortunate to grow up in a science fictional community. We, my family and neighbors, were in love with the FUTURE. We loved everything we were going to do there. The promised land. Peace and Justice. Equality. Thinking machines! Robots. Everybody told me I was getting my butt into a very good college, and if I wanted to visit the planets, discover the cures, solve some tricky, wicked cosmological problems, well, that's exactly what I and all the neighborhood kids would be doing. In the Future. Never mind what nasty was staring us in the face. Never mind if the present didn't want to include us in the halls of power, if the news didn't mention us, if movies and TV avoided our stories. We'd be storming the world stage soon enough. Science fiction was a necessity. Science fiction energized us, got us up early in the morning, 'cause we had to get busy making that tomorrow where we could share peace and prosperity and get high on freedom.

Personally, I intended to find life forms in the stars, fall in love with the great mysteries, and ask every question that came to my mind. True, I was also part of the 1950s generation that did duck and cover rehearsals for the nuclear holocaust. But, when the air raid sounded, I refused to skulk under my desk and use bare arms to shield my head. I told my teacher:

If the fools drop that bomb, we'll all be vapor or shadows on stone. Who needs to rehearse that?

So, don't get me wrong. I had a clear-eyed, front-row view of the dystopia. Riots ravaged row-house neighborhoods. Water hoses ruptured kidneys as folks marched to be counted full citizens. Soldiers died for lies, killed for lies, and came home ghosts. On TV, I saw ruins where they'd bombed little children, right down the road and across the sea. Women were afraid to walk the night, dying at the hands of family and friends, killed softly in kitchens, classrooms, and typing pools. Pod people were running

our lives, and I certainly didn't want to get body-snatched! Still, I was convinced, science and technology would show everybody the way to a miraculous, undiscovered country. THE FUTURE! And folks would just get on board, get their mojo working, and boldly go, you know? 'Cause in addition to being science fictional to the bone, my family, friends, and neighbors were hoodoo conjurers: the make-something-out-of-less-than-nothing magical folks! Bring on the danger; bring on the demons and dragons! I just knew we could survive ourselves, become the better angels of our nature. No more shucking and jiving, no more ducking and covering, I was certain we could take back the night, turn the ships around, and make the Future fantastic.

My grandfather was a Baptist Minister. He filled the church with his spirit. People came to Sixth Mount Zion Baptist Church for the show, for my grandfather calling down the power and sharing it with everybody. Coming of age, I couldn't accept Jesus as my personal savior like all my cousins who said: *What's the big deal? Hold your breath and just do it.* They didn't take dipping back into the baptismal waters to declare your FAITH as seriously as I did.

I had witnessed FAITH. I went with my grandfather to visit the shuts-ins. Folks got better as soon as he walked in the door. I sat in my grandfather's third-floor study while he wrote his rock-the-church sermons. He told fabulous, high-drama stories, to make sense of this mean old world in God's light. He always ended with a call to action. And every Sunday, folks in the pews jumped to their feet, a stampede, marching to the FUTURE on FAITH.

One day after doing house calls, my grandfather and I were on the way to our ritual ice cream treat. We turned the corner on two young men, strangers, fighting over nothing, knives in their hands, blood dripping. They were spitting and cussing. I was terrified. I wanted to run the other direction. My grandfather walked right between these guys and their big knives, cloaked in FAITH, ready to die for what he believed. I was shocked. They were shocked too.

Old man, what are you doing?

What are you doing? he asked. *Who do you mean to be?*

We all had ice cream together, chocolate with chocolate sauce. I let them eat my whipped cream. He made them promise, you know, to get their foolish behinds into very good colleges, and if they wanted to visit the planets, discover the cures, solve some tricky, wicked cosmological problems, why, he'd be checking up on them and spread the Good News on Sunday. So these bad boys were on THE LIST. Reverend Hairston didn't mess around. He showed up for you, and you showed up for yourself. They both graduated from college.

Yes, I had seen FAITH hoodoo folks for sure. So despite the more or less harmless lies I might tell for personal gain, like the money my brother and I scammed out of my father and grandmother to go to the movies and buy comic books for my brother's vast comic book library, no way was I going to get my hair wet and all balled up in knots to front some face-down-a-knife-FAITH I did not possess.

Got to cast your own spell. That's what my great-aunt told me. She was a union organizer who spoke her mind and lived how she saw fit. *You know Estelle, can't nobody tell her nothing.* According to my storyteller mother, my Great Aunt left New York City in a big hurry one night, bullets whistling at her union-organizing back. A LOOSE WOMAN, A RED—if standing up for working people and loving when you had a mind to turns you red. She ended up rabble-rousing and raising hell for working folks in Fall River, MA. A serious conjurer, my Great Aunt was always sharing her braggadocios spirit.

I ain't scared of nothing. You don't need to be either. I got the key. Her voice boomed; fire blazed in her eyes; smoke practically curled out her nose. *The key to every lock!*

She'd wave a chain of keys, ancient and brand new. Whatever we'd been afraid of seemed like nothing then. My Great Aunt was a Drama Queen, like my grandfather. She worked her props, and the world was her stage. At eighty-something, she jumped on the

notorious, scare-you-to-death-for-a-dollar, leave your stomach in the clouds roller coaster that plunged from rocky hillside down into a coal-mining ravine.

Let's do that again. Nothing like going fast and furious over the edge!

Just after I turned Jesus down, I visited my Great Aunt in Fall River, a bus adventure on my own. I wasn't there a day before she got me up early to go visit the sick and shut-ins with her. Everybody got better when she stormed in the door. Kids hit the books. Folks agitated and organized.

Estelle Hicks don't take no stuff!

My Great Aunt did talking spells, hyperbole you had to repeat with her, spells to talk you to wherever you needed to go. She started a Head Start Program at seventy-five and got a ten-year service plaque at eighty-five.

Let's work on the impossible. It'll take longer and be more fun!

She came to my graduation from Smith College. I was the first woman in her family to go all the way there. We stood in her Science Fiction and Fantasy dream come true.

I pour libation to my Great Aunt and grandfather. I am the song they sung.

On the way to the Future in physics or math or as a lawyer or a linguist, I ran off to the theatre.

Gotta cast your own spell.

My Great Aunt was still bursting with pride, but family, friends, and community were VERY disappointed. How could I waste my talents, their boldly-go investments? We needed everybody's brilliance to make something out of nothing, to conjure that fantastic Future in the face of unrelenting nasty. Suddenly these SF&F folks turned into hard-core Realists.

Have you lost your natural mind?

Going into theatre, into the arts was going over to the dark side! Oh the horror!

I'd be giving up numbers and photons and the arcane esoterica of quantum physics to engage in metaphors and intuitive, magical thinking!

The arts, really? You were such a devout geek, you wouldn't even pretend to get baptized!

Right. I'd originally planned to do theatre and writing on the side. Isn't that why I applied to law school? Who squanders a gift for numbers, a head for quantum theory, the fire to argue anyone into the ground? Hadn't I been the standard-bearer, showing what colored people, what women could really do? If they finally let you into Harvard Law School, weren't you supposed to go? *You know Ann. Can't nobody tell her nothing.*

Like a boatload of folks in the American Empire, we, my community, family, neighbors, and friends, we thought and still think we must escape so-called magical thinking by being REALISTS, by refusing to hide in the sweet, squishy fantasies that humanity created in its primitive infancy to comfort and shelter us in a hostile universe. As adults now, as civilized citizens of a post-Enlightenment scientific world, we must dump childish illusions and comforting fantasies. We should entertain and enlighten ourselves with hard-edged, rational "reality."

Okay, for the skeptics who resent spending money on the arts that could go to bombs or even vaccinations there are studies that show music training can improve student math scores, or if you let them do plays, they'll be better citizens. In April 2012, Forest Whitaker and Sarah Jessica Parker signed up for the new federal initiative to turn around failing schools with the arts. But what about—math will help you play that concerto or be a composer whiz? Or study anatomy; it'll help with plotting great fiction or drama. Take civil engineering; it'll make you a kick-ass stage manager or director, a master at reverse engineering your way to opening night.

Yeah. Nobody says that.

This asymmetry is a given. We colonize the magical, metaphorical mind. We valorize one mode of thinking and exploit another. We associate the metaphorical mind with primitive, feminine, irrational, uncivilized, childish minds! Inferior, yet, the unfettered, exotic, erotic thrills and spills of the feminine, the primitive is always the best fun. Wild Knowledge. The metaphorical mind is a handmaiden at the service of better, rational things. Art in general, fantasy and science fiction specifically, are not to be taken seriously if we want to make it to the FUTURE!

Tales of the city

I didn't go to Law School. I did a year as The First Black Women-Person Editor of math textbooks at Houghton Mifflin. I started a theatre in my spare time, wrote scripts in the wee hours of the night, stage-managed community play, produced meaning. Landlords and fire chiefs burned our buildings down for the insurance. Race riots rocked Boston. On Boylston Street a man wailed on a woman in broad daylight. *Do you need help*, I asked her. She said, *No, no, please, no, go away*. He came for me anyhow, grabbed my arm, and shook my brain up. Without thinking, I punched him in the face with my Great Aunt's loose woman, hunkajunk bracelet and then hit him in the solar plexus. After that I was so scared I couldn't talk, at all. Me. Nothing to say to the policeman who'd appeared out of nowhere. Helpful bystanders explained that although I looked like an angry Black woman who'd just go off on random 6'2" white bruiser minding his own business, actually the guy coughing and sputtering on the ground grabbed me first—see bruise?

Back at work, we women pressed a class-action suit against Houghton Mifflin. They were paying the boys more, but calling in lower-paid me and other women on the weekends when they needed fast quality work to meet impossible deadlines. It was a Saturday afternoon, solving three-dimensional calculus. What was I doing? Waitressing of the mind? This was the wrong Future.

I escaped to graduate school in playwriting. I was still in the thrall of an early writing teacher who declared SF&F off-limits, an edict I had accepted without a fight. Still I got there by way of Medea riding her chariot of fire. Following the secret passage, I came through *The Tempest* and Lorraine Hansberry's *Les Blancs* to enchanted lands. In *RUR* robots took over the world. A shape-shifting woman wrestled with simple-minded Gods in *Der Gute Mensch von Sezuan*.

I was drawn to the anti-realists, to the surrealists, expressionists, to the Brechtian *Verfremdungseffekte*, to alienation, to estrangement, and the urban Indian storyweaving of Spiderwoman Theatre. I embraced the polyrhythmic epistemology in Caribbean festival drama, Carnival, Junkanoo, Crop Over. I couldn't get enough of *Funnyhouse of a Negro*, *Day of Absence*, *Woza Albert*, *Fires in the Mirror*, *Play of Giants*, and that *Dream on Monkey Mountain* Derek Walcott was having. Caryl Churchill's clones and Tess Onwueme's mythical kingdoms were speculative theatre delights. These anti-realists didn't worship the spectacle of the real.

Berthold Brecht said, "Art is not a mirror held up to reality but a hammer with which to shape it."

Or as the Hopi say: "The one who tells the stories rules the world."

My love of anti-realism made some folk wonder if I was really Black. I lost my first college teaching job because the Chair of Afro-AM wasn't sure I was Black enough. I didn't get invited to major Black theatre gathering because I was too multicultural, too queer, too anti-real! Black folks need to keep it real.

Theatre is live, immediate, amazing. You've got the presence of the actor, the presence of the audience. It's in-your-face art! I had a large dog-friend rescue me when a belligerent audience member got out of his car to chastise me for telling a story that shook up his world. It wasn't my dog, so I couldn't call him off. I've had a sold-out audience shiver in freezing February sleet (while the fire department checked out the bomb threat), and then return to

the theatre for the last act. I've worked with Bosnian, Sudanese, Sri Lankan, and Guatemalan refugee women to storyweave their anti-real truth and claim the world stage like Spiderwoman. I've had an audience member stand up and say thank you for giving me back to myself.

In 1995 as a guest artist at a north German University, I felt like an alien. It was Hamburg, not Bavaria, not MY Germany. On *Rothenbaumchaussee*, alien me remembered who I was: a science fiction baby, from a family of hoodoo conjurers. I intended to find life forms in the stars, fall in love with the great mysteries, ask every question that came to my mind, solve some tricky, wicked cosmological problems. So, I declared myself a Science Fiction and Fantasy writer and invented the world of *Mindscape*.

Much SF&F did not disturb obligatory Empire realism. Much SF&F omitted me, my dreams, hopes, and facts, despite a dragon flight of fancy or a faster-than-light trip through the galaxy. So I had to write myself into the story. This is every writer's glorious task.

We're in a state of emergency. We face born-again predatory capitalists worshipping the magic hand of multinational corporate greed, instituting deadly and precarious monoculture, monetizing our souls, and crushing spirited entrepreneurship for the sake of cancerous monopoly. They're making apocalyptic Armageddon Arias. If the fools keep doing that, we'll all be vapor or shadows on stone. Who needs to rehearse that?

As a child, I felt invincible, immortal, and almighty. If I put my mind to it, there was nothing I couldn't learn or be or solve. I use the energy of my child self to conjure the FUTURE. We have to invent the story technology that would help make a way outta no way to that miraculous, undiscovered country. TOMORROW is an ongoing impossible show that we're busy rehearsing.

I pour libation to all you Dreamers and Imagineers.

You're on The List. Get your mojo working and boldly go!

What're you going to believe until it's real?

Guest of Honor Speech: Debbie Notkin

It's ironic to be standing here in this particular year. Last year, when guest of honor selection was going on, I was advocating having a year without guests of honor, but instead declaring that the entire membership were the guests of honor. Yes, really. I was concocting schemes for Hyde Park-type public speaking opportunities and a few members speaking tonight through some kind of lottery. Obviously, not everyone on the committee thought this was a good idea. If I had succeeded, I wouldn't be standing here. You—some assortment of you—would. At least one of my good friends was afraid I would turn down the invitation and stand for my original idea—I have to say that idea never crossed my mind. But I still think that the real honor of WisCon rests in all of us.

Normally, I'm a facile writer—I figure out what I have to say and then I write it quickly and straightforwardly. If I'm writing something important, I go over it once or twice, maybe ask someone else to take a look at it, and it's done. This speech is different: I have literally been writing it in my head for more than a year. It's gone through probably ten major possible topics, thirty variations on the best ones, uncountable numbers of mental false starts and changes of direction. I didn't put a word down until two days before the convention started.

Finally, I had to ask myself why this was being so difficult. Honestly, I think it would be easy at almost any other convention. A Worldcon guest of honor speech would be a snap; I could stand up there and say some basic things about feminism, privilege, or body image. Some people would clap and some would be offended, and the ones who knew more about what I was talking about than I did would also know enough about the general engagement of the audience with the subject to appreciate the attempt.

But any topic I know a lot about, dozens or hundreds of you in this audience know just as much or more about. I can't lecture you; I can't start with basics; I can't proclaim. This makes speeches harder. And this is why I wanted all of you to be the honored guests.

Last month, I mentioned my slowness writing the speech to Jeanne Gomoll, who said, "That's why you have to be personal." I knew she was right, but this just raised new questions. What's personal but not private? What's personal but not self-serving?

For the past several years, Timmi Duchamp at Aqueduct Press has asked the guests of honor to put together a book as part of their WisCon experience. As part of this year's book, Andrea and I decided to interview each other, which we did in email. One question she sent me surprised me: she said, "What's the secret of your bounty and generosity?"

I haven't asked her where she got that question. I think of myself as a generous person, but I don't know what reasons Andrea has to know that about me. "Bounty" is a more complicated, loaded word: a lovely word, except that lurking behind it is that dread overtone of Lady Bountiful, showing off her riches and kindness by bringing food to the poor. I always imagine her stepping disdainfully over the mud in the road and walking away thinking more about herself than about the people she brought food to.

Anyway, Andrea got me thinking about generosity, a topic that is personal but not private, personal but not primarily (I hope) self-serving. And the closer the calendar got to May, the more I thought I might have something worth saying about generosity.

In the Internet neighborhoods I frequent, it's common for people who are having a hard time to say, "Tell me something good." When I was really starting to focus on generosity, Marissa Lingen, a Minneapolis fan and writer whom some of you know, did something different. She said, "Tell me something that's important to you right now. Easy or difficult, positive or negative: tell me something important."

She set things up so that people's responses were private. A few days later, she made a follow-up post, saying, "The overwhelming bulk of the responses told me that a lot of us—really really a *lot* of us—are struggling. There's good stuff, but there's a lot of hard stuff. Like the man says, 'We're dealing with some serious shit here.' And I mention this just to say: we are going to need to cut each other some major slack. Kindness and patience are so, so very much called for."

The topic is in the air. On the Thursday morning before WisCon, I found a link to a superb online journal post by writer Michelle Sagara (whom I don't know), talking about help—what it is, what it isn't, how it works. In the elevator lobby yesterday, I heard a woman saying, "But that medication is sixty dollars a month, and I don't have insurance." The woman with her, a previous WisCon con chair, said, "I have sixty dollars a month for you to have the medication you need."

Generosity, like anything important, is more complicated than it sounds.

Here's one complication: taking is important. Giving is not an action one person performs and another one receives. It's a *mutual* action; it takes two. This is what we are really talking about when we say "give and take." All too often, however, both the identified giver and the identified taker forget that each one is in both roles: accepting requires its own very particular generosity of heart and mind. I'm not talking here about gratitude or even politeness—we'll get to that—but simply the choice to accept. Whether you accept generosity easily or (for any number of reasons) you have trouble being on the receiving end, accepting what's offered is an active choice.

Giving always means choosing, being a gatekeeper. The pool of need is so deep—we're dealing with so much serious shit—that anyone with anything to give (which is everyone) has to decide where and when to give it. And we're all dealing with our own serious shit too, so there's a lot of self-care in the mix. When are

we helping others before adjusting our own masks? It's not easy to know, especially in the moment when the air flows out of the room.

Money is the most easily recognizable form of generosity; you might say it's the form with the most privilege. Money is easy to identify: we know when we have it, we know when we need it, we sometimes even know the difference between how much of it we want and how much of it we need. A huge part of my teens and twenties was about pushing back against accepting money—my mother always wanted to give it to me, partly out of genuinely generous impulse and partly because she had a core belief that that's how you kept your children's love—and I never wanted to accept it, because I could only hear the offer as an implication that I couldn't manage on my own. (My brother, not bothered by my desperate need for independence, would always put his hand between us and offer to take the offending money himself.) I never succeeded in convincing my mom that not offering it to me would be a bigger act of love than offering it—that was a form of generosity that she, as the giver, couldn't step up to. So eventually, as I got older and more confident, I found the generosity to accept it: grudgingly and even rudely at first, and more graciously as time went on. Now, my ability to be generous with money comes from a cushion I wouldn't have if she hadn't given it to me. Life is full of ironies.

I'm extremely fortunate to have more money than I need—right now—and I find it to be one of the easiest things to give. In this capitalist culture, it's one of the hardest things to take. As it did between me and my mother, money stands in for so many things that it's not. It's the primary measure of power in our world, so needing it can feel like failure. (Doing anti-foreclosure work in my home city, I've been learning that when a homeowner in foreclosure doesn't ask for help—and most don't—one of the major reasons is that they feel ashamed, as if what was happening to them was their own fault.) Giving money can stand in for purchasing part of someone's life: I gave you this money, now you are accountable to me for your choices. Giving it can also be a way of

establishing one-up/one-down relationships. If money is, as my brother calls it, “how people keep score,” then having it to give identifies you visibly with the winners, and having a reason to take it can conversely identify you—to yourself—as being among the losers.

Fortunately, at least most of the time, I don’t see money that way. I distrust and dislike it, but I decided a long time ago not to let that get in my way. I see money as what it can provide: the difference between living on people’s couches and having your own bed; the difference between coping without the medications that can actually make you feel better and having access to them; the difference between being able to buy that wheelchair-accessible van and not being able to go where you want; the difference between taking that dream trip and watching a slide show of your dream destination on YouTube.

This is where the gatekeeping and the mutuality starts coming in: if I see a need, do I offer? What are my guidelines for when I say, “Can I help?” and when I hold my peace? If I do offer help, is it welcome? If someone asks, how much do I take their courage to ask, and the style they used to make the request, into account? In those long painful arguments with my mother, I learned that not pushing a gift on someone who doesn’t want to take it is also a form of generosity. I offer once, and step back if I don’t get a positive response. I offer again if I felt that the response was ambiguous. I try to always say, “You can come back to me if you change your mind.” And then I practice the skill I’ve had to work harder to learn than anything else in the world: I shut up.

Generosity, of course, isn’t just about money. Time is much less flexible than money; it’s the one thing that we all absolutely know we will run out of. So, in a sense, it’s harder to give. Helping a friend move, taking an evening to listen to a tale of woe or make sure an overburdened friend gets a break—these things will always take time away from whatever else we need to be doing, “should” be doing. What’s more important, the unwashed

dishes or the craft project for a birthday? The homework or overtime office work, or the home-cooked meal delivered to a household in deep stress? People talk about life/work balance, but this is within-life balance: relationships and chores are both part of life. For me, an extrovert self-identified as a giver, I almost always make the relationship choice and squeeze the other things into the corners (which is one reason I finished this speech this morning). And yet, I have a disturbing list of unmade phone calls, unanswered emails, disconnections I could fix, time I could put into mending fences or being there for people who could really use the time. I'm a more conscious gatekeeper with giving money than with giving time; I have a clearer set of internal guidelines and make better choices. This is, no surprise, why I make more glaring mistakes with time—both in giving too much and in withholding too much—than I do with money. (That's something I taught myself by writing this speech.)

A third thing that we have to give each other, which is tied up with time but is not the same thing, is attention. Do I really look at you? Do I know who you are? Do I want to hear the “something important” that you are carrying? Will I think about you when we're not together, will I remember what's important to you when I see you again? Attention is, I think, less of a limited quantity than either time or money, but simultaneously slippery and hard to identify. Ability to give it varies hugely from person to person, from moment to moment, whether you want to call that variation neurology, personality, stress, or whatever.

There's a paradox here. The best kind of attention we can give each other is the kind that attends to individuality. What does this person experience as helpful attention, rather than over-solicitous hovering or rudeness? How does this person express “back off” or “please help”? At the same time, only some of us are good at recognizing those individual attention cues: a combination of nature, nurture, ability, and skill development. Sometimes, the generous choice is to recognize that someone isn't configured to meet you

in your favorite form of attention and to look elsewhere. It's also really important to cut yourself slack about how you give, well, everything, but perhaps especially attention.

In a panel I was on yesterday, I watched a hard-of-hearing friend sit in a back corner, his hand cupped around his ear. I thought several times of inviting him to come sit in an empty blue-tape chair up front, but I kept deciding that the model of him in my head would be more embarrassed by being singled out than appreciative of the result. I talked to him later, and he seemed to agree with my choice, but Kate Yule, standing with us, pointed out what I could have done: I could have said, "There are chairs up front for anyone who's having trouble hearing." I tell this story because it illustrates at least three things: noticing the problem, making a choice among obvious solutions, and not having the ability in the moment to come up with an out-of-the-box alternative. I could also have made myself miserable for not thinking of Kate's option in the moment, but instead I just tried to file it away for the next opportunity. We'll see.

If all these complications are part of the giving side of generosity, how complicated is taking? At least as complicated, and perhaps more, because it's even less examined. Especially in America, the land of imaginary individualism, we claim to be skeptical about *all* taking. We have a deeply built myth that we are supposed to be able to build our own log cabins, grow our own food, keep ourselves healthy by strength of character, and somehow dig our own graves. We manage to preserve that myth while being, as a culture, crazy incapable of doing anything for ourselves and more than willing to take endlessly from people who don't have much to give, with little or no regard for what our continuous taking costs them.

This inescapable cultural morass, inevitably, reflects on how taking applies to individuals. Some people take easily; either they are good at asking for what they need and want, or they are good at getting it without asking. I admire them; when being good at

taking is done with awareness, it's a beautiful skill. It makes the givers happy, it makes the takers happy, and balance is maintained. Some people who are good at taking are also extraordinary givers, probably because they're getting the nutrition they need to keep giving.

For other people, taking is a challenge. When my partner Alan's mother was dying, I kept seeing her having to learn to ask for help while she was in more and more dire straits. I made a conscious decision then to get better at asking and get better at taking—it's not an easy road for me, but I've made strides along it, and I'm very lucky that (unless something changes suddenly), I still have time to get better at it. I find it useful to think of asking and taking as learnable skills, valuable skills, rather than either a character trait I was just born or raised without, or a reflection of weakness. In fact, taking is something we're all likely to need skill at, and doing it makes us stronger.

I said I would get to acceptance, gratitude, and politeness, which are inextricably intertwined with taking. Giving with a main motive of being paid in gratitude is problematic. Let's face it, gratitude is lovely. I appreciate it when I get it. But I try not to make it a condition of the gift (especially not one of those internal secret conditions that I never tell the other person about and then get grumpy when they don't follow my secret script).

I also like showing gratitude; I usually feel like it's a good simple response to generosity. But sometimes my need goes too deep, or my resentment of my own need is too strong, or I'm too focused on the inequity between my need and the giver's having whatever it is to spare, or I'm just plain distracted, and all I can do is grunt. If that's not enough for the giver, well, that's the giver's problem. If they decide not to give to me again, their choice. If I decide not to take from them again, my choice. I've never been sure that good fences literally make good neighbors, but I am sure that good boundaries make good relationships. One of the most important things about recognizing that taking is a choice is that

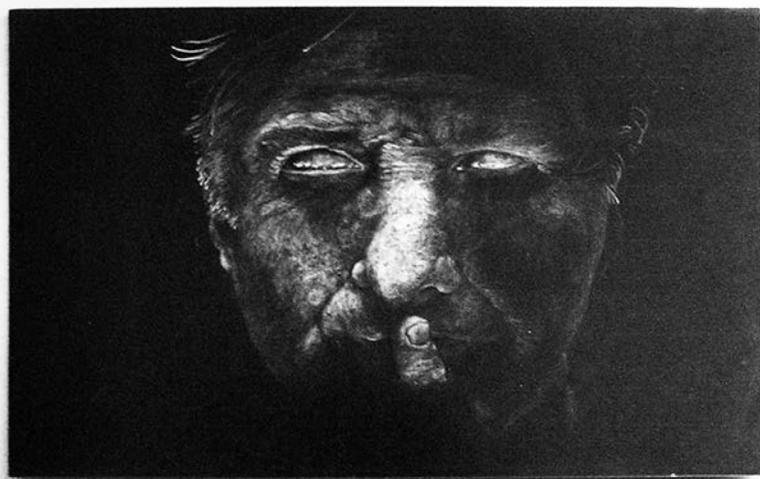
knowing this reminds us that some of the power is in the hands of the identified taker — the power exchange is not as simple as it usually looks. The more I can remember that taking is giving, and giving is taking, the easier the whole transaction gets.

As if all of these complications of generosity weren't enough, there's one more that none of us can afford to forget. The easiest way to be generous is with the people we know, which means that whatever kind of privilege we carry is a form of control over who gets whatever bounty we have to offer. I find it easier to be generous to people I know than to strangers. I find it easier to give serious time, money, or attention to someone at WisCon, or someone I hear about through friends on the Internet, than to the homeless people in my neighborhood. I find it easier to give to the homeless people in my neighborhood than to the children starving in the Sahel. Because I prefer personal connection to generosity mediated through nonprofits and NGOs, I have to think about the ways in which that limits who I help. If I help pay for medications for a friend who has a partner, a home, a loving family, and a wide network of friends, that money isn't going to someone with similar health problems *and* no other safety net. If I spend a weekend helping a disabled white friend build a ramp into her home, I have to remember she has more people who will help her than the disabled African American ex-heroin addict across the street, who also needs a ramp. And, at the same time, if I give my money to Doctors Without Borders and my time to Habitat for Humanity, then my community doesn't get the benefit.

We each find our own balance amid all of these tangles — giving and taking, money/time/attention, within our circle or outside our comfort zone. Writing this speech helped me to think these things out and give the question some structure. But is this speech a gift to the members of WisCon, or is the opportunity to stand up here and talk a gift from all of you to me? See how it's complicated?

I want to close by thanking you for giving me your time, your attention, and for the choice to honor me. I take your gift very seriously and accept it as graciously as I know how.

II. Disability and Identity



"Shhh" Eli Ellison

Defining Disability in a World that Fears Disability

s.e. smith

“Disability” is a concept that can be surprisingly difficult to define, especially in the context of a swirl of political and social movements built around disability and resistance to social constructions of disability. Government agencies have their own guidelines for disability,¹ while people with disabilities² may have their own definitions, depending on their specific disabilities and lived experiences. Members of the nondisabled community also have their own perceptions of disability, which play a role in how they define and conceptualize disability.

Many of the definitions and outlines of disability developed by outsiders are rooted in a culture of fear, where disability is viewed as alien and other and thus must be clearly outlined in an attempt to neutralize it. By trapping disability within the confines of definition, nondisabled people can protect themselves from it through distancing measures.

By government and medical definition, for example, a person who uses a wheelchair for mobility due to a spinal cord injury that makes it difficult or impossible to walk is a person with a disability. The spinal cord injury is treated as a specific impairment that renders the person incapable of performing certain tasks of daily living. This model positions the disabled body as inherently other and abnormal; there is something wrong with the body, which must be identified and, if possible, fixed.

Social models of disability explore the interaction between the body and society, arguing instead that society itself, rather than a

specific impairment, is what is disabling. In the example above, the issue is not that a person with a spinal cord injury might have difficulty walking, but that the world is constructed for people who walk, rather than roll, to reach their destinations. Under this model, the issue lies not with the fact that it is hard to navigate stairs in a wheelchair, but with the decision to put stairs, rather than a ramp, at the front of a building.

The medical model embraced in the US is deeply flawed. It places a heavy emphasis on personal responsibility, treating disability as an individual problem. It also plays directly into cure culture and the argument that disability is a tragedy that must be fixed; under this model, disability pride is inconceivable, and it is frightening to imagine a world where someone might be content in a disabled body.

By contrast, the social model examines impairments within a social context, incorporating the need for a more open and accessible society with an acknowledgment that impairments cannot be magically erased. Disability activist Lisa Egan notes that “the social model [distinguishes] between ‘impairment’ (the things you can’t do because of your body/brain) and ‘disability’ (the social barriers disabling you on the grounds that you have an illness or impairment).”³ Rather than medicalizing a person as “other,” the social model focuses on the need to respect all bodies, all people, and all lived experiences.

Both models place an external frame on the lived experience of disability that may not necessarily leave room for the experience of disability on a personal level. Individuals may frame their individual relationships with disability in more personalized ways; the same spinal cord injury may result in loss of sensation or difficulty performing tasks that were once easy. Two people with the same injury may not experience it in the same way and may individually express varying levels of impairment; one person could consider it a career-ending disability, for example, while another might view it as a more moderate impairment that results in the

need for some assistance with tasks of daily living and some lifestyle shifts, but not the end of the world.

Who are the definers?

The determination of who is permitted to define disability has a tremendous impact on the lived experience of disability. Some disabilities are widely recognized—blindness, mobility impairments, deafness, for example. Others are less well-known and in some cases viewed with active hostility. Chronic fatigue syndrome, multiple chemical sensitivity, and fibromyalgia, for instance, are dismissed with labels like “yuppie flu” and considered “not real.” Those who live on the wrong side of the definers can encounter obstacles such as difficulty accessing treatment and accommodations because they do not fit within the categories neatly accepted and promoted by the nondisabled world.

Simplistic models of disability as advanced by society neglect the fact that there is considerable diversity within the disability community. That, in fact, disability can take numerous forms, and the same conditions may cause varying experiences depending on where someone lives, the severity of the condition, and the support available. One person with bipolar disorder, for instance, may be “highly functional” as defined by others, able to work in a high-powered job, maintain relationships, and achieve social distinction. Another may have difficulty with even the most basic tasks, like personal hygiene and creating functional relationships.

Some disabilities may be acquired later in life, while others are congenital, and this may have a profound impact on an individual’s relationship with disability. A woman diagnosed with fibromyalgia at age thirty who ends up using a wheelchair for mobility could have a radical adjustment period and may experience very different emotions than a woman born with cerebral palsy who also uses a wheelchair for mobility. Both women use a chair, but for different reasons, and with different underlying experiences.

An individual with a clearly documented, diagnosed, and known medical condition will also have a radically different experience of disability than someone with an unknown or nebulous condition. Some chronic illnesses resist diagnosis and treatment, requiring months or years of medical evaluation with no clear outcome; the patient knows she is sick, but has nothing to point to in conversations about what is “wrong” with her. People in such positions may struggle to navigate a world where social expectations demand a clear and definable diagnosis.

Considerable tension also lies between those with evident physical disabilities and those with so-called “invisible disabilities,” those which may not be readily apparent without explicit disclosure. Even the definition of “invisible disability” is variable, as not all conditions labeled as invisible are necessarily so — mental illness, for example, can be very evident for those looking for specific cues, while a condition like mild cerebral palsy could be entirely invisible.

This creates questions about who is “allowed” within the disability community. When outsiders define disability, their framework may exclude people who would self-identify as disabled, given space to do so. Policing within the disability community can also become exclusionary in nature; having a disability does not necessarily make someone friendly to self-identified people with disabilities, or to people with other kinds of disabilities. Cascading tensions can also arise between those who are self-diagnosed and those who have official medical documentation, as in the case of the autistic community and some corners of the mental health community, where considerable controversy swirls around self-diagnosis.

We are the Borg

From the outside, the disability community is often viewed as a hivemind or as a herd of identical individuals who can be readily interchanged with each other. This not only erases the consider-

able variance in terms of lived experiences of disability and the broad diversity within the disability community, it also ignores the key role of intersectionality, another component of the disabled experience.

People who are both disabled and transgender, for example, have very different experiences in the medical system and within the disability community than those who are cisgender, and these can contribute to their views on disability as well as their own self-perception. Likewise, people of color and nonwhite people have very different experiences within both the medical establishment and disability community. Black men, for example, are more likely than white men to be forcibly labeled with mental health diagnoses that pathologize normal behavior, such as rational responses to racism.⁴ Likewise, people of color,⁵ particularly women, are more likely to be identified as drug seekers when they report problems like chronic pain,⁶ while women's medical complaints and those of gender-variant people are often dismissed because their symptoms don't match a medical model based on the bodies of the "normal" person: one who is a white and cisgender man.

The end result can create a hostile external environment for people with disabilities. Individuals with invisible disabilities may have difficulty getting accommodations because their conditions are not recognized or understood by society at large, and they may be disbelieved and ordered to "prove it" by friends, family, employers, and even random strangers on the street if they ask for accommodations in the workplace and other settings. Their lack of clear visual cues confuses nondisabled observers, who may believe they are lying or exaggerating about the nature of their conditions in order to access the imagined social benefits that come with disability. Among these many supposed perks of being disabled are lavish payouts from the government, full-time personal assistants, special treatment on examinations beyond reasonable accommodations such as more time or provision of

materials in accessible formats, free cars, and other preferential treatment.

They're also subjected to casual ableism from the people around them, who assume they are "safe" because they aren't read as disabled. Whether it's using disability as the butt of a joke or attributing horrific acts such as mass shootings to someone's disability status, nondisabled people feel free to make their hostility for disability evident when they are in environments they believe are populated by fellow nondisabled people.

Those with less-evident disabilities are also subject to the peculiar double bind of forcible passing. They may be envied by some with evident disabilities for their ability to move through public spaces without carrying obvious markers of disability status, but at the same time, when they are read as nondisabled by the people around them, a fundamental part of their identity is torn away. For people struggling with entering the disability community and identifying as disabled, forcible passing can be another reminder that they are not "disabled enough" and lack the credentials to present as disabled and request accommodations and acceptance.

While passing may be considered a form of social privilege by some, it is not always experienced that way by people who endure forcible passing. For those engaged in disability pride movements who want to celebrate their disability statuses, or those who require accommodations on a regular basis even though they may appear nondisabled, every day becomes a constant parade of exposures and disclosures; asking for a seat on a train, for example, requires explaining medical details to someone in the disabled seating, and running the risk of not being believed because your body doesn't mesh with social expectations of what disability is, and what disability should look like.

Meanwhile, people with evident physical disabilities have no choice when it comes to passing, as their bodies out themselves when they move through the world. Instead of the pernicious ca-

sual ableism embedded in social attitudes, they experience direct ableism, whether in the form of inaccessible structures, offensive comments, active discrimination, or other means. They, too, may be denied accommodations if their bodies fail to fit anticipated social norms; a part-time wheelchair user, for example, may be told to “just walk up” a few steps to get into a building, despite the fact that this could be exhausting and dangerous.

Who speaks and who listens?

The spectrum of experiences within the disability community can create tensions when representatives emerge to speak for the community as a whole. Like many marginalized communities, people with disabilities have long been silenced in conversations conducted by advocates about them, rather than *with* them, leading to the slogan “nothing about us without us”⁷ to stress the need to put disabled persons first, and advocates second, when it comes to conversations about disabilities.

Emergent figures in the movement who become well-known can be faced with a significant burden, as they’re asked to represent the disability community as a whole despite the fact that they are, at root, individuals, and that they may not have been elected collectively to represent the community. Differing views on the subject of disability, accommodation, and social attitudes can lead to conflict between spokespeople, and to situations where people who don’t want to be positioned as advocates or authorities are forced into those roles because they’re articulate and well-spoken, particularly in the case of people with stories that fit dominant narratives.

Thus the queer woman of color who uses a wheelchair for mobility and engages in direct action to raise awareness about cuts to social services doesn’t enjoy the social profile of a conventionally attractive white Deaf woman who doesn’t use mobility aids advocating for captioning, though both are supporting important causes and both may be equally impassioned. This reflects external

pressures on the movement to produce spokespeople with the right kind of social credentials, creating faces of the movement who will be viewed as credible by outsiders, but who may not necessarily be the most appropriate advocates for all people with disabilities. This is a problem shared across social justice movements, where difficult decisions need to be made when selecting test cases, advocates, and representatives to make a movement palatable to the rest of the world. These kinds of compromises can end up weakening, rather than strengthening, movements.

Sharing an experience of disability doesn't necessarily mean that two people with disabilities have the same views or beliefs, and this can lead to anger when it comes to determining who should speak, and be viewed as credible, for the disability community. Disability activists in turn can find themselves torn by conflicting tensions within the community even as they attempt to push for specific movement on particular disability issues.

What is known as the "hierarchy of disability"⁸ can play an important role in the self-conception of disability as well as interdisability politics. In this stratified view of disability, evident physical disabilities like mobility impairments can be viewed with more weight than invisible disabilities, particularly those that lack definitive diagnoses or tend to be more prevalent in minority groups, such as fibromyalgia, chronic fatigue syndrome, and mental illness. People with disabilities higher up in the hierarchy may consider themselves better authorities on the disability experience, while those with disabilities lower down resent being spoken for by people who do not share their lived experiences.

Living with visible disabilities can lead to frustration about passing privilege, which allows people with non-evident disabilities to move through the world and perform tasks of daily living without drawing attention to themselves or having all their actions revolve around their disabilities. This can contribute to irritation when people with non-evident disabilities speak up on behalf of the disability community, on the grounds that they don't

experience ableism or don't bear the full brunt of social attitudes about disability.

This is a limited view of ableism and disability, and it's one that is mirrored in the way some people with non-evident disabilities think about people higher up in the disability hierarchy. They in turn believe that having an evident disability can equal automatic accommodations and access, and greater interpersonal understanding because the disability is so apparent that it doesn't require explanation.

Those who experience both evident and non-evident disabilities can be caught in the middle by a conflict that seems to require that they pick a side, drawing lines in the sand where none need exist. And conflicts can arise in conversations about who should speak for the disability community and how, and how disability issues should be handled in society at large. Depending on one's disability, for example, there are varying views about the most important priority when it comes to breaking down social barriers. Attempting to collapse disabled identities into one commonality ignores the variance, but focusing on the variance can result in interdisability politics that lead nowhere.

A voice for everyone

Solidarity is a key component of disability rights activism and must be a heavily stressed element of direct action, legislative lobbying, and other activities used to advance the position of people with disabilities in society. When intercommunity tensions break down solidarity and drive wedges between groups of disabled persons, it can be difficult to seek common ground and unite on specific issues. This can be especially true of issues that affect a limited number of people, as some may not understand why they should join the effort instead of focusing on subjects more directly relevant to them.

Such tensions can be a reminder to people with the "wrong kind" of disabilities that they are not considered disabled enough

to be full members of the community. This in turn can feed into internalized ableism, which can hinder the ability to self-advocate and practice self-care, but can also contribute to destructive relationships with other people with disabilities. Those who believe themselves to be “less than” may become resentful of others, creating tense, unproductive relationships that interfere with inter-community solidarity. Meanwhile, those who consider themselves “greater than” may not understand why it is important to act in solidarity with minority groups within the disability community.

This is not a case of “why can’t we all just get along,” but a case of needing to build a more inclusive movement that recognizes all members’ intersectionally, which includes an acknowledgment of the diversity of the disabled experience. Disability is not one-size-fits-all and cannot be, because it involves such a wide range of bodies and minds; what is good for a wheelchair user is not necessarily relevant for someone who is mentally ill, and may do nothing for someone who is D/deaf.

Opening up a discussion within the disability community also allows for richer, and more complex, conversations about issues like conflicting accommodations, which have historically been swept under the carpet rather than dealt with. For example, when one person needs a service animal and one person is allergic to animal dander, how are both needs balanced? If one autistic person needs silence to focus and feel safe while a person with ADHD needs loud music, how does one create an environment that serves both? Who gets to make decisions about priorities?

A movement that admits the diversity of disability can also admit the varied individual approaches to disability; some people may fit well within some models but not others. The disability movement can at times be prescriptive about the relationships individuals are allowed to have with their disabilities and does not provide room for people who feel differently. A cane-user who is angry and resentful, still actively mourning the loss of mobility, is hidden away, while someone engaged in disability pride, or some-

one willing to serve as an inspirational model to nondisabled people, is celebrated.

In a broader movement, there is no one true way to feel about disabled bodies and the experience of disability. Those who seek cures or fixes are as welcome as those who do not, and who in fact actively reject them.

Within a community that divides disabilities into “visible” and “invisible” as though there is a clear demarcation line and that this is the only aspect of disability that matters when characterizing variance within the community, there is considerable room for disability policing, as well as anger. Those who can be forcibly passed as nondisabled may be targets of resentment and anger, particularly when they advocate on behalf of the disability community as a whole—even when they themselves acknowledge the considerable diversity of the community and note that experiences of disability can vary widely. At the same time, there is no recognition of the high cost paid when people allow themselves to be erased in order to “pass,” turning themselves into members of the nondisabled community long enough to accomplish simple tasks.

Meanwhile, there is a certain lack of understanding from those with non-evident disabilities about the daily cost of living with a very visible and unavoidable disability, where there is no option to pass and shrink into the background. There may be assumptions that those with clearly evident disabilities are more able to access accommodations and are treated with respect, when in fact they are subject to routine ableism and exclusion made easier by their very visible markers of disability.

As the two sides face off over a divide of visibility, it raises important questions about balancing the needs of a community as a whole with those of individual members. Liberation for some is justice for none. Justice requires balancing conflicting experiences and needs to ensure that *all* have a voice, rather than just those who fit specific dominant narratives, or reinforce social understandings of disability.

Further reading

- Bell, Christopher. *Blackness and Disability*. East Lansing, MI: Michigan University Press, 2011.
- Bordo, Susan. *Unbearable Weight: Feminism, Western Culture, and the Body*. Berkeley, CA: University of California Press, 2004.
- Clare, Eli. *Exile and Pride: Disability, Queerness, and Liberation*. Cambridge, MA: South End Press, 1999.
- Davis, Lennard, ed. *The Disability Studies Reader*. New York, NY: Routledge, 1997.
- Dellar, Robert, Esther Leslie, and Ben Watso. *Mad Pride: A Celebration of Mad Culture*. Spare Change Books, 2001.
- Disability and Society*. <http://www.tandfonline.com/loi/cdso20>.
- Disability Studies Quarterly*. <http://dsq-sds.org/>.
- Longmore, Paul K. *Why I Burned My Book and Other Essays on Disability*. Philadelphia, PA: Temple University Press, 2003.
- Longmore, Paul K and Lauri Umansky, eds. *The New Disability History: American Perspectives*. New York and London: New York University Press, 2001.
- McRuer, Robert and Anna Mollow, eds. *Sex and Disability*. Durham, NC: Duke University Press, 2012.
- McRuer, Robert and Abby Wilkerson, eds. *Desiring Disability: Queer Theory Meets Disability Studies*. Durham, NC: Duke University Press, 2003.
- New Mobility*. <http://www.newmobility.com/>.
- Ouch!* <http://www.bbc.co.uk/blogs/ouch/>.
- Smith, Bonnie and Beth Hutchison, eds. *Gendering Disability*. New Brunswick, NJ: Rutgers University Press, 2004.
- Snyder, Sharon, Brenda Jo Brueggeman, and Rosemary Garland-Thompson, eds. *Disability Studies*. New York, NY: Modern Language Association, 2002.
- Wendell, Susan. *The Rejected Body*. New York, NY: Routledge, 1996.

Notes

- 1 As, for example, in the US: “Under ADA, an individual with a disability is a person who: (1) has a physical or mental impairment that substantially limits one or more major life activities; OR (2) has a record of such an impairment; OR (3) is regarded as having such an impairment.”
- 2 There is a debate within the disability community over person-first language versus language used under the social model of disability. In the United States, “person with a disability” is preferred under the medical model of disability, which is predominant. In regions like the United Kingdom, “disabled person” is preferred. I will use these terms interchangeably throughout this essay.
- 3 “I’m Not A ‘Person With a Disability’: I’m A Disabled Person.” <http://xojane.com/issues/i-am-not-a-person-with-a-disability-i-am-a-disabled-person>.
- 4 J.M. Metzler, *The Protest Psychosis: How Schizophrenia became a Black Disease* (Boston, MA: Beacon Press, 2009).
- 5 K. Crenshaw, “Mapping the Margins: Intersectionality, Identity Politics, and Violence Against Women of Color.” *Stanford Law Review*, 43, no. 6 (1991): 1241–1299.
- 6 Michelle van Ryn and Steven S. Fu. “Paved With Good Intentions: Do Public Health and Human Service Providers Contribute to Racial/Ethnic Disparities in Health?” *American Journal of Public Health* 93, no. 2 (2003): 248-255.
- 7 This term was popularized by South African disability rights activists William Rowland and Michael Masutha, who first heard it in use by an Eastern European activist who was probably familiar with its early roots in Polish social policy. In 1998, James Charlton used it as the title of a key work in the disability studies field, and shortly thereafter it exploded into popular consciousness and began to be adopted by other social movements.
- 8 Deal, Mark. “Disabled people’s attitudes toward other impairment groups: a hierarchy of impairments.” *Disability and Society* 18, no. 7 (2003): 897-910.



"Woman Reading" Erin Harrop