DISABILITY AWARENESS SERIES:  
Come Out Disabled and Proud, Even If You Have a Non-Stereotypical Disability  
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The documentary film “Crip Camp” did not win an Oscar, but it’s still a win for disability pride. The movie focused on a unique summer camp where people with many different types of disabilities formed a community that was ultimately the catalyst for the American disability rights movement. At the Academy Awards, three wheelchair users (and a service dog) celebrated on the red carpet while many in the disability community held their own Oscar parties at home. As a disabled psychology professor who studies disability pride, I want to encourage disabled people to build on this momentum, come out proud, and come together in service of the mission of improving the lives of all people with disabilities.

What do you picture when you think about disability? You probably envision a wheelchair user, the literal symbol of disability plastered on parking spots and bathroom doors. However, disability is much broader than most people think. Disability can be physical or mental, like cerebral palsy or bipolar disorder; common or rare, like chronic back pain or narcolepsy; visible or invisible, like Down syndrome or learning disabilities. In fact, most disabilities are invisible. Despite differences across disabilities, the one experience most people with disabilities share is ableism, or stereotyping, prejudice, or discrimination toward people with disabilities.

I have a rare, non-stereotypical disability. I was born with Moebius syndrome, a condition resulting in facial paralysis. My disability is very visible, but because of its rarity, most people don’t understand the cause or nature of my different appearance. Even though many are quick to judge me as different or even, erroneously, as intellectually disabled, I did not consider myself to be disabled for most of my life. In my early 20s I worked as a support coordinator for people with disabilities. While I took pride in the job and cared deeply for my clients, I considered myself an ally, not one of them because it didn’t fit the stereotype of disability, I wanted to skirt the stigma. I look back now and wonder how much more passion and connection I could have brought to my clients if I had identified as disabled.

People like me with non-stereotypical disabilities seem less likely to identify with the term “disability.” A major reason is that the term disability is mired in stigma; we think of it as a “bad word.” To identify with disability in most cultures means to be limited or weak. That’s why a common but misguided compliment is “I don’t think of you as disabled.” Disability is not a bad word. It just is. It’s a common form of human variation, like hair color. It can also be a source of community and pride. Many people have been previously taught to use “person-first” language, but nowadays, some prefer “identity first” language to reflect that disability is a valid identity, not something to be qualified.

The Americans with Disabilities Act (ADA) defines disability as a physical or mental impairment that substantially limits one or more major life activities, having a history of such, or being regarded as such. At least 25% of American adults have a condition that is considered a disability, according to the ADA. Disability intersects all other identities, like sexuality, race, and gender. Far fewer consider themselves to be people with disabilities. In a study of people with any kind of health condition, we found that people were unlikely to identify as a person with a disability unless they had experienced ableism and their condition was severe. This is a missed
opportunity because my research finds that disability identity and pride enhances self-esteem and well-being which is an intrinsic good.

We can learn a lot about pride from the LGBTQIA+ community; they have earned legal rights and a great deal of public attitude change within a single lifetime. Harvey Milk, the first openly gay elected official in California, implored gay people to “Come out, come out, wherever you are.” Doing so made LGBTQ issues visible. Americans realized that trusted community leaders, friends, and family members among them were gay. Disabled people need to do the same to create a critical mass of visibility.

Another reason people may not want to identify as ‘disabled’ is that they don’t want to take away resources from others with a disability. Someone with impairing chronic back pain may feel that identifying as disabled may diminish the legitimacy of an impairment that is perceived as more severe. Again, this is well-meaning, but it serves to perpetuate the idea that disability is rarified and hierarchical.

Like the early gay pride movement, disability pride is a radical shift from the typical way of thinking. Why would someone be proud of their disability? I, for example, am proud because my disability motivated me and gave me the specific expertise and emotional lived experience to devote my career to improving quality of life for disabled people. I am proud because my face makes me distinctive -- I have a tiny bit of a celebrity status. People remember me after seeing me once, far better than I remember them. I am proud because my disability gives me a unique perspective of the world. I am proud because my disability has connected me to so many interesting and kind people in my disability community.

All social groups face a question of “lumping vs splitting.” Many social groups with nuanced differences come together collectively for political organizing, like LGBTQIA+ and Latinos. Although there are meaningful differences in history, art, food, and politics among, for example, Cubans and Mexicans living in America, activists made an intentional effort to count them as one in the U.S. Census to illustrate the size of the group. The fact that Latinos are now counted means that affirmative action, vaccine distribution plans, etc., use the population base rate as a lodestar, meaning strength in numbers has afforded them rights.

Maybe Crip Camp didn’t win because the Academy viewed disability as a niche market instead of something that affects a quarter of Americans. Disabled people, especially those with invisible and non-stereotypic disabilities, need to come out and come together with pride. Our rights depend on it.

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