

Enabling Intersectional Theory: Narrating the Messy Beginnings of Disability Awareness

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I am interested in the ways we write the convergences of our experience and our thinking. Intersectional feminist theorizing is an embedded (and embodied) dynamic process. We enable the construction of transformative theory when we illustrate how the mistakes, ambiguities, enlightenments, and ironies of our lived experience influence our thinking. Our everyday selves are in constant conversation with our academic selves, but we often ignore their dialogue. Increasingly, feminists and others are calling attention to the importance of those conversations and finding ways to bring them into our academic work.

I value intersectional theorizing for what it allows us to understand about the complex interrelations between multiple subjectivities, power, and knowledge. Grounded in critical race studies, intersectional theory comes from a field that values narrative, a field that courageously brings stories into legal discourses. Intersectionality has traveled, more or less successfully, into other areas but is often divorced from narrativity. In this essay I bring the two back together to assist in exploring the beginnings of my disability awareness, which can also be understood as my recognition of myself as nondisabled (AB or temporarily able-bodied) ¹, a previously unexamined element of my positionality. I bring the two into conversation by juxtaposing journal entries with related information about disability. Narrating my experiences has helped me be able to understand, theorize, and eventually teach from them – though in a more nonlinear, uncomfortable and often embarrassing process than that implies. Intersectional theory was never meant to be neat and tidy, or static and therefore finished.² Narrativity enables us to keep it messy, and therefore productive.

Alana and I go for our first “walk” (she calls rolling down the sidewalk in her motorized wheelchair “walking” – a disconcerting notion to my nondisabled mind set). I’m fascinated, uncomfortable, but mostly just scared (of what, I don’t know). Her body is tiny and curved. Her legs swing freely as the chair hits bumps in the pavement. She takes hits off her respirator tube waiting for me to say something. She has invited me to move in with her until I find a place. I finally offer that I’ve never known anyone with a disability before—a statement I’m now sure confirmed for her what she must have already discerned about my lack of disability awareness. Later I will realize how naive this was, tantamount to someone saying they’ve never known a gay man or lesbian before.

Due to the relatively quick passage of the federal Americans with Disabilities Act (ADA) in 1990, U.S. policy has been far ahead of popular awareness with regard to disability.³ As the most important civil rights legislation since the 1964 Civil Rights Act, the ADA was written to ensure “equality of opportunity, full participation, independent living, and economic self-sufficiency” for people with disabilities.⁴ Since passage however, the strength of the legislation has been continually eroded by the courts. The ADA estimated some 43 million Americans were living with one or more disability.⁵ A 2010 Census Bureau report on the 20th anniversary of the act put the new number at 54 million or 19% of the civilian noninstitutionalized population.⁶ Including those people in institutions, we are talking about at least 1 in every 4 Americans. This makes people with disabilities the largest “minority” group in the U.S.⁷ That means each of us has, or will have, some direct link with disability in our lifetime.

*My girlfriend has stepped out on me,
I have no job, few friends, no
permanent housing, little money.
I'm preoccupied with all of this as
Alana begins telling me her story.
How her parents put her in a nursing
home when she was young. How
she had to fight her way out for her
own survival. How she celebrates
the anniversary of her
independence every year. How her
disability is progressive – she used
to be able to do many things she
can't do now. How her lungs have
very limited capacity, which is why
she must use a respirator 24/7 to
force air into them. How her bones
are extremely fragile and apt to
break. Later I go to sleep thinking, if
she could get through all that, then I
can surely make it through this
rough spot in my life.
Comparatively, I feel better.*

Nondisabled people often idealize people with disabilities. This is not entirely our fault, popular culture, when it bothers to deal with disability, perpetuates notions of people with disabilities as either courageous heroes or pitiful subjects of charity. Those with disabilities have been encouraging the rest of us to resist this heroic/tragic dichotomy because, while it might make us feel better, it badly misrepresents their realities. Nancy Mairs writes, "People with whole bodies sometimes mistake cripples for heroes. They forget that I'm doing just what they're doing, only more clumsily."⁸ As a result of this valorization, and in a culture that prizes individual achievement, "super crip" becomes a toxic internalized ideal, especially for many women with disabilities.

I've just moved to Berkeley and have gone to the new National RESIST⁹ office – "headquarters" for a network of grassroots groups opposing U.S. interventionism and militarism. I don't know it then, but this office is to become the focal point of my life for the next few years. A rag-tag group of activists has gathered to paint and carpet. The first person I meet upon entering is Pat. I've been warned about her – "stubborn," "opinionated." She's single-handedly painting the hallway, her paint-roller duct-taped to a long pole. She pauses briefly to greet me and I feel discomfort and awkwardness engulf me. I can handle "stubborn," but this I'm not at all sure about. I mumble something and quickly slip into the next room keeping as much distance as possible between myself and her paint-splattered wheelchair.

The avoidance impulse comes from the same place as the impulse toward, as disabled author Eli Clare puts it, "gaping, gawking, and staring."¹⁰ Unless we have become accustomed to interacting with disabled people through our work or personal lives, "disability disturbs people who think of themselves as nondisabled."¹¹ Perhaps we are thinking "there by the grace of god..." Perhaps we are worried we will do or say the "wrong" thing, thus exposing our ignorance. Perhaps we harbor the age-old fear of contagion. Perhaps all of these things and more are going on. Recognizing disability as another form of human variation is a huge challenge, not to mention getting to a place where we recognize its value. "If disabled people were truly heard, an explosion of knowledge of the human body and psyche would take place."¹²

I'm talking with Alana about a short story she's writing. It's about a group of friends with various disabilities who are each given the chance to become nondisabled if they choose. The story explores how they come to their decisions and what the consequences are. Alana isn't sure what she would do if given such a choice and is interested in how her characters work it out. I'm flabbergasted. I assumed, as I believe most nondisabled people do, that above all else, people with disabilities desire to be "normal." Alana tries to explain to me that she can't imagine her life without the part of her that's firmly rooted in disability politics, community, and culture. I'm still having trouble understanding when finally she asks me to think about how I would feel if I were suddenly straight. I think I'm beginning to get it...

"A system of compulsory able-bodiedness repeatedly demands that people with disabilities embody for others an affirmative answer to the unspoken question, Yes, but in the end, wouldn't you rather be more like me?"¹³ Like others who do not fit dominant molds, people with disabilities struggle against the suffocating constraints and violences of normalcy. They have built a culture and politics that insists on their value, that celebrates and nurtures their differences. Disabled performance artist Cheryl Marie Wade provides an excellent explanation of disability culture as "naming and claiming" ancestors buried in history, fighting "separate but equal" policies, enabling the creative and political voice of those often silenced ("passing the word"), recognizing power in difference and in solidarity, and demanding the power to chose.¹⁴ Disability theorist Lennard Davis writes, "Disability Studies demands a shift from the ideology of normalcy... to a vision of the body as changeable, unperfectable, unruly and untidy."¹⁵

I'm pushing Pat up the steep hill by the Castro Safeway. Cops are all around us now. This is the third day of roving demonstrations after the Rodney King verdict—cops and demonstrators are tired and tense. A seasoned organizer, Pat has become an important mentor for me. I'm still amazed at how many people know her, whether they be Central America, immigrant, anti-nuclear, AIDs, queer, labor, homelessness or other activists. I'm thinking about all of this, and about how in all the demos Pat and I've been to, we've never once been swept up (i.e. involuntarily arrested). When I tune back in I realize we're being pushed back and corralled against a wall. Damn, no way out this time and Pat will never let me live it down. I'm reminded that activists aren't the only ones who know Pat, as a cop calls out, "Hey Pat, what are you doing here?" (read: what's a disabled white woman like you doing at a police brutality demo?). She responds, without missing a beat, "No justice, no peace."

Disability is perhaps the most obviously fluid and heterogeneous social category. There are differences in type of disability (physical/sensory/cognitive), in severity (minor hearing loss versus progressive MS), in onset (disabled from birth/gradually becoming disabled/suddenly becoming disabled), in perceptibility (having a "hidden disability" and "passing" as nondisabled versus being unable to hide a disability), in variability (most disabilities change across time and location), and in prevalence (disabilities vary by sex, "race," age and environment). All of this variance is, of course, interrelated and simultaneously occurring with other lived modalities including race, class, gender, age, and sexual orientation. Disability activists and theorists have considerable information to share about coalition building across and within multiple subjectivities.

I'm doing personal attendant work for Alana. She's decided to go through her files and paperwork. From my perspective her papers are totally chaotic—milk crates of various file folders, stacks of reading material, bills, personal mail. Her way of "organizing" seems haphazard to me (I have a penchant for systematizing). And yet, as her paid hands, arms, legs, I need to follow her instruction—this here, something else over there, distraction of an old letter, never purging anything. I can feel myself getting frustrated. How long can I stand this? I want to throw up my hands in exasperation. I want to do it my way. As I am biking home, luxuriating in once again being the agent of my own body, I begin to wonder how much ableism played into my exasperation. Did I think I know better how to organize stuff because I am (temporarily) nondisabled? Did I second-guess Alana's decisions just because she had never physically done it? Was that fair?

"Ableism (sometimes spelled 'ablism') is a term for discrimination against, and subordination and oppression of, people with disabilities. Ableism exists at all levels of our society – ideas, attitudes, practices, institutions, social relations and culture. Its 'ism' suffix is used to highlight institutional or systematic forms of oppression, putting ableism in the same family with sexism, racism, heterosexism, ageism, and other systematic forms of oppression. As with these other forms of bias, ableism also names unfair or unearned advantages – in this case, the privileges given to those perceived to be able-bodied."¹⁶ Feminist philosopher Susan Wendell believes that full integration of people with disabilities into society will require that social ideals "change in the direction of acknowledging the realities of our interdependence and the value of depending on others and being depended upon."¹⁷

I am with Tracy¹⁸ at one of her in-service trainings for drug and alcohol service providers. I sit in the back of the room listening as she tries to explain that the greatest barriers for disabled people seeking services are attitudinal. At first I have no idea what she's talking about. I'm beginning to understand that accessibility does not just mean ramps/elevators; that it also means large print media, TTDs, ASL interpreters, scent-free environments, etc. But "attitudinal barriers?" As she talks and people ask questions about how to make their programs accessible, I begin to understand. Many of the counselors want to be given a simple formula in order to comply with ADA requirements. Tracy struggles to express the need for flexibility, for awareness, for asking the disabled consumer/client what s/he needs, for not making assumptions, for creativity, for not addressing disability as a tragedy necessitating charitable response. With some counselors, I can almost see the light bulbs going on.

The late disability historian Paul Longmore wrote, "the danger is not that we will ignore disability, but that we will reach intellectual, socio-cultural, ethical, political, and policy conclusions about disabled people without examining the ignorance, fear, and prejudice that deeply influence our thinking."¹⁹ Because of this unexamined ignorance, fear and prejudice, the reasonable accommodations and access mandated by the ADA have met with considerable resistance. Even the most well intentioned service providers, educators and employers often see compliance as a burden. There continues to be the misperception that accommodations are all about the built environment and technology, and therefore necessarily costly. The reality is that most employment and educational modifications are made through staff/teacher training (addressing attitudinal barriers and lack of knowledge), and low-tech solutions.

I'm sitting in a tiered law classroom at Syracuse University listening to disability rights attorney Harriet McBryde Johnson. Already small in her chair, the perspective from my seat makes her appear even smaller, and yet, her presence fills the room. She is talking about debating Peter Singer and her NYT article "Should I have been killed at birth?" about the encounter.²⁰ I think of myself as fairly disability savvy at this point, but the title of that article still disturbs me. As Johnson speaks I feel myself becoming increasingly uncomfortable. I wonder if those around me, especially those with disabilities, can tell I'm guilty. If I take what Johnson is saying to heart – if I allow her to become speaking subject rather than abstract socio-political dilemma – I will have to rethink my pro-choice politics.

Ideas about which lives have value, or potential value, are inherently connected to the thorny issues of prenatal testing, genetic screening, new reproductive technologies, abortion, and euthanasia. Disabled activists are challenging the self-assured feminist stance for "the right to choose," asking us to further consider the context in which decisions to terminate a pregnancy, or a life, are made. If a woman or couple have little information about disabled people living full lives, how does that impact the decision to selectively abort a potentially disabled fetus? If adults with disabilities are not given the support they need to lead full, productive lives –the right to live –how can we champion "the right to die?" In the NYT article, Johnson wrote: "Strangers on the street are moved to comment: *I admire you for being out; most people would give up. God bless you! I'll pray for you. You don't let the pain hold you back, do you? If I had to live like you, I think I'd kill myself.* I used to try to explain that in fact I enjoy my life, that it's a great sensual pleasure to zoom by power chair on these delicious muggy streets, that I have no more reason to kill myself than most people. But it gets tedious."²¹

I am teaching an intro Women's Studies class to a large, diverse group of undergraduates. I think I've done a good job accommodating students with various disabilities. There are two with low-vision for whom I provide large-text materials. Another with a learning disability takes tests at the Disability Services Center. It's several weeks into the semester when a young woman approaches me after class and tells me she's dyslexic. She's gotten little help in school, but has developed some strategies. She asks if I can use capital letters on my multiple choice quizzes rather than lower-case, as it's much easier for her to distinguish them. I immediately agree, feeling badly that I hadn't thought of it before. When I give the next quiz, I use the change in format as a teaching moment (without identifying the student) for how easy it is to make many accommodations, and I introduce the concept of universal design. Later in the semester when we are studying disability, this student voluntarily talks about her dyslexia spurring others to talk about their disabilities as well.

"Silence about disability most often works to preserve exclusion, requiring the disabled [sic]²² to assimilate to physical and social environments that remain unchanged and unchallenged, environments intended for others, not them. While there is no single answer ..., teachers need to reflect on ways they might acknowledge and creatively accommodate differences without turning a disabled student into an object, a token representative, or a victim."²³ The more disability can be normalized in the classroom, the better. The concept of universal design is a useful one because it is all about positive normalization. It says that built and social environments should be developed with the fullest spectrum of abilities in mind. This allows for the greatest access, and benefits everyone. The example of the curb cut is useful. It provides access for people using wheelchairs or walkers, but also people on bikes, pulling luggage, or pushing strollers.

I'm participating in a UC Berkeley Disability Brown Bag Seminar Series. An assortment of faculty, students and community members of varying (dis)abilities, we meet in a tiny room, told we are lucky to have any space at all. It's a particularly packed day and we've spent 10 minutes negotiating wheelchairs, guide dogs and furniture to squeeze everyone in. The talk has started when a visually impaired man using a cane appears at the door. Others enthusiastically greet him and look around trying to figure out 1) how he's going to manage to navigate the room, and 2) where he will eventually land. As one of the few nondisabled people present, I determine I should help facilitate this. I stand and make room for him, waiting for him to come and sit. The seasoned disability advocate next to me gently urges "Go and lead him in Judy. Speak so that he knows where you are." Embarrassed, I comply, and the man generously says something reassuring – as he probably has innumerable times – to cover my mistake and awkwardness.

"There are rewards for making the world physically and emotionally accessible to all people, including benefits that accrue to society as a whole. The more perspectives can be brought to bear on human experience, even from the slant of a wheelchair or a hospital bed, or through the ears of a blind person or the fingers of someone who is deaf, the richer that experience becomes. If it is both possible and pleasant for me and my kind to enter, the world will become a livelier place. You'll see."²⁴

I asked the “seasoned disability advocate” (Corbett O’Toole) featured in my last journal entry to read this essay for me. Among other useful comments, she had a different perspective on the incident I describe above. She asked why I would assume that the burden for access is on my nondisabled shoulders. Immediately I knew she was right, and that I had been once again caught in my own ableism. She wrote, “that implies a societal/privileged role for you and assumes that people with disabilities are less able to deal with this situation – when, as your example shows, their collective knowledge and multiple experiences of this make them the experts. Implied, but unstated, is his willing acceptance that his friends will figure it out for him since his disability would make it hard for him to figure it out by himself.”²⁵

I have clearly not arrived, but am on a continuing journey. There is, therefore, no clever (or otherwise) conclusion to this essay, as there is none to this dialogue. I want to indicate the on-going – if interrupted, messy, and uneven – nature of this conversation. Examining intersectionalities, especially when they involve our own privilege(s), challenges us intellectually, emotionally, and politically. There will be gaps, silences, retractions, and so forth, but I expect I will continue to have experiences with ability/disability that influence my thinking and keep the dialogue going – in fact, it would be impossible not to. Discussions about these experiences occur regularly in grassroots communities but rarely make it to the academy. My purpose for the piece has been two-fold: to work with a new form for writing the convergences of experience and thinking (particularly intersectional theorizing); and to share some of what I have learned about disability in this particular convergence.

End Notes

1. “AB,” short for “able-bodied,” is a common descriptor in the disability community for the (temporarily) nondisabled. I use “nondisabled” in this essay as it centers disability and decenters the body, helping us remember the wide range of cognitive, sensory and physical disabilities.
2. Kimberlé Williams Crenshaw, *Keynote Address*. Intersectionality: Challenging Theory, Reframing Politics, Transforming Movements. March 13 2010. UCLA Critical Race Studies Annual Symposium. Video available from: <http://www.law.ucla.edu/academic-programs-and-courses/specializations/critical-race-studies/annual-symposium/Pages/4th-Annual-Symposium-2010.aspx>
3. Simi Linton, *Claiming Disability: Knowledge and Identity* (New York: New York University Press, 1998) 3, Joseph P. Shapiro, *No Pity: People with Disabilities Forging a New Civil Rights Movement* (New York: Times Books, 1994) 323.
4. “Americans with Disabilities Act of 1990.” 12101, 2nd session (1990) of 101st Congress, Section 2.
5. “Americans with Disabilities Act of 1990.” Section 2.
6. U.S. Census Bureau, “Ada 20th Anniversary U.S. Disability Facts and Statistics,” (2010), Dec. 9, 2010 <<http://www.disabled-world.com/disability/statistics/ada-anniversary.php>>.
7. Shapiro, *No Pity: People with Disabilities Forging a New Civil Rights Movement* 4-6.
8. Nancy Mairs, *Carnal Acts* (New York: Harper Collins, 1990) 72.
9. Names and organizations have been changed to protect individual privacy.

10. Eli Clare, "Gawking, Gaping, Staring," *GLQ: A Journal of Lesbian and Gay Studies* 9.1 (2003).
11. Lennard J. Davis, *Bending over Backwards: Disability, Dismodernism, and Other Difficult Positions* (New York: New York University Press, 2002) 38.
12. Susan Wendell, *The Rejected Body: Feminist Philosophical Reflections on Disability* (New York: Routledge, 1996) 274.
13. Robert McRuer, "Compulsory Able-Bodiedness and Queer/Disabled Existence," *Disability Studies: Enabling the Humanities*, eds. Sharon L. Snyder, Brenda Jo Brueggemann and Rosemarie Graland-Thomson (New York: Modern Language Association of America, 2002) 93.
14. Cheryl Marie Wade, *Disability Culture Rap*, 2010, YouTube, Available: www.youtube.com/watch?v=j75aRfLsH2Y, Dec. 9 2010.
15. Lennard J. Davis, "Crips Strike Back: The Rise of Disability Studies," *American Literary History* 11.3 (1999): 505.
16. Judy Rohrer, "'Ableism' Entry," *The Encyclopedia of American Disability History (3-Volume Set)*, ed. Susan Burch (New York: Facts on File, 2009), vol. 1, 1-3.
17. Wendell, *The Rejected Body: Feminist Philosophical Reflections on Disability* 151.
18. Name changed to protect individual privacy.
19. Paul K. Longmore, *Why I Burned My Book and Other Essays on Disability*, American Subjects (Philadelphia: Temple University Press, 2003) 3.
20. Harriet McBryde Johnson, "Should I Have Been Killed at Birth? The Case for My Life," *The New York Times Magazine* February 16 2003.
21. Johnson, "Should I Have Been Killed at Birth? The Case for My Life."
22. "The disabled" is seen as an othering and essentializing label. Disability advocates generally prefer "people with disabilities" as it puts their humanity first and recognizes the multiplicity of disability.
23. James C. Wilson and Cynthia Lewiecki-Wilson, "Constructing a Third Space: Disability Studies, the Teaching of English, and Institutional Transformation," *Disability Studies: Enabling the Humanities*, eds. Sharon L. Snyder, Brenda Jo Brueggemann and Rosemarie Graland-Thomson (New York: Modern Language Association of America, 2002) 299-300.
24. Nancy Mairs, *Waist-High in the World: A Life among the Nondisabled* (Boston: Beacon Press, 1996) 106.
25. Personal communication with Corbett Joan O'Toole, January 8, 2011.