

Activists with disabilities recognized that we have a lot in common with other minorities, including civil rights, financial, education, and health disparities, a lack of role models, and underrepresentation in the media and politics.

DISABILITY PRIDE

WHY DISABILITY IS NOT A BAD THING

BY KATHLEEN BOGART

About 19% of Americans have some kind of disabling condition but most reject the label “disability.” As a reaction to the stigma surrounding the term “disability,” disability activists have started a disability pride movement. As a psychology professor and a person with a disability myself, I was interested in understanding why some people choose to identify as disabled and develop pride.

In a series of recent studies, my colleagues Dr. Adena Rottenstein, Dr. Emily Lund, Lauren Bouchard, and I conducted a survey of factors related to disability identity and disability pride. One study in the journal *Rehabilitation Psychology* surveyed 1,105 adults online—710, or 64 percent, of those people indicated they had any type of health condition or impairment. We then focused on the responses of people with health conditions or impairments to the question of whether they considered themselves to be a person with a disability. Only 12 percent of people with a health condition agreed or strongly agreed that they were a person with a disability. A variety of factors were associated with considering oneself to be a person with a disability, including lower income, older age, experiencing greater stigma, and severity of impairment, with stigma and severity being the strongest predictors. Social stigma is considered by many disability scholars to be the main cause of disability, and our finding suggests that it also plays a role when people think about their own identities. The role of severity suggests that people with significant

impairments experience more stigma, thus contributing to “disablement” by society.

In another study, also published in *Rehabilitation Psychology*, we examined more questions from the sample of 710 people with impairments. Participants answered questions from a disability pride questionnaire developed by Dr. Rosemary Darling, a sociologist at Indiana University of Pennsylvania. The questionnaire included items such as: “I am proud of my disability,” “I am a better person because of my disability,” and “my disability enriches my life.” We found that social support, being a person of color, and, once again, experiencing stigma, all predicted disability pride. Experiencing stigma was associated with greater disability pride, and in turn, greater pride was associated with greater self-esteem.

That means that disability pride is a promising way for disabled people to protect their self-esteem against stigma.

Other research I’ve conducted indicates that disability identity is associated with a variety of positive outcomes, including lower depression and anxiety among people with multiple sclerosis. Compared to people who

acquired mobility disabilities at some point after birth, people who were born with mobility disabilities have higher satisfaction with life, and this can be explained by a more positive disability identity and better ability to manage their disability. I suspect this is because people with congenital disabilities go through their initial development learning about themselves and the world with their

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disability. In comparison, people who acquire disabilities must relearn how to navigate the world and often report feeling that they have lost their identity.

Disability pride is still rare. Most disabilities are invisible and people have to choose to disclose them. To avoid discrimination, many people do not disclose their disabilities or even hide them. But not identifying perpetuates the idea that disability is an undesirable and uncommon experience. “Coming out” as disabled and expressing disability pride seems to protect people against the negative effects of stigma. One reason is that it helps people find others who share their identities, or allies to support them. When people with invisible disabilities come out, they often discover that friends they have known for years share their identities. Coming out also has the power to change society’s views about disability. Expressing pride will show society how common it is to experience disability and that so many valued members of the community are touched by it. Chances are, about 20% of your neighbors, co-workers, friends, and family members have a disability. Coming out increases representation in the media and politics so disabled voices are heard. Once a critical mass of people come out as disabled, it won’t seem as risky to disclose a disability. But lots of brave people will need to risk discrimination when coming out to get to us to that point.

The idea of disability pride comes from the recognition that disabled people are a minority group. Activists with disabilities recog-

nized that we have a lot in common with other minorities, including civil rights, financial, education, and health disparities, a lack of role models, and underrepresentation in the media and politics. Much like pride movements for other minority groups (i.e. gay pride, black pride), this movement is designed to turn what has been a very stigmatized identity on its head. Rejecting the idea that disability is a bad thing (search the Twitter for the #disabilityisnotabathing and you will find lots of empowered tweets), people with disabilities embrace the unique experience of having a disability. Disability Pride parades have been held in several states, including New York and Chicago.

What does all this mean if you or someone you care for has a disability? Words play an important role in shaping disability identity.

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Many disability scholars, including myself, advise against using words that imply that disability is not desirable. Although it may seem controversial, we suggest avoiding the terms “special needs” and other terms than euphemize disability. These terms can perpetuate the shame behind disability because they suggest that the word disability is too awful to use. If family

members of a person with a disability avoid using the word or the name of the child’s condition, this may send subtle hints to the child that they should be ashamed of their disability. Again, search the internet for #saytheword to learn what others have to say about reclaiming the word “disability.” Teach your child to talk frankly and matter-of-factly about disability when explaining it to friends

and teachers. Your child will feel empowered, and it will likely put others at ease and help spread awareness. When people are open about their disabilities, it makes others feel more comfortable. Encourage your child to think about what their disability means to them, and how it makes them who they are. A useful exercise for a child could be writing a story about what their disability means to them, including both positive and negative feelings about it. Giving your child the language and strategies to think and talk about their disability means they will be successful self-advocates as they transition into adulthood. This will empower them to disclose when appropriate to request accommodations in college or employment, or explain their needs to healthcare providers.

Your child may feel ashamed of his or her disability because of comments from

others, or bullying. Talk with your child and their school about how to handle bullying. Encourage your child not to hide a disability, because doing so is like rejecting a part of oneself. For example, instead of trying to make a prosthetic or piece of medical equipment blend in, help your child decorate it.

Unlike other minorities, people with disabilities are often the only one in their family that has that minority status. Parents, healthcare workers, teachers, and other students are often non-disabled. This means that it is hard for people with disabilities to find others like them. People with disabilities are even faced with subtle or overt pressure to avoid other people with disabilities. People with disabilities may internalize stigma, rejecting the idea that people with disabilities can be desirable companions. Also, they may be worried about stigma conta-

tion, meaning they might feel that associating with people with disabilities might make other people stereotype them. For these reasons, it is normal to feel awkward or hesitant about interacting with other people with disabilities at first. However, research from disabled psychologist Dr. Arielle Silverman finds that even one friendship with another person with a disability is associated with better life satisfaction, so taking steps to get to know others with disabilities is important. Think beyond a specific diagnosis: people with diverse health conditions and impairments are all part of the same minority group, so cross-impairment friendships can provide solidarity.

To build disability pride, we need to include disability in conversations about diversity. Doing so will make it clear that disability is a valid identity. Disability history and culture should be included in multicultural diversity programs. For example, some schools are already offering American Sign Language courses that teach about Deaf culture and history. Disability pride could be bolstered through social groups, mentoring, political activism and media representation. •

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Resources

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