

# **THE RAGGED EDGE**

**THE DISABILITY EXPERIENCE  
FROM THE PAGES OF  
THE FIRST FIFTEEN YEARS  
OF THE DISABILITY RAG**

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# Questioning Continuum

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**C**ontinua are in fashion these days. The farther we drift away from each other in society — the more that classism divides us and violence tears us apart — the more some people seem determined to project unity, or at least continuity, onto human-kind. I don't believe this "reframing" of reality helps anyone. It trivializes the experience of us who must face the cold facts of marginalization while it ignores the value of our different experience.

There's a concept in statistics called "regression toward the mean." It says that measurements tend to cluster toward the average or middle. Anything extreme is unlikely to be repeated. For example, if my average time of swimming a lap is 40 seconds but one day I have an incredibly short time of 25 seconds, all factors being equal, my next time is likely to be longer — closer to average.

Sometimes I think human preference is ruled by this law of probability. Many people are distressed by the unusual. They want it normalized, brought to the middle where they are. In fact, it's the rare person who feels perfectly comfortable with anything discrepant from her/his realm of familiarity.

I think this tells us a lot about the continuum-seekers. They need someone to tell them it's all a bad dream, that there really are no discrete differences between people or their

experiences of life. They like hearing that what's important is that we're all part of the same human family. This takes away the confusion, loss of control and untidiness of genuine diversity. It eliminates both the tension of admitting you may be unable to completely understand someone different and the "stretch" of accepting their culture as valid anyway.

True confessions: I am an ex-homogeneity-junkie, myself. In college I rhapsodized over constructs like brotherhood and fellowship (not yet seeing any gender considerations there!). It served me twice to idealize unity. First, it seemed like the path out of my own marginalization, i.e., disability would be insignificant in the universal family. Second, it made it so much easier for me to accept poor people and gays and cultural/racial minorities if I could simply imagine they were all like me under the skin. I wanted to believe differences were illusory. Along with many other pubescent idealists, I longed to dump the melting pot into the Cuisinart and make a pablum smooth enough for me to swallow.

But my black and gay and Jewish friends refused to go gently into that good blender. They insisted on being exactly what they were (and letting me know exactly what I was!). I got over the rejection and disillusionment to learn that it wouldn't kill me to be tense over differences. I even learned that I could be enriched by cultures I didn't understand, cultures that didn't exist for my enrichment. I learned that both the world and my own mind were big enough to encompass messy, noisy heterogeneity — that people didn't cease to exist as human beings because they didn't resemble me, that I could interact with them without pulling them toward the middle. I could appreciate separate colors without needing them to be my rainbow.

When I was growing up, my father frequently talked about a man that he worked with who came from Japan. He really liked this man. He would visit the guy's house and then come back and tell us all the ways he was different: the foods he ate, his furnishings, his clothes, the way he counted on an abacus, the way he reasoned about life. My father's world view was enriched by his association with that friend. His accounts conveyed tremendous respect without ever needing to find ways the man was similar to us.

Respect is a key concept in accepting differentness. Many years ago, I was sitting on a stage with Judy Heumann and an

interviewer asked us what we found most disturbing about others' attitudes toward us. Judy said she most resented their need for us to be nondisabled. I'm ashamed to say I didn't totally get it then, but I do now. There is a great lack of respect for who I am as a disabled person conveyed by people who either wish I could be normal or who need to see my disability as an unimportant part of me.

So when is a person disabled and not something else? I tend to think you're disabled when society says you're disabled. I agree with activists who believe that "disability" is mostly a social distinction — one that is triggered by some physical/sensory/mental/functional/cosmetic difference. How much of a difference is significant enough to count as a disability? That's usually decided by the majority culture tribunal. What is barely noted in some cultures can be a great stigma in another (e.g., being born with a missing digit). In sum, I believe disability is a marginalized status that society assigns to people who are different enough from majority cultural standards to be judged abnormal or defective in mind or body.

There seems to be an underlying social requirement that in order to qualify as a disability, the defect must lie beyond the individual's immediate control. Maybe by working hard, the disabled person can improve, but not too easily. If persons can control their impairment at will (occasional recreational drug use; charley horses) they are not seen as disabled but as "bringing it on themselves." However, if they are unable to stop hurting themselves, they may be seen as disabled (someone with an addiction). Similarly, if they "brought it on themselves" but now can't reverse it, they are disabled (someone injured via driving drunk).

Although I am emphasizing society's role in determining disability status, I am not suggesting that, in the socially ideal world, all physical, mental and sensory conditions would be irrelevant or unnoticed. I am not a complete environmentalist or cultural relativist on this score. Many people who are considered disabled now would still have an experience of "differentness" in a more accessible and socially accommodating world. I believe I would be one of them. I would still experience struggle, pain, slowness, and things I couldn't do the way most people could (e.g., run spontaneously) even if I had all the human and

technical help currently imaginable. (I admit my imagination is limited — I don't know if something like virtual reality, for example, would be the ultimate leveler of experience.) Further, I would still have a disability history or heritage behind me affecting my worldview. No, you can't take that away from me.

But in the ideal world, my differences, though noted, would not be devalued. Nor would I. Society would accept my experience as "disability culture," which would in turn be accepted as part of "human diversity." There would be respectful curiosity about what I have learned from my differences that I could teach society. In such a world, no one would mind being called Disabled. Being unable to do something the way most people do it would not be seen as something bad that needed curing. It would be seen as just a difference. Differences might make you proficient in some contexts, deficient in others, or not matter at all. For example, if I can't run, I might be an inferior messenger if time is critical. However, my inability to run might just as likely have stimulated me to address time more creatively or to develop ways to send messages swiftly that are as efficient as running, or vastly superior. In other words, ideally, even if I had a difference that might hinder me in some contexts, I wouldn't be judged *generally* deficient because a recognized feature of Disability culture would be the fact that such limitations can be fodder for innovation and for a rich and valuable human experience. Once again, respect.

Returning to the present world, given my understanding of disability as a social status, what about people who say they are disabled but society does *not* so label them? What about things like alcoholism, chronic fatigue, compulsive behaviors? Conditions like these seem to be judged by society as either too insignificant or too voluntary to be real disabilities. Consider also the borderline conditions, like eyeglasses, limps, the fingertip lost in a factory accident, the gradual hearing loss with age, the so called slow learner at math. These are the differences most people downplay out of embarrassment or fear of social devaluation. They are also the differences some pull out of their back pockets when they want to prove that there is a continuum of disability or if they have something to gain from being disabled — a parking space, priority treatment, a place of power in a disability organization. Are any of the above disabilities? (The terrain is looking a little gray, but since I started the discussion

with my own thoughts, I'll humbly continue — hopeful that readers will understand that I'm just taking a stab at an analysis that I think is important to continue through others' responses.)

I would say that it's possible to have a disability without society's agreement. Society may simply be too ignorant about some disabilities to include them in the classification. If the public knew how "debilitating," involuntary, and physiologically-based such conditions as alcoholism and chronic fatigue were, it's conceivable these would be viewed more generally as disabilities. The critical issue seems to be whether they affect life functioning or are weird enough by society's standards that they would be labeled disabilities once they were fully revealed. Anything potentially labeled as a disability by society is a disability, in my book.

But I have met people whose claim to disability truly annoyed me. I find it hard to embrace as brothers and sisters those folks who spend their whole lives comfortably in the nondisabled world without any mention of personal disability until a disabled person challenges their authority to speak for us. Then they justify their position of profit or leadership in a disability organization by trotting out their spectacles or trick knee or rheumatiz'. "Actually, we're all disabled in some way, aren't we?" they ask. "No!" I say. If the only time you "walk the walk" of disability is when it's convenient for you and you even admit your disability has little impact on your life and no one regards you as disabled, give me a break — you ain't one of us! You aren't in danger of the marginalization we experience or expect on a daily basis.

Here's a possible rule of thumb: If a person who has *not* been labeled disabled has some physical, sensory or mental difference or limitation that does *not* significantly affect daily life and the person does *not* present himself/herself to the world at large as a disabled person, chances are the person is not disabled.

Is it a disability if it's invisible? If it's disabling enough to affect your life, it's also potentially visible. Your learning difference, your fatigue, your pain or depression could all be revealed under certain circumstances. You know you have a "real" disability when you know society will label and marginalize you once your difference shows.

I am increasingly tired of disabled people who don't believe

the hidden disabilities of others are significant or "real" disabilities. But I also have a hard time with people whose disabilities are completely unapparent who complain of being "shut out" by the disability community. If you are not willing to openly identify as disabled, I'm sure you have your reasons, but don't be surprised if you are taken for an AB. If you are truly disabled you must realize why we need sometimes to shut the nondisabled world out — why we need to grab precious privacy, community and identity for ourselves when we can. I could not belong to the Black Student Union (BSU) at my school, and after I learned how oppression robs a people of their power and identity, I understood I had no place there. I also knew some African Americans who could and did pass for white. They knew without complaint that the price of entry into BSU was identifying as black. I have heard retorts from some persons with hidden disabilities along the lines of: "What do you want me to do — wear a sign?" Well, if that's the only way you can think of to "come out" as disabled, I recommend you get suggestions from a gay friend or ask yourself if you really want to be a part of the disability community.

What about nondisabled people who say they belong in our community because they experience disability through a loved one? Nondisabled people, no matter how much they love us, do not know the inside experience of being disabled. Moreover, they are in a position to escape the stigma. They can leave our sides and go out among strangers as "normal people," if only for a few minutes of peaceful anonymity. They may know the day-to-day pressures of being associated with a disabled person, they may deal with their own stigma for loving us, and they may grieve for our oppression (and their own if they share our lives), but they don't know the relentless feeling of dealing directly and inescapably with both the difference and the public invalidation it inspires. That stiff smile, that condescending pat, that flight of stairs, that slick elevator devoid of braille signs, that loneliness on prom night, that aching just to live our lives without having to argue for equality — unfortunately, they are ours.

Are people with illnesses disabled? Only when they have the temerity to neither get well nor die. Society has a niche for ill people. They should be on the move, traveling the arc from health to sickness and back to health. There's another niche for people with terminal illnesses. They should move from health to death. If they know their manners, they get on with it, too — no

"lingering." If you remain in the limbo of ill-health for too long and you can't do everything you used to do the way you used to do it when you were healthy, you get stigmatized. And that stigma sure looks and quacks like disability stigma. People who linger in abnormal states, who don't work normally, or who need help acquire a status of invalidation.

Looking at the connection between illness and disability another way, people who learn to live with chronic illnesses often demonstrate the same resilience, modified values and creative pragmatism that mark the disability culture. Chronic illness and disability seem to teach people similar lessons about life. Furthermore, some illnesses definitely make people disabled (e.g., ALS) while some disabilities lead to problems that are painful, progressive or weakening to the point of being experienced as not just a difference but as a sense of real malaise.

To my mind, people with lingering illness are definitely in the club. This used to bother me because I didn't like reinforcing the misconception that all disabled people are sick or dying. Who needed more stigma? True, some of that discomfort may have been my own prejudice and denial about illness. Still, robust disabled people with stable conditions — for example persons simply born without a body part — would not seem to qualify in any way as ill. I think it makes sense at times to keep a distinction between disability and illness because prejudice against "healthy" disabled people offers a pure case for studying what ableism is all about. People with disability can experience horrendous discrimination and abuse simply because they look different. Until we learn more about how this compares to discrimination based on illness, I favor keeping a line, however flexible, between illness and disability, or seeing them as two entities with a large area of overlap, neither one subsumable into the other.

I am left with many questions that I believe would be helpful to answer: Are disabled, ill and elderly people similarly stigmatized because of society's dread of disability in each group? In other words, is it all just disability prejudice, or is there an illness stigma separate from a disability stigma (Is contagion a factor?) and an aging stigma separate from both? What part does appearance play? How much is due to public fear of our dependency on others? What about others' belief that we can't do enough of the things that AB's think are essential to life

to be considered attractive or fully human? How much is due to our perceived lack of power and our reminder to others of *their* vulnerability to loss/change? I appreciate the ideas of disabled scholars, including Irv Zola and Harlan Hahn, who have tackled issues involving disability v. illness and the components of disability prejudice. But I think we need to continue exploring the remaining unknowns, especially when so many of our children are being "integrated" and "included" in the mainstream in the belief that this will result in, among other benefits, a reduction of disability prejudice in AB's proximate to them.

I'm already bracing myself for the criticism of the "human race" brigade. I expect to be accused of encouraging divisiveness when we should all be promoting our common experience and goals. Let me respectfully submit that people with disabilities, including myself, have not created our own marginalization. We got that from society. Now we must find the best way to survive that fact physically and emotionally.

If we've learned anything from other oppressed minorities it's that you gain nothing from efforts to assimilate into the culture that devalues you. We will never be equal if we accept token acceptance as slightly damaged AB's. Politically and psychologically our power will come from celebrating who we are as a distinct people. I'm not content being a pale version of the majority culture. I want to be a strong version of something else — different but equally valid. (I'm being humble here; in fact, I believe a fully articulated disability culture that honors differentness and interdependence would be a vast improvement over the corrupt intolerant culture I was born into!)

As the British Disability Arts activists said so often during their 1993 tour of the U.S., the struggle shouldn't be for integration but for power. Once we have power, we can integrate whenever we want. Once we command respect for who we are, we can afford to join forces with the rest of the human family, free from the danger of losing our power, losing ourselves. The "respect for who we are" has to start with us. We need to work on our own heads about who we are, our value and the value of our culture. When we develop a stronger identity as a community, we can really serve notice on society, or integrate into it, from a position of strength — on no one's terms but ours.