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ON DISABILITIES

How to talk about disability sensitively and avoid ableist tropes

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People participate in the first annual Disability Pride Parade, in July 2015, in New York City. The parade calls attention to the rights of people with disabilities and coincides with the anniversary of the Americans With Disabilities Act.

Stephanie Keith/Getty Images

Disability can be difficult to talk about sensitively because of how embedded ableism is in our language, biases and perceptions of disability.

Conversations about disability are slowly increasing, especially when it comes to ableist language and how disabled people are represented in the media.

Disability advocate Talila A. Lewis' working definition of ableism is a "system that places value on people's bodies and minds based on societally constructed ideas of normalcy, intelligence and excellence."

NPR spoke to Cara Reedy, the director and founder of the Disabled Journalists Association, and Rosemary McDonnell-Horita of LaVant Consulting, a disability-focused communications firm, about common ableist tropes, the importance of avoiding them and how to talk sensitively about disability.

Common tropes to avoid

Avoid inspirational narratives

Inspirational narratives of disability are directly tied to a term called "inspiration porn." Coined by activist Stella Young, inspiration porn is defined as "objectifying disabled people for the benefit of nondisabled people."

McDonnell-Horita said an example of inspiration porn is the viral videos that get spread around prom season of a high school football player asking a girl with Down syndrome to prom. Being asked to prom is something that almost everyone wants, she said. But videos of disabled people getting asked to prom get amplified because society perceives disabled people as pitiable and "unlovable." This is just one example of how inspiration porn degrades, exploits and others disabled people.

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"It's really dangerous to have that be the trope because then it really limits and continues to infantilize disabled people and their potential," McDonnell-Horita said. "It's very patronizing, and it only continues to other disabled people, as if they don't deserve to have access to regular life milestones that other young people have."



People take part in a disability pride parade on July 14, 2019, in central Rome. Andreas Solaro/AFP via Getty Images

Another example of inspiration porn is videos of disabled people standing up out of their wheelchair at a wedding. This directly ties into the "overcoming disability" narrative. Reedy points out that these tropes come back to disabilities being seen as a deficiency and that they serve to dehumanize disabled people.

"If the stakes are lower and the assumption is that you can't do anything, that you're not that smart and that you aren't supposed to achieve anything, [then] any time you achieve something, it becomes like a party. But what that does is it erases all of the disabled person's effort, all of the barriers they've had to overcome," Reedy said.

These tropes frame disabled people as being held back by their disability and imply that it's something that they have to overcome. McDonnell-Horita said that her disability identity isn't something she has had to overcome. Instead, she has had to overcome the shame she was taught to feel about herself as a disabled person, ignorant questions that people ask her and the systemic ableism that keeps disabled people out of certain spaces.



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"It's not really necessarily my disability that I've had to overcome. It's the negative attitudes and stereotypes that come with being a disabled person. That is more exhausting," said McDonnell-Horita.

Reedy said that most of the time, it isn't a person's disability holding them back, but rather barriers such as inaccessibility and lack of accommodations. Reedy doesn't fault the general public for paying so much attention to these inspirational narratives, because they're constantly being perpetuated by films and TV and in journalism. But storytelling is a powerful tool in changing the narrative.

"If you're still writing stories about inspirational people and disability and not really digging into the barriers, then you're creating — and this is going to sound extreme, but — you're creating violence. You are perpetuating violence among a group of

people, which, by the way, is a quarter of the American population," Reedy said.

Disability is not a monolith and shouldn't be treated as such

Within the disability community, there are several subcommunities that have a wide range of experiences and subcultures. Disability isn't a monolith, and it's important to acknowledge that not everyone has the same experiences.

"If you have interviewed and spoken to one disabled person, that's only one perspective in the whole community. So trying to even diversify the voices who are speaking about the disability community, I think, is really important," McDonnell-Horita said.

For example, McDonnell-Horita emphasized how person-first ("a woman with autism") versus identity-first ("an autistic woman") language preferences vary within subcultures and even from person to person. She points out how important it is to ask the person what their preferences are and to not make assumptions if you're ever unsure.

Aside from language preferences, disability identity is a journey that is very individualized. It's important to show the disabled experience from all sides.

For instance, many individuals within the disability community emphasize the harm in writing stories about disabled people that frame them as being pitiable, unhappy or bitter all the time due to their disability. The same is true, however, for stories that center disabled people as being saint-like and positive all the time.



People from Italian disability organizations hold a banner reading "For a new way of experiencing disability" as they participate in a disability pride parade in central Rome on July 14, 2019.

Andreas Solaro/AFP via Getty Images

McDonnell-Horita pointed out that as a disabled person, there are days when she is frustrated when her body doesn't cooperate with her. Similarly, she noted that many disabled people are also exhausted from experiencing two pandemics: living under a government and society that doesn't care whether disabled people live or die, as well as constantly fighting against their rights being taken away.

Framing disabled people as being one or other — either happy all the time or bitter all the time — only further perpetuates the idea that the community is a monolith. "It's not always pride," said McDonnell-Horita. "I think that there is this new wave of young people, and newly disabled people because of COVID, who are really trying to embrace all of the sides and the human aspect of being disabled."

The destructive nature of infantilization

McDonnell-Horita defines infantilization as a nondisabled person having more power

than a disabled person and using that power against them to invalidate their thoughts, opinions or experiences. This can show up in numerous ways, such as indirectly speaking to a disabled person or assuming that the individual can't advocate or speak for themselves.

Reedy said that infantilization once again goes back to the constant perception that disabled people are less than. For example, Reedy said that as a dwarf, she has experienced situations in which people would raise their voice or speak to her as though she were a baby.

The infantilization in such language is harmful, as it leads to people not being able to make choices in their lives and the assumption that they shouldn't. For example, 1.3 million disabled adults are in conservatorships in the United States, according to the National Council on Disability. Additionally, 31 states plus Washington, D.C., have laws that allow the forced sterilization of disabled people.

"There's language that infantilizes, but there's also actions. The actions are the insidious part that the language is sort of covering for," said Reedy.

Best practices when talking about disability

Center disabled voices

Centering disabled voices is one of the best ways to avoid infantilization. Similar to how disabled people are spoken to indirectly in interpersonal settings because of infantilization, their voices are often excluded from articles and stories about disability issues.

Reedy said she has seen journalists interview the parents of disabled people, or nondisabled people in organizations, over actual disabled people. Nondisabled people have no lived experience of disability and don't understand it the way disabled people do. And often, with parents of disabled people, unless they're disabled themselves, their first encounter with disability is when they have a disabled child. Reedy isn't saying that parents of disabled people shouldn't have input, but that it is infantilizing to step over an entire community of disabled people and go to them first.

"They have no lived experience — they don't understand. And quite frankly, there is no way for you to completely understand how it is to live as a disabled person until you become disabled yourself. Because seeing it is very, very different from living it," Reedy said.

Recognize that disability is a culture and identity, not a problem

Disability is a cultural and social identity and should be recognized as such. But historically, disability has been seen through a medicalized lens.

The medical model is a biomedical perception of disability that supposes that disability may reduce one's quality of life and that aims to correct or diminish it through medical intervention.

"The medical model says that disabled people have to be fixed, or there's inherently something wrong with us, and there should be science and we should all aim to have a cure or live more 'normal,'" said McDonnell-Horita.

While some aspects of the medical model are relevant and important to some disabled people's lives, many critique the medical model as rooted in eugenics and anti-Blackness. It places expectations on what a perfect body looks like and emphasizes it as something that we should all be striving for.

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People take part in the first annual Disability Pride Parade in New York City on July 12, 2015. Stephanie Keith/Getty Images

Many disabled people subscribe to the social model of disability, which sees disability as the result of the interaction between people living with disabilities and an environment filled with physical, attitudinal, communication and social barriers. While it doesn't deny the reality that comes with living with a disability or the impact it has on an individual, it emphasizes the need for social change in order to accommodate disabled people.

"The social model says that a disability is not my inherent problem and that something isn't inherently wrong with me as a person. I think it's more of the community aspect and how you can have diversity in your culture, versus the medical [model] of, like, you have to be fixed, you have to blend in with the norm and this is how we're going to do that to fix you," said McDonnell-Horita.

The disability pride movement stemmed from the social model of disability, as it frames disability as a cultural identity and a natural part of human diversity. Disabled

people have used pride to affirm the self-worth and agency of disabled individuals and as a tool for combating systemic ableism.

Do research beforehand

Awareness around ableist language has been shifting over the years. Reedy noted that the R-word isn't used as much as it was in the past, but that other words with ableist and eugenic origins, such as "moron" and "idiot," are embedded in our vocabulary and need to be omitted.

"Ableist language is so intertwined with our culture we don't even realize we're using it. Most people understand that if you're working on something, you're going to make mistakes, but you have to start. The refusal to even address it — that is the most harmful thing," said Reedy.

McDonnell-Horita said that unlearning ableism and omitting harmful words that are embedded in our language take practice and commitment; it's important for nondisabled people to be involved in this work. Resources such as the National Center on Disability and Journalism's Disability Language Style Guide and activist Lydia X. Z. Brown's glossary of ableist language are easily accessible online to help people in the learning and unlearning process.

"It takes the weight and the burden off of disabled people to have to do the work every day if we can have more people who understand why the language can be harmful and more people interrupting ableist conversations or even ableist thinking," said McDonnell-Horita.

Recognize intersectionality

Disability crosses every other community and marginalized identity group. According to the Centers for Disease Control and Prevention, 1 in 4 Black people in the United States has a disability, while 1 in 10 Asian Americans has a disability.

Yet within disability rights spaces, the voices of white men with physical disabilities have been centered and uplifted the most historically. McDonnell-Horita said that this

Here's what to say and not to say when discussing disability: NPR

isn't representative of the diverse experiences within the community.

"When we talk about disability, it's important to not just think about those that are visible, but also nonvisible disabilities and those communities who have historically been marginalized and left out," said McDonnell-Horita.

It's important to recognize intersectionality, a term coined by Kimberlé Crenshaw, which is an analytical framework for understanding how aspects of a person's social and political identities combine to create different modes of discrimination and privilege.

For example, Reedy said that she experiences the world as a Black dwarf woman and can't separate those identities when speaking about disability. In storytelling, she emphasizes how you can't talk about poverty without discussing how that impacts disabled people, especially communities with high disability rates such as Black, Indigenous, LGBTQ and transgender communities.

"When you're not talking about poverty and race and disability together, you're not telling the story, you're not digging in. Journalism in particular, we're supposed to be holding power to account. But if you're not checking all those boxes and figuring out how to tell all those stories mixed together, I don't know what you're doing," Reedy said.

Additional resources

Books

Disability Visibility anthology

Demystifying Disability: What to Know, What to Say, and How to Be an Ally, by Emily Ladau

The Pretty One, by Keah Brown

Videos

Stella Young:	"I'm not your	inspiration,	thank you	very much"

"War on the Weak: Eugenics in America"

Crip Camp

"Disability Justice & Access-Centered Pedagogy in the Pandemic"

Podcasts

The Heumann Perspective

The Accessible Stall

"Ed Roberts and the Independent Living Movement," from *Stuff You Missed in History Class*

The Disabled Standard (produced by former NPR intern Shruti Rajkumar)

Resource guides

The Asian Americans With Disabilities Initiative's Resource Guide

Disability Masterdoc

Hashtags

#DisabilityTooWhite

#DisabilityTwitter

#CripTheVote

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