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Disability Writing & Journalism Guidelines

There is a common expression in the Disability Community, “Nothing about us, without us.” Unfortunately, many media outlets are currently telling stories that are “about us, without us,” if we are included at all. Doing so is harmful and should not be a widely-accepted practice. It renders the “voices” (note: not every disabled person communicates verbally) of actual disabled people silent and sets a precedent that disabled people cannot communicate or advocate for ourselves. Parents, caregivers, doctors, and even strangers have more say in telling our stories than those of us living disabled lives. It is problematic when non-disabled individuals are given the authority to communicate as the authentic voice of the Disability Community.

The media must think about and tell stories that reflect their audience and this certainly includes the Disability Community. This guide is intended to help journalists and other members of the media learn about the Disability Community as a demographic and a source, while exploring how to talk about disability in a way that is not harmful.

Understanding Disability & the Media

The Disability Community is a multi-cultural, multi-faceted community. Making up [1 billion people worldwide](#), and [over 56 million domestically](#), the Disability Community includes members of every marginalized group – every gender/gender identity, sexual orientation, race, religion, and nation. Anyone can become disabled at any point in their lives. In fact, the longer you live, the greater chance you have of [becoming disabled](#). In this document, the word disability is being used as an umbrella term to mean anyone that has a physical, sensory, psychological, chronic health, neurological, cognitive, or social disability. These examples show that disabilities can be both visible and invisible. Ultimately, it is important to understand that there are many different people that have a multitude of different experiences with disabilities.

A journalist should care about disabled people just out of principle. However, including us can be economically and politically advantageous. Disabled people have multibillion dollar spending power. In 2002, the buying power of the Disability Community was \$220B¹ and it has increased since then. Considering disabled people are also close to

¹ Source: Shackelford, Ellen L. and Marguerite Edmonds. 2014. *Beyond Disability Etiquette Matters: Step Outside Your Comfort Zone Useful Tools to Educate Yourself!*. Bloomington, Indiana: XLIBRIS Publishing. Page 117

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20% of the U.S. population, the Disability Community makes up a huge voting block. There are [over 30 million eligible](#) disabled voters in the United States, currently, and that number will grow exponentially as baby boomers continue to age.

So, if disabled people are consumers, voters, and otherwise productive citizens, why does exclusion persist? One significant reason is the poor representation of disability in the media. Representation matters. If actual disabled people are not accurately portrayed in the media, the public will not understand disabled lives and experiences. This significantly impacts whether legislation is passed that is helpful to the disability community or not. It can also impact how disabled folks are treated, and various other aspects of disabled lives.

Avoiding Stereotypes

Journalists need to be sure that they are telling stories that are not causing harm to disabled people. For example, when tragedy strikes and a parent kills their disabled child, it is deeply problematic to focus on the “sad circumstances” of the “poor” parental figures who were so desperate, while completely ignoring the disabled victims who were murdered. In turn, audiences end up pitying and condoning the perpetrators of these horrific actions, making excuses for why they did it. The disabled person who has been murdered is ignored and remains forgotten as nothing more than a burden that was too great to bear. Further, when telling these stories, it is often assumed, both explicitly and implicitly, that it is better to be dead than disabled. Having a disability is regarded as an ultimate tragedy that destroys a life, rather than a natural part of life and a legitimate way to live.

These stereotypes are one of many examples of ableism. Ableism is a set of biased attitudes and beliefs about disability that harm and disadvantage disabled people through both individual discriminatory actions and large scale, discriminatory social institutions and systems. Ableism can explain anything from an employer denying a qualified wheelchair user a job to a Deaf person not being able to understand a politician’s stump speech because of a lack of a sign language interpreter to a child with a reading disability failing a class because their grade was determined entirely by timed, written exams.

Thus, the stories that need to be told are about the ableist social structures that keep disabled people at a disadvantage, and the community of disabled people that are fighting to disrupt and dismantle this ableism. Inaccessibility severely limits equality, equitable treatment, and inclusion. For example, in spite of [over 30 million disabled people](#) being eligible to vote, only about half that, [around 16 million disabled voters](#), were actually able to get out and vote in 2016. This was largely due to inaccessibility at the polling stations or with the overall voting process. Additionally, disabled people are twice as likely to live in poverty. In fact, a 2014 report by the U.S. Senate’s Health,



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Education, Labor and Pensions Committee found that [1 in 3 Americans with disabilities](#) are currently living in poverty.

Institutional bias also plays a major role in marginalizing disabled people. Institutional bias is the term used to describe the laws and regulations keeping many of those with disabilities locked away in nursing facilities or in another institutional setting. Most of the civil rights victories of the past few decades that grant protection to disabled people are useless to those forced to live in an institution. Activists have been fighting for years for disabled people to have the right to live in their communities. Some progress is being made, but there is still much more to do in this area.

Disability Culture & Community

Just like other marginalized groups, the Disability Community has its own culture, as well as individual community cultures (i.e. the Deaf community, the Autistic community, etc.). There is an overall sense of connection many disabled people embrace through a variety of shared or similar experiences. Disability culture allows disabled people to share ideas and solutions, find camaraderie, protest injustice, celebrate victories, mourn tragedies, and fight together for equal rights. As more and more people embrace their disabilities, they are reaching out to others who are also disabled. From there, many disabled people are learning to be proud of their disability identity.

A great place to start is with challenging common ableist beliefs that can make life with a disability difficult. Media outlets can do so by telling stories that focus on the experiences disabled people have when they come together to celebrate disability culture and resist ableist systems of oppression. For instance, there are Disability Pride Parades every July that are held across the country, which celebrate disability, and often take place near the summertime anniversary of the passage of the Americans with Disabilities Act. Covering these events could be greatly beneficial to the Disability Community.

Inclusivity in Journalism

For the Disability Community, it is common for outsiders to control the disability narrative in the press. Typically, reporters reach out to non-disabled parents or doctors as the primary sources for stories about disability. Family members can only understand disability from an external lens, so you should only reach out to them when telling stories about their personal experiences. They should never be allowed to speak as the "authentic voice" of any disabled person. Instead, reporters should seek out actual disabled people to talk about disability.

You can ensure you have access to authentic disability representation for future stories by following disabled activists on social media. Check out hashtags like #CripTheVote, #ADAPTandRESIST, #ActuallyAutistic, #DisabilityTooWhite, #DeafTalent, or #FilmDis.



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Intersectional Representation

Disabled people come from all walks of life, but the dominant narrative about disability usually comes from white, cisgender, straight, disabled men. When women are included, they are almost always white. Black and brown voices are consistently missing from the narrative. It is imperative that diverse representation be included. If your work is not intersectional, then it is excluding someone. A person's identity can intersect to include race, ethnicity, immigration status, gender, [gender identity](#), sexual orientation, disability, age, nationality, and social class. Contrary to popular belief, disabled people have a [higher prevalence](#) of being LGBTQA, but we rarely see stories about LGBTQIA disabled people. This is especially true for those further marginalized by race. Including diverse disabled people ensures that there is not just one experience of disability that is conveyed in the media, but many.

Stories to Avoid

When you focus the message around disabled voices and actually let disabled people actually lead the discussion, you are on the right track. However, it is important to understand a very popular trend in media stories about disability. It is called [inspiration porn](#). Inspiration porn slants stories and images of disabled people in a way that allows a nondisabled audience to feel warm and fuzzy, but regards the disabled person as nothing more than an object that produces these positive feelings. Inspiration porn often also highlights how nondisabled people themselves are considered “inspiring” for doing things that would be considered mundane in a context that didn’t involve a disabled person as an object of pity.

An inspiration porn story may be about how a disabled teen was asked to prom by a popular girl or boy who felt sorry for them or sacrificed their “real date” to be nice and compassionate. It may show a disabled person being photographed without their permission as a “good Samaritan” helps them get their lunch or cross the street. It might feature a disabled athlete, and promote the message that disability is nothing more than a bad attitude. These messages are not only exploitative, they are also dangerous. Inspiration porn is violence, because it creates an unnecessary hierarchy where nondisabled people are better than disabled people, and disabled people only live to inspire and entertain the nondisabled masses.

A good question to ask is whether this would be a story if disability was removed, and if the answer is no, it really isn’t a story that should be told.



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Being Responsible with Sources

When you are dealing with disability organizations it is important to know exactly who they really represent. Just because an organization claims to represent disabled people that does not mean disabled people are actually included. Try to research the organization before you use them as a source. There are organizations controlled by non-disabled people, such as Autism Speaks, that have a record of harming disabled people. If the organization is not run by disabled people, there is a good chance it is not offering up authentic disability inclusion and representation.

That being said, just because an organization is run by disabled people does not mean that accurately represents the Disability Community, either. Respectability is an organization that has had multiple incidences with racist words and actions coming from its leadership. Black disabled people and other disabled POC have spoken out against the harm this organization has caused. They also have been in trouble for using intellectual property and ideas from multiply-marginalized disabled people without permission or credit. Not all organizations have the best interest of all disabled people, so do your research before using any organization as a source.

Examples of Respected Disability Run Orgs and Groups:

AAPD, ADAPT, ASAN, Autistic Women's Network, Center for Disability Rights, DREDF, FilmDis, Harriet Tubman Collective, Krip Hop Nation, National Association of the Deaf, National Coalition for Latinxs with Disabilities, NCIL, National Federation of the Blind, NMD United, Not Dead Yet, Rooted in Rights, Yo! Disabled & Proud

Examples of Problematic Disability Orgs and Groups

Alexander Graham Bell Association for the Deaf and Hard of Hearing, Autism Speaks, Goodwill, MDA, Respectability, Treatment Advocacy Center, VOR

Words & Phrases to Use or Not Use

One of the most important things that journalists can learn is how to properly discuss disability. Today, the vast majority of articles written about disability or disabled people are harmful, in part, because they use stigmatizing language. Here is a glossary of terms to reference when writing or speaking about disability.



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What to Avoid	What to Use
Impairment, Special Need, Deficit	Disability
<p>Wheelchair bound, Confined to a wheelchair</p> <p>Handicapped, Differently abled, Lame, Crip/Cripple/Gimp (when used by someone non-disabled), Spastic, Spaz, Physically challenged, Handicapable, Wheelz/Speed Racer/Speedy, Making speed limit/racer jokes</p>	<p>Wheelchair user, Disabled (preferred by most activists), People with Disabilities or PWDs,</p> <p>Cripple/Crip/Gimp (if someone self-identifies this way), has (insert disability), Physically disabled</p>
<p>Retarded, Feeble-minded, Slow/Delayed, Developmental delay, Mentally deficient, Stupid, Dumb, Dimwitted, Idiot</p>	<p>Person with a Developmental Disability, Person with an Intellectual Disability, Person with Down Syndrome, Intellectually or Developmentally Disabled</p>
<p>Psychotic, Mad, Crazy, Demented, Mental, Loony, Nutjob, Nutso, Whacko, Psychopath, Crazyed, Psycho, Deranged, Lunatic</p>	<p>Psychiatric disability/diagnosis, Mad* (reclaimed – there is a Mad pride movement), psychosocial disability, person with [specific diagnosis/disability]</p>
<p>Aspie (some do like this, but many abhor it), Person with autism</p>	<p>Autistic, Neurodivergent</p>
<p>Midget</p>	<p>Dwarf, little person</p>
<p>Patient (do not use in general disability discussion)</p>	<p>Refer to them by name or identity choice</p>
<p>Vegetable</p>	<p>Person, Human being</p>
<p>Nuthouse, Loony Bin</p>	<p>Asylum, Institution</p>
<p>Normal, Whole, Able-Bodied, Healthy</p>	<p>Nondisabled, Neurotypical (for non-Autistic)</p>
<p>Deaf-and-Dumb, Hearing Impaired</p>	<p>Deaf or Hard of Hearing (HoH)</p>
<p>Mute</p>	<p>Doesn't communicate verbally, doesn't speak verbally</p>



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high functioning or low functioning	Most autistic people say they have moments of both and prefer no functioning labels
Visually Impaired (some people with low vision still use this term)	Blind or low vision
Special needs	Accommodations, modifications
Handicapped accessible	Wheelchair accessible (as in parking)
Freak (in most circumstances)	Freak (when self-identifying as such), just don't use it otherwise
Epileptic fit	Seizure
Sufferers, suffers from, afflicted Stricken with	Has [disability]
Victim	Survivor (unless a victim of murder)
Abnormal, Atypical Broken, Defective, Deformed Invalid Special Ed (to refer to a person especially) Short bus (to refer to a person) Angel baby Special snowflake, Pillow angel Inspiration Superhuman, Special Brave/Courageous, Heroic Referring to disabled people by their medical label, diagnosis, mobility device (i.e. don't call people "the wheelchair") Putting "the" in front of terms (i.e. the Deaf)	

**Terms may also vary depending on the country where a disabled person lives. For example, most people in the UK and Europe prefer identity first language while individuals in the United States and Canada tend to go back and forth between people first and identity first depending on the specific disability being represented. Much of the world uses the term disabilist to mean ableism, while the U.S.,*



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Canada, and Australia all use the term ableism. Make sure you understand the rules in the country or region being represented.

While most people in the Disability Community agree these terms and usages are overwhelmingly problematic, there are always exceptions. Always ask a disabled person how they wish to identify, and respect that. If you find the term problematic, you can always say this is how the person self-identifies in your article, video, or other piece of media. Identifying as disabled is a personal choice each person must make for themselves. Some are very proud, while others are uncomfortable with their disability. Everyone is in different places of their journey to acceptance.

It should be noted that the terms, *crip*, *cripple*, and *gimp* have been “taken back” by some in the Disability Community. These words have a terrible history, in terms of how they have been used by the nondisabled majority against disabled people. That is why it is rarely appropriate for nondisabled people to use them.

Person First vs. Identity First Language

Identity First: Disabled, Autistic, Deaf, Dwarf etc.

Person First: Person with a Disability, Person with autism, Person who is Deaf, etc.

Many journalists have been taught to use person first language (PFL), because it puts the person first, before the disability. However, an emerging camp of disabled people are making it known they prefer identity first language (IFL), especially those involved in disability activism.

Those who use IFL feel that PFL supports the idea that the disability itself is harmful, so it needs to be ignored or de-emphasized. They believe their disability is a part of their identity, while acknowledging it can sometimes make their life harder, especially due to lack of accessibility and other forms of ableism. Their disability is not something they are ashamed of, and they do not wish to de-emphasize it. Identity first language allows disabled people to acknowledge both the good and bad aspects of having a disability. IFL is still an emerging concept in the United States, although it is preferred in many European countries including England.

On the flip side, those using PFL believe the emphasis is always on their disability, and they are more than that. These individuals do not identify as disabled. They are people first. Certain communities, such as the Down Syndrome community, prefer people first language. Many people working in fields that heavily interact with disabled people, such as social work or physical therapy, have been taught to use person first language, and many parents of disabled children use it, as well. Some insist on using PFL, even to the point of ignoring the wishes of disabled individuals. You should never force language choices on anyone. It is up to each individual to determine how they wish to identify,



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and that should be respected. Please make sure you know and respect the preferences of those you feature in your work.

Social Model vs. Medical Model

The social model is a concept that focuses on the idea that the disability itself is not the primary issue creating harm or disadvantage for disabled individuals. Rather, the harm of having a disability is produced by the way disabled people are treated and the way society has been constructed with barriers that prevent their inclusion and participation (ableism). This idea is overwhelmingly preferred by disabled people around the world.

Unfortunately, the medical model continues to be the dominant way of discussing disability in journalism, and in society in general. The idea is that the disability itself is the problem that causes harm to a disabled person, and ultimately, to those in their family, community, and society. The medical model infers disabled people need to be fixed in order to gain equality and this is often focused on what is called *cure mentality*. In fact, disabled people are often only discussed in the media in a medicalized context, especially highlighting the inaccurate belief we are all sitting around waiting for a cure.

The medical model can be very harmful, as it implies that disabled people will inevitably live low quality lives because they are disabled, regardless of whether social structures become more inclusive. The idea is that if the disability itself is the problem, then a disabled person cannot possibly be a fully participating member of society so long as they are not cured/fixed. They are thus excluded, sent away, ignored, and forgotten.

It should also be mentioned that some disabled people do have health related issues exacerbated by their disability. Some do want a cure, and most do want better treatment options. Choosing to move from talking about the medical model should not invalidate the very real issues and often very complicated feelings disabled people experience relating to their disability. It should be recognized that the Disability Community is not a monolith, and a cure is not required to have a decent life.

Final Thoughts

As a member of the media, you may have many questions about this press guide, and that is okay. This is just the beginning of a discussion on inclusion for disabled people, which will continue as you start to reach out to disabled people, and integrate their stories into your work.

If you have any questions about this guide contact our Advocacy Team at advocacy@cdrnys.org



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Appendix

For examples of “**Inspiration Porn**”:

https://www.buzzfeed.com/leticiamiranda/this-girl-asked-her-friend-with-a-disability-to-prom-in-the?utm_term=.nkIOBJRZB#.icL6aYL7a

<https://aleteia.org/2017/09/15/teacher-finds-unique-way-to-help-disabled-student-participate-in-class-dance-video/>

<http://www.eonline.com/news/699703/mcdonald-s-employee-helps-disabled-man-with-his-dinner-reminds-us-kindness-still-exists-see-the-pic>

For examples of articles that rely on non-disabled voices as their primary sources (i.e. the **Inclusivity in Journalism** section of this guide) and that deploy the **Medical Model** instead of the **Social Model** of disability:

<https://themighty.com/2017/10/two-words-child-disability/>

<http://www.azcentral.com/story/news/local/arizona/2017/09/18/z-pitt-hopkins-syndrome-awareness-day-arizona-what-is-it/669929001/>

<https://themighty.com/2017/10/worries-parent-of-child-undiagnosed-disabilities/>

<https://themighty.com/2015/02/strangers-acts-of-kindness-helped-me-as-a-special-needs-parent/> (this one is *also* considered **Inspiration Porn**)

For an example of an article headline that uses several of our “**What to Avoid**” words and phrases:

<https://successtory.com/inspiration/10-best-successful-personalities-with-disabilities>

For information on **Harmful Organizations**:

<https://autismwomensnetwork.org/is-autism-speaks-a-hate-group/>

https://www.huffingtonpost.com/entry/an-open-letter-to-the-disability-organization-respectability_us_57e88457e4b05d3737be6276