Guidelines:

How to Write and Report About People with Disabilities



The difference between the right word and the almost right word is the difference between lightning and the lightning bug.

- Mark Twain

Your Words, Our Image

Writers, editors, reporters and other communicators strive to use the most accurate terminology about people with disabilities. However, inaccurate, archaic and offensive expressions are still commonly used, perpetuating negative stereotypes and beliefs about people with disabilities.

For example, a person who uses a wheelchair – an objective fact – is often described as wheelchair-bound, a subjective description that implies victimhood.

As one wheelchair user puts it, "I personally am not 'bound' by my wheelchair. It is a very liberating device that allows me to work, play, maintain a household, connect with family and friends, and 'have a life.'"

Who Says?

Since the first edition was published in 1984, we have consulted with hundreds of disability groups and individuals who have disabilities to produce *Guidelines:* How to Write and Report About People with Disabilities. The eighth edition presents the latest terminology preferred by people with disabilities.

The Associated Press Stylebook, the Publication Manual of the American Psychological Association (6th edition) and the American Association for the Advancement of Science have all adopted some of the recommendations from previous editions of the Guidelines.

The first edition of the *Guidelines* was produced with funding from the National Institute on Disability and Rehabilitation Research. Since then, more than one million copies have been distributed, and the electronic version is now used by people around the world.

Please use the *Guidelines* when you write or report about people with disabilities. We also offer a poster that presents a short list of disability writing style dos and don'ts.

@ 2013 EIGHTH EDITION. No part of this booklet may be printed without prior written permission of the RTC/IL.

I

Portrayal Issues

The Americans with Disabilities Act (ADA) defines disability as a physical or mental impairment that substantially limits one or more major life activities.

That said, people with disabilities are like every other human being – they have strengths and weaknesses, successes and failures, hopes and dreams. Like other minority groups, they don't want to be stereotyped when their stories are told. By following these guidelines, you can portray people with disabilities in an accurate and objective manner.

Put the person first, not his or her disability. Use person with a disability, woman with multiple sclerosis or a child who has an intellectual disability. This "person-first language" puts the focus on individuals, not their functional limitations. Labeling a person (for example, an autistic) dehumanizes him and equates a person with a condition. Think people first, too, for indicating disability groups, such as people who have cerebral palsy.

Emphasize abilities, not limitations. For example, uses a wheelchair or uses a communication device rather than confined to a wheelchair or unable to speak. In reality, wheelchairs and other assistive devices represent independence for their users, not a burden. To emphasize capabilities, avoid negative words that portray the person as passive or suggest a lack of something, such as victim, invalid or defective. While the term disability itself implies a negative, it is the most objective term we have in English.

Do not focus on a disability unless it is essential to a story. Avoid tear-jerking human interest stories about incurable diseases, congenital disabilities or severe injury. Focus instead on issues that affect the quality of life for those same individuals, such as accessible housing and transportation, affordable health care, employment opportunities and discrimination. Focus on personal characteristics that aren't related to disability, such as artist, professional, mother, etc.

Bypass condescending euphemisms. Terms such as special, handicapable, differently abled and challenged reinforce the idea that people cannot deal honestly with their disabilities. While special is used in the names of some educational programs and organizations, the use of special needs is offensive to many adults with disabilities, who want to be treated like everyone else in their community. Special also implies a paternalistic need to be taken care of, which is frequently not true. Just say children with disabilities.

Do not portray successful people with disabilities as heroic overachievers or long-suffering saints.

Every human faces challenges in life. Even though the public may find such portrayals inspirational, these stereotypes raise false expectations for people with disabilities.

Avoid sensationalizing and negative labeling. Saying afflicted with, crippled with, victim of or suffers from portrays individuals with disabilities as helpless objects of pity and charity. State the facts in neutral terms, saying a person who has AIDS. Avoid emotional descriptors such as unfortunate or pitiful.

Do not equate disability with illness. People with disabilities can be healthy, though they may have chronic diseases such as arthritis, heart disease and diabetes. People who had polio and experienced after-effects have post-polio syndrome; they are not currently experiencing the active phase of the virus. Also, do not imply disease if a person's disability resulted from anatomical or physiological damage (for example, a person with spina bifida). Finally, do not refer to people with disabilities as patients unless their relationship with their doctor is under discussion, or if they are referenced in the context of a clinical setting.

Respect the person. Do not use offensive words such as retard, freak, lame, subnormal, vegetable and imbecile. If you maintain the dignity and integrity of each individual, there is no need to panic about being politically correct. When appropriate, you may ask a person how she prefers you to describe her disability. While some common phrases can be hurtful, such as blind as a bat, it's fine to use everyday expressions like See you later.

Person-First Language: A Partial Glossary of Disability Terms

We know that language shapes perceptions, so a small word choice can make a big difference in communicating attitudes towards people with disabilities and assumptions about the quality of their lives.

Person-first language literally puts the person first instead of his or her disability. By referring to an individual as a person with a disability instead of a disabled person, you are providing an objective description instead of a label. While opinions differ on some words, this partial list offers preferred terms for many visible and invisible disabilities, illustrated with person-first language.

AD/HD (Attention Deficit/Hyperactivity Disorder) is the clinical diagnosis for a genetic neurobehavioral condition that is characterized by symptoms in three categories: inattention, excessive activity and impulsive behavior. While the medical community includes **ADD** (Attention Deficit Disorder) as a subset of this condition, disability advocates consider the two conditions as distinctly different. A person who has ADD has difficulty focusing attention and a high level of distractibility, but does not experience hyperactivity or impulsive behavior. Say person with ADHD or student with ADD. Do not use hyper or lazy.

Autism spectrum disorders (ASD) refers to a group of complex disorders of brain development that may cause difficulty with social interactions, problems with verbal and nonverbal communication and repetitive behaviors. In terms of symptoms, Asperger's syndrome is on the milder end of the spectrum. People with an ASD can have severe limitations in one area with no limitations in others. Use child with autism or Asperger's syndrome or person on the spectrum. Do not say autistic. (See also "A Few Exceptions" on page 11.)

Blind describes a condition in which a person has loss of sight for ordinary life purposes. A person is *legally blind* when vision with best correction is no better than 20/200. *Low vision* and *vision loss* are generic terms for

vision loss caused by macular degeneration and other conditions. Low vision usually denotes someone who is legally blind, but can still see large print, bright colors, light and shadow, and large shapes, while vision loss refers to those who have lost vision after birth. Say boy who is blind, girl who has low vision or man who is legally blind. (You may ask which term best suits the person.) Some blind people consider themselves visual thinkers so they regard visually impaired and visually challenged as negative terms.

Brain injury or traumatic brain injury (TBI)

describes a condition where there is temporary or long-term disruption in brain function resulting from injury to the brain. Difficulties with cognitive (thinking remembering, learning), physical, emotional and/or social functioning may occur. Use person with a brain injury or employee with a traumatic brain injury. Do not say brain damaged.

Chemical and/or electrical sensitivities describe chronic medical conditions characterized by neurological impairment, muscle pain and weakness, respiratory problems and gastrointestinal complaints. Reactions for those with chemical sensitivities are triggered by low-level exposure to everyday substances and products including pesticides, solvents, cleaning agents, new carpeting and adhesives, fragrances and scented products. Electrical sensitivities are triggered by electromagnetic fields from electrical devices and frequencies. These conditions are also called environmental illness, toxicant-induced loss of tolerance or sick building syndrome. Use person with chemical intolerance or people with environmental illness. People with this condition should not be called chemophobic or described with the term idiopathic environmental intolerance.

Chronic fatigue syndrome refers to a chronic condition in which individuals experience six or more months of fatigue accompanied by physical and cognitive symptoms. Chronic fatigue, immune dysfunction syndrome and myalgic encephalomyelitis are currently preferred. Do not say Yuppie Flu. Also, don't confuse this syndrome with overlapping or similar conditions such as Epstein-Barr virus syndrome and fibromyalgia.

Cleft palate or **lip** describes a specific congenital disability involving the lip and gum. Say *person who has a cleft palate*. The term *hare lip* is anatomically incorrect and stigmatizing.

Congenital disability describes a disability that has existed since birth but is not necessarily hereditary. Use person with a congenital disability or disability since birth. Do not say birth defect or deformity.

Deaf refers to a profound degree of hearing loss that prevents understanding speech through the ear. Hearing impaired or hearing loss are generic terms used by some individuals to indicate any degree of hearing loss, from mild to profound, although some dislike the negative term impaired. Hard of hearing refers to a mild to moderate hearing loss that may or may not be corrected with amplification. A person who has hearing difficulties may have speech difficulties, too, but deafness does not affect mental abilities. Say woman who is deaf or boy who is hard of hearing. People who have some degree of both hearing and vision loss prefer the term deaf-blind. Also acceptable is person with combined vision and hearing loss or dual sensory loss. Never use deaf and dumb. (See also "A Few Exceptions" on page 11.)

Developmental disability is a broad term that describes any physical and/or mental disability that starts before the age of 22. Examples include cerebral palsy, autism spectrum disorders and sensory impairments. People with developmental disabilities have a wide range of functioning levels and disabilities. Although the term *intellectual disability* is often used in conjunction with developmental disability, many people with a developmental disability do not have an intellectual disability. Say she has cerebral palsy, he has autism or he has a developmental disability. Do not say she is mentally retarded.

Disability is a general term used for an attribute or a functional limitation that interferes with a person's ability, for example, to walk, lift or learn. It may refer to a physical, sensory or mental condition such as Lyme disease, depression, irritable bowel syndrome, post-

traumatic stress syndrome, diabetes, multiple sclerosis and other conditions that restrict the activities of daily living. Do not use the term *handicapped* because many people with disabilities consider it offensive.

We recognize the need for succinctness, but when possible, avoid using the disabled as a generic label. It describes a condition, not people, and has connotations of "non-functioning" (as in a disabled car). It also implies a homogenous group separate from the rest of society. Instead use people with disabilities or the disability community.

Disfigurement refers to physical changes caused by burns, trauma, disease or congenital conditions. Do not say burn victim. Say burn survivor.

Down syndrome describes a chromosomal disorder that causes a delay in physical, intellectual and language development. Say person with Down syndrome. Do not use Mongol, mongoloid or Down person.

HIV/AIDS is a disease of the immune system. Over time, HIV (human immunodeficiency virus) can weaken the immune system to a point where the body becomes susceptible to certain illnesses that healthy immune systems resist. People with HIV are diagnosed with AIDS (acquired immunodeficiency syndrome) when one or more specific conditions are met. Use person living with HIV or people who have AIDS. Do not use AIDS victim.

Intellectual disability refers to limitations in intellectual functioning and adaptive behaviors that require environmental or personal supports for the individual to live independently. Though mental retardation was previously accepted as a clinical term, many consider it an insult, so people who have this condition, their families and related organizations have campaigned to end its use. (See "Rosa's Law and the Language of Bullying" on page 8.) Say people with intellectual disabilities. Do not use mentally retarded or subnormal.

Learning disability describes a neurologically based condition that may manifest itself as difficulty learning and using skills in reading (called dyslexia), writing (dysgraphia), mathematics (dyscalculia) and other cognitive processes due to differences in how the brain processes information. Individuals with learning disabilities have average or above average intelligence, and the term does not include a learning problem that is primarily the result of another cause, such as intellectual disabilities or lack of educational opportunity. Say person with a learning disability. Do not use slow learner or retarded.

Rosa's Law and the Language of Bullying

Signed into U.S. law in 2010, Rosa's Law replaces the term *mental retardation* with the phrase *intellectual disability* in federal health, education and labor statutes. The law was named for nine-year-old



Rosa Marcellino, whose brother Nick explained the change this way: "What you call people is how you treat them. If we change the words, maybe it will be the start of a new attitude towards people with disabilities."*

Most states have also changed their laws to use more respectful language in statutes and the names of state agencies.

The disability community supports a national campaign called "Spread the word to end the word," which raises the public's awareness about ending use of "the R word." This movement is also part of the battle against bullying, which often begins with demeaning and destructive words.

*From "Remarks by the President at the Signing of the 21st Century Communications and Video Accessibility Act of 2010," http://www.whitehouse.gov/the-press-office/2010/10/08/remarks-president-signing-21st-century-communications-and-video-accessib, accessed 12/7/12.

Nondisabled is the preferred term when the context calls for a comparison between people with and without disabilities. Use *nondisabled* or *people* without disabilities instead of *healthy*, *able-bodied*, *normal* or *whole*.

Post-polio syndrome is a condition that affects some persons who have had poliomyelitis (polio) long after recovery from the disease. It is characterized by new muscle weakness, joint and muscle pain and fatigue. Say person with post-polio syndrome. Do not use polio victim.

Psychiatric disability refers to a variety of psychological conditions. Say person with a psychiatric disability or mental illness. In a clinical context or for medical or legal accuracy, use schizophrenic, psychotic and other diagnostic terms. Note, too, that bipolar disorder has replaced manic depression. Words such as crazy, maniac, lunatic, schizo and psycho are offensive and should never be applied to people with mental health conditions.

Seizure describes an involuntary muscle contraction, a brief impairment or loss of consciousness resulting from a neurological condition such as epilepsy or from an acquired brain injury. Say girl with epilepsy or teen with a seizure disorder. The word convulsion should be used only for seizures involving contraction of the entire body. Do not use epileptic, fit, spastic or attacks.

Service animal or service dog describes a dog that has been individually trained to do work or perform tasks for people with disabilities. In addition to guiding people who are blind, they may alert people who are deaf, pull wheelchairs, alert and protect a person who is having a seizure, remind a person with mental illness to take prescribed medications, or calm a person with post-traumatic stress disorder during an anxiety attack. Miniature horses are also considered service animals under the Americans with Disabilities Act (ADA), though monkeys no longer are. Do not use seeing eye dog.

Short stature describes a variety of genetic conditions causing people to grow to less than 4'10" tall. Say person of short stature, although some groups prefer little people. Dwarfism is an accepted medical term, but should not be used as general terminology. Do not refer to these individuals as midgets because of its circus sideshow connotations.

Speech disability is a condition in which a person has limited or impaired speech patterns. Use *child who has a speech disability*. For a person without verbal speech capability, say person without speech. Do not use *mute* or *dumb*.

Spinal cord injury describes a condition in which there has been permanent damage to the spinal cord, resulting in some degree of paralysis. Quadriplegia denotes loss of function in all four extremities, while paraplegia refers to loss of function in the lower part of the body only; in both cases the individual might have some function in the affected limbs. While people with spinal cord injuries often refer to themselves as a para or a quad, communicators should use man with paraplegia, woman who is paralyzed or person with a spinal cord injury. Don't say cripple or handicapped.

Substance dependence refers to patterns of substance use that result in significant impairment in at least three life areas (family, employment, health, etc.) over any 12-month period. Although such terms as alcoholic and addict are medically acceptable, they may be derogatory to some individuals. Acceptable terms are people who are substance dependent or person who is alcohol dependent. Individuals who have a history of dependence on alcohol and/or drugs and are no longer using alcohol or drugs may identify themselves as recovering or as a person in recovery.

Survivor is used by people to affirm their recovery from or conquest of an adverse health condition such as cancer survivor, burn survivor, brain injury survivor or stroke survivor. Avoid calling them victims.



A Few Exceptions

Language is continually evolving, and no rule is absolute. Here are a few notable exceptions to person-first language.

Deaf/deaf. As a group, this population typically refers to itself as the Deaf or Deaf community (with a capital D) rather than people who are deaf. They identify with a specific community made up of those who share a common language, American Sign Language, and culture.

Disability humor. Some people with physical disabilities who embrace the culture of disability refer to themselves with the same offensive terms that we urge you to avoid. This familiarity is a form of disability humor and should not be adopted by those outside of the group.

Identity language. Some people prefer "identity language" to person-first language as a way to signal their disability pride. Thus, a person who values her autism as an inseparable and important part of who she is might proudly say, "I am autistic," in the same way she describes herself as an American. Similarly, many regard a blind man as a neutral descriptor (the same as a tall man), and amputee is more often used than a person with an amputation.

Still, the guiding principle remains: Accord people with disabilities the dignity that all people want. By using person-first language, you will maintain objectivity and convey respect.

10

Key Concepts in the Disability Community



These terms and concepts may be helpful when writing about people with disabilities.

Accessible describes the nature of accommodations for people who have a disability. Say an accessible parking space rather than handicapped parking or disabled restroom. Accessible

also describes products and services for people with vision or hearing disabilities, such as when a hospital provides patient education materials in large print or a university adds captions to a recruitment video. Handicapped has negative connotations because it suggests that obstacles to participation are in the person rather than in the environment.

Advocacy is an active process designed to make institutions and social and political systems more responsive to the civil rights, needs and choices of individuals. Through individual and group advocacy, people with disabilities can assert their rights under various civil rights laws and participate in decision-making that affects them.

Consumer is the term used by many in the disability community to refer to someone with a disability. The civil rights movement in the U.S. inspired the independent living movement of the 1970s, which maintained that people with disabilities are consumers of assistive services and have a responsibility to evaluate and control those services. On a similar note, some people prefer to be described by what they use, such as wheelchair user, ventilator user or mental health service user.

Independent living (IL) refers to the philosophy that people with disabilities should be able to make decisions that affect their own lives. IL also refers to a civil rights movement that advocates for equal participation in community life and a service system

made up of centers for independent living. These nonresidential resource centers are run by and for people with disabilities, as well as for the benefit of the entire community. Their core services include advocacy, information and referral, independent living skills training, peer counseling and, most recently, de-institutionalization of people with disabilities.

Inclusion is perhaps best known for its role in public school programs, though the concept has a wider significance. It means that people with disabilities are considered full citizens, with equal opportunity to participate in community life. As the largest minority in the U.S., people with disabilities should also be included in conversations about diversity.

The medical model is an attitude and practice that regards disability as a defect or sickness that must be cured or normalized through medical intervention.

People in the disability community prefer the social or independent living model, which regards disability as a neutral difference between people — and acknowledges that people with disabilities can be healthy. In the social model, problems related to disability are caused by the interaction between the individual and the environment rather than the individual's disability itself. These problems can be remedied by changing social attitudes, physical environments, public policies and other barriers to full participation.

On the cover: Jeff Gordon, Ranita Wilks, Rachel Magario and Magario's service dog, Nettie, on the University of Kansas campus. Photo by Diane Guthrie.

The University of Kansas prohibits discrimination on the basis of race, color, ethnicity, religion, sex, national origin, age, ancestry, disability, status as a veteran, sexual orientation, marital status, parental status, gender identity, gender expression and genetic information in the University's programs and activities. The following person has been designated to handle inquiries regarding the non-discrimination policies: Director of the Office of Institutional Opportunity and Access, IOA@ku.edu, 1246 W. Campus Road, Room 153A, Lawrence, KS, 66045, (785)864-6414, 711 TTY.



Want a quick overview?

Download our poster that lists disability writing style dos and don'ts at www.rtcil.org/guidelines.

Thanks to Our Reviewers

We are grateful to many individuals and disability organizations for their input on this edition of the Guidelines. A partial list of endorsers includes:

American Association of People with Disabilities Association of Programs for Rural Independent Living Beach Center on Disability, University of Kansas Brain Injury Association of America Christopher & Dana Reeve Foundation

Hearing Loss Association of America

Institute for Disability Studies, University of Southern Mississippi Learning Disabilities Association of America

National Ataxia Foundation

National Council on Independent Living

National Center for Environmental Health Strategies, Inc.

Post-Polio Health International

Rocky Mountain ADA Center

Scientific and Consumer Advisory Panel, Research and Training Center on Community Living

Spinal Cord Central, United Spinal Association Tarjan Center, University of California, Los Angeles United Cerebral Palsy/Community Living and Support Services



Life Span Institute

Research and Training Center on Independent Living The University of Kansas 4089 Dole Center, 1000 Sunnyside Ave. Lawrence, KS 66045-7561 E-mail: rtcil@ku.edu

Phone: 785-864-4095 TTY: 785-864-0706 Web: www.rtcil.org



