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Reported Features

## Writing Well about Disability

October 24, 2017 Rachel Zamzow



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In June, dozens of protesters with disabilities stormed Senate Majority Leader Mitch McConnell's office in response to Medicaid cuts that were part of a proposed repeal of the Affordable Care Act. Headlines and striking images called attention to the many people who were removed forcibly by Capitol Police, some being lifted out of their wheelchairs. But s.e. smith (spelled in lowercase), a disabled journalist and disability-rights activist who lives in Northern California, was frustrated by most of the coverage. Story after story not only had little substance about the cuts, but also failed to quote a single disabled person.

Fed up, smith took action. In three 80-hour weeks, smith launched [Disabled Writers](#), a database that connects journalists with sources who have disabilities. Many of the people on the list are also writers whom editors can hire. On the site, you can search profiles of some 150 sources by specific disability, such as cerebral palsy or blindness, or by area of expertise, from public policy to the sciences to medieval history.

Resources like smith's are a response to persistent problems in media coverage of disability-related topics. (The same issues that aggravated smith plagued stories about September protests against the Graham-Cassidy health care bill, another attempt to repeal Obamacare.) The biggest problem: Though disabled people make up the nation's [largest minority group](#), their voices are often left out of stories about disabilities. That omission is particularly egregious, according to members of that community.

Reporting on disability often stumbles in other ways. Many media stories frame disability in a negative

light and perpetuate damaging stigmas. Other coverage reflects a misguided attempt to inspire, but often ends up devaluing people with disabilities in the process.

Ideally, many stories about disability would be assigned to disabled journalists, who would bring an invaluable perspective to the reporting. But this is often not the case—newsrooms and freelancer pools lack diversity when it comes to the disability community. As such, nondisabled science journalists who cover research on disabilities are responsible both for including people with disabilities in stories and for being thoughtful about how disability is represented in the media. “The way that we choose to discuss disability has a profound impact on how people read what we’re writing and how people think about disability as a result,” says Smith. For journalists who want to do better, there are a few major areas to consider improving.

### Think before You Pitch

Many disability-related stories simply aren’t worth covering. As journalist Wendy Lu [reported](#) in the *Columbia Journalism Review* in September, many stories about people with disabilities fall into the category of so-called inspiration porn. As Lu notes, stories centered on ideas such as “teens with Down syndrome crowned homecoming king and queen,” or “football player sits with autistic kid eating alone,” are touted by news publications as heartwarming and uplifting.

*Treating disabled people as sources of inspiration simply because they have a disability reduces them to objects of others’ entertainment and curiosity.*

But such stories tend to backfire, says science journalist Steve Silberman, author of *NeuroTribes: The Legacy of Autism and the Future of Neurodiversity*. “It’s a good-hearted attempt to correct for stigma, but it goes too far in the other direction, where you’re actually condescending or demeaning to the people that you’re writing about.”

Treating disabled people as sources of inspiration simply because they have a disability reduces them to objects of others’ entertainment and curiosity. It also implies that having a disability is inherently a tragic fate, and that even ordinary life experiences such as eating with friends are extraordinary gifts for a disabled person. The same is true of stories that paint disability as an obstacle to be overcome, says autistic self-advocate Julia Bascom, executive director of the [Autistic Self Advocacy Network](#). For example, media outlets may incessantly fawn over an amputee running a marathon. Stories that fail to quote disabled people compound the problem by making those people a prop in someone else’s narrative.

When a possible story like this comes up, journalists should check themselves before taking the bait, says Kristin Gilger, senior associate dean of the Walter Cronkite School of Journalism and Mass Communication at Arizona State University. Ask what makes it newsworthy, she advises—and as a general rule, avoid stories you wouldn’t otherwise write if a disabled person wasn’t involved.

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Also deserving of a wary eye are stories that sensationalize findings related to disabilities. Sacrificing scientific accuracy for hype reinforces stigmas tied to disabilities and spreads misinformation. In August, CBS News ran a [segment](#) on the decreasing incidence of Down syndrome in Iceland. The report contained a striking statistic: Nearly 100 percent of pregnant women whose babies test positive for Down syndrome choose to have an abortion. Critics said CBS mishandled the information by using callous

rhetoric, such as talk of “eliminating” or “eradicating” the disability. Subsequent coverage by other news outlets was also problematic, sensationalizing the report’s findings by suggesting that they revealed eugenics at work, or by inaccurately claiming that Iceland is mandating abortions. This subpar reporting does a disservice to the disability community, says Smith.

The same goes for coverage of preliminary studies of promising treatments, Silberman says. Reporters too often report overenthusiastically on early studies of new drugs or therapies, and too seldom follow up after more rigorous trials. That pattern can lead people with disabilities and their families to get their hopes up, only to never hear about a treatment again.

*“Social media has been the game changer, because now people with disabilities, disability organizations, and disability-rights advocates are able to kind of drive the coverage.”*

Science journalists should also be careful not to veer too far into the narrative of fixing or curing people with disabilities, says Beth Haller, a professor of journalism and new media at Towson University in Maryland. Seek out stories about easing symptoms that come along with a disability instead of only reporting on efforts to decode its cause. “Those kinds of stories are not about a cure, but they’re about improving people’s lives through medicine and science, and it’s not about changing who they are,” she says. For example, a story about a possible treatment for tremors is probably more directly beneficial to people with Parkinson’s disease than one about a series of candidate gene studies, though both have their scientific merits.

Stories that bring the focus to challenges that people with disabilities face, such as insufficient accommodations, often go underreported, Silberman says. It’s also important to call out areas that are underfunded and thus lacking research, including the roots of health concerns associated with some disabilities. Haller suggests staying connected on social media to see what issues are trending within disability communities. “Social media has been the game changer, because now people with disabilities, disability organizations, and disability-rights advocates are able to kind of drive the coverage,” she says.

The [National Center on Disability and Journalism](#) (NCDJ) aims to highlight quality stories that journalists should emulate with its Katherine Schneider Journalism Award for Excellence in Reporting on Disability. The [archive](#) of past winners includes a wide range of stories, from an [investigation](#) into a state system of group homes for Minnesotans with developmental disabilities to a [feature](#) about a woman who solved the mystery behind her own genetic condition.

### **Go to the Source**

Once you know you’ve got your hands on a real story, make sure you actually talk to disabled people. Far too many stories leave out the perspectives of those who have firsthand experience of disabilities—an omission that, as Silberman notes, is like writing a story about women and only interviewing men. Talking with and learning from autistic adults while researching *NeuroTribes*, he says, “completely changed the tone of my writing.” Through these interactions, he came to realize that many depictions of autism in the research literature—and to some extent, in early drafts of his book—were subtly demeaning. They framed autism in stark medical terms, from the perspective of doctors describing a series of symptoms. In his writing, Silberman worked to convey more nuanced characteristics of autism that don’t get as much attention, such as a keen sense of humor and a sensitivity to social injustice.

Instead of seeking out disabled people themselves as sources, journalists may be tempted to talk to parents or representatives from advocacy organizations who speak on behalf of people with disabilities, says Alice Wong, a disability-rights advocate and creator of the [Disability Visibility Project](#), which aims to amplify the varied voices of the disability community by encouraging people to record their oral histories. “We are often the objects of the research, but very rarely are we actually included in the narrative,” she

says.

*When placing the comments of people with disabilities alongside those of typical experts, be wary of letting their voices get overshadowed.*

Similarly, much of the science reporting on disability focuses on people traditionally viewed as experts, such as scientists and doctors. Bascom says an expert still doesn't know as much about autism as someone who has experienced it her whole life. She also notes that talking to researchers and other traditional experts who have disabilities themselves can be particularly useful.

When placing the comments of people with disabilities alongside those of typical experts, be wary of letting their voices get overshadowed, says smith. "With science journalism, we need to acknowledge that researchers have systemic institutional power," he says. "Their voices tend to carry much more weight." To rectify this, smith suggests occasionally flipping the usual narrative of outside researchers evaluating scientific results. Instead, after the primary source, try centering your story on what people with the disabilities being studied think about the new findings, and then include other scientists as secondary sources. An example of a story that struck the right balance is Marilyn Marchione's Associated Press story about [gene therapy for blindness](#), published earlier this month. Marchione opens her piece with the experiences of children who gained sight after experimental gene therapy, quoting them before inserting comments from medical experts and diving into the science of the treatment.

Emphasizing those voices will also help avoid inadvertent ableism in science stories, which often frame disabilities as strictly medical conditions needing treatment. This view may bother many people who consider their disability as a core part of their identity, Bascom notes. "It doesn't fit with the way we view ourselves," she says.

For example, reporters writing stories about exoskeletons or high-tech wheelchairs that allow people to climb stairs may assume that all people who use wheelchairs want these technologies. As smith notes, that assumption reinforces the idea that someone with a disability is broken and needs to be fixed. "That preconceived notion of disability as a negative really colors the way that people read stories about disability and medical research," he says. Interviewing several disabled people for stories about new technology will help ground your reporting in what different members of the community think.

*Journalists can connect with sources through the large number of advocacy organizations for different types of disabilities.*

Thanks to social media, finding sources with disabilities shouldn't be a challenge. "There's a lot of great hashtags and online communities that are really vibrant that reporters can tap into," says Wong. She suggests following several hashtags to find sources and gauge what different disability communities are talking about.

For instance, #CripTheVote encourages discussion about political issues affecting people with disabilities. Disabled people are also tweeting with #SayTheWord to share their experiences and remove stigma attached to the word "disability." The autistic community uses #ActuallyAutistic to call out the media and researchers for excluding them from conversations about autism. And people with chronic illnesses, such as Lyme disease and fibromyalgia, are telling their stories using the [#spoonie](#) hashtag. (This catchphrase analogizes what it's like to live with a limited energy supply. Imagine having a handful of spoons, and each daily activity, like a conversation, costs you a spoon—until you run out and need to rest. The

#spoonie hashtag also draws attention to the fact that many people have so-called invisible disabilities that are not obvious physically. Science journalists should remember that people with these forms of disability, including both mental and chronic illnesses, are also important to seek out as sources.)

### Editors: Work with Disabled Journalists

Diversity within freelancer pools and especially newsrooms has a lot of room to grow when it comes to including writers with disabilities, says Smith. Editors can search through [Disabled Writers](#), a database that includes journalists with disabilities who have varied beats and levels of expertise. In addition, this [Twitter list](#), created by writer and producer Rose Eveleth, has several journalists with disabilities.

Additionally, journalists can connect with sources through the large number of advocacy organizations for different types of disabilities. The NCDJ has a running [list of disability organizations](#). And take advantage of [Disabled Writers](#), Smith's growing database of sources with disabilities.

Once you find the right sources for your story, be flexible with how you conduct interviews, Wong says. For example, editors and journalists should understand that email communication might be better for some people who have difficulty speaking. The NCDJ has a list of [helpful tips](#) for interviewing people with disabilities. But in general, use the same standard interview techniques you would use with any other person, even if he or she has an intellectual disability. It is especially important to speak to your source directly instead of to a family member or interpreter .

#### Words Matter

Science writers should also be sensitive to the language they use. Some of the don'ts, such as the hurtful "[r-word](#)" or the term "wheelchair-bound," are obvious. But in other cases, the correct language to use is not as clear. "The language itself is kind of like a field of landmines," says NCDJ's Gilger.

Some phrases can demean people with disabilities more subtly. For example, using the term "able-bodied" to describe someone who does not have a disability implies that all people with disabilities have a physical impairment, according to the NCDJ. The word "normal" is also discouraged, as it suggests that disabled people are abnormal or strange. Instead, saying "nondisabled" or "typical" is preferable.

*Avoid language that paints disability in a needlessly tragic light, casting people as sufferers.*

The NCDJ website has a comprehensive [style guide](#) with recommendations for how to use over 100 terms related to disabilities. The resource breaks down the meaning of each term and what, if any, consensus there is within the disability community about its use. For example, the guide recommends the use of "deaf" or "partially deaf" to describe a person with hearing loss—instead of "hearing impaired," which emphasizes a deficiency. When applicable, the guide also mentions where *The Associated Press Stylebook* stands on a particular term.

Also, avoid language that paints disability in a needlessly tragic light, casting people as sufferers. This type of narrative was especially prevalent in the past few years of Zika virus coverage, as journalists described microcephalic babies as "misshapen," "stricken," and "heartbreaking." Microcephaly and other disabilities do involve medical challenges that need to be reported on, but using the language of suffering further stigmatizes having a disability. Instead, preserve scientific accuracy with more neutral descriptions, such as "significantly reduced head size," in the case of microcephaly.

Another key, Bascom says, is to avoid using euphemisms for the word "disability." For example, "special needs" is commonly used to refer to children, but some [parents of disabled children](#) and many adults with

disabilities find the phrase condescending. The term “disability” is attached to laws like the [Americans with Disabilities Act](#) and provides a sense of identity and community for people with all kinds of disabilities.

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When referring to sources, keep in mind that many individuals prefer to be identified by their disability, such as saying “autistic” instead of “person with autism.” This identity-first language embraces a person’s disability as inseparable from his or her life. “It is a really integral part of who we are,” Bascom says. Members of the autistic and Deaf communities in particular tend to use identity-first language.

But there aren’t absolutes. The opposite phrasing, known as person-first language, is sometimes preferred by the families of people with disabilities or doctors because it emphasizes the humanity of the person being described. Some disabled people, such as those with intellectual disabilities, may also favor person-first language. Still, others find that phrasing offensive. According to Bascom, the best rule of thumb is to ask interviewees how they would like to be described. This approach may bring up conversations with editors about adjusting a publication’s style to better reflect the views of disabled sources. Similarly, quoting multiple people with disabilities may involve finessing a balance between both types of language in the same story.

Beyond just choosing the right words, science journalists can tweak story angles to describe disability as an identity held by many versus a medical flaw in need of fixing. In an [opinion piece](#) for the October issue of *JAMA Pediatrics*, Toronto-based physician Paige Terrien Church wrote that “medicine oversimplifies the discussion of disability.” Church, who is disabled herself, went on to say that “like most things in life, and medicine, disability is sharp, painful, humbling, as well as tremendous, giving, awe-inspiring. It is human.”

Framing stories to reflect this nuance downplays stigmatizing language and better reflects the viewpoints of many disabled people. For instance, amidst coverage of the scientific possibilities of CRISPR, smith would like to see a story capturing the reactions of people who have the same disabilities that gene-editing technology has the potential to eliminate. “One thing science journalists in particular may learn if they start looking at disability as a social identity,” smith says, “is that there’s a whole wide world of really fascinating and cool stories out there that you could be telling that are not being covered.”

[Rachel Zamzow](#) is a *TON* fellow sponsored by the Burroughs Wellcome Fund. She is a freelance science writer based in Waco, Texas. The brain is what makes her tick, so most of her stories have a psychology or neuroscience slant. But she’s always interested in anything new and exciting science has to offer. She’s written for a variety of publications, including the award-winning autism research news site *Spectrum* and *The Philadelphia Inquirer*, where she was a 2014 AAAS Mass Media Fellow. She tweets [@RachelZamzow](#).



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