Shaping attitudes through person-first language

Journalists, public speakers, human service providers, educators and other communicators play a critical role in changing attitudes toward disability. This is not political correctness but a fundamental responsibility to communicate a straightforward image of people with disabilities or those with chronic health conditions.

Since 1984 the Research and Training Center on Independent Living (RTC/IL) has distributed more than 1 million copies of its groundbreaking style sheet, Guidelines for Reporting and Writing About People with Disabilities. With its succinct explanation of person-first language, the brochure has become the gold standard for describing disability issues in a way that does not perpetuate perceptions that can lead to discrimination.

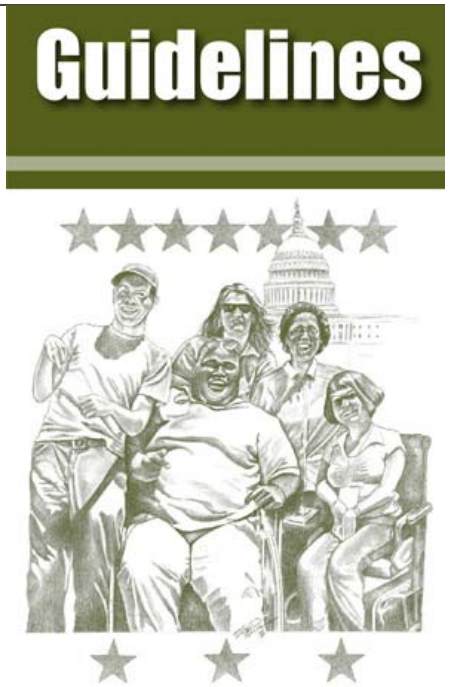
Developed with input from more than 100 national disability groups, the guidelines have been adopted by the Associated Press and the American Association for the Advancement of Science and are referenced in the American Psychological Association's Publications Manual 6th Edition.

The seventh edition of the Guidelines is now available, along with a poster called "Your Words, Our Image" which lists negative and positive terminology for describing people with disabilities – a quick reference useful for public display or in offices and classrooms.

"How authors, scientists and reporters write and report on people with disabilities has great influence on society's perceptions of this oft-forgotten demographic population," says Glen W. White, RTC/IL director. "'Your Words, Our Image is more than a slogan. It's a call to responsible and accurate portrayal that does not objectify or treat people with disabilities as mere human-interest stories. Rather, it focuses on the humanity of the individual and the fact that the experience of disability is a natural part of being human."

Download a PDF of the brochure

Order a printed copy of the brochure or poster



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A GREAT PLACE TO BE FOR RESEARCH

Guidelines

for Reporting and Writing about people with disabilities

Seventh Edition

Introduction

As writers, we should all strive for accuracy and use current terminology regarding people with disabilities. To do so otherwise is not only substandard journalism, it also can offend readers.

This revised *Guidelines for Reporting and Writing about People with Disabilities* explains preferred terminology and offers suggestions for accurate ways to describe people with disabilities.

Although opinions may differ on some terms, this booklet reflects input from more than 100 national disability organizations and has been reviewed and endorsed by media and disability experts throughout the country. Portions of the *Guidelines,* which originally were funded by the National Institute on Disability and Rehabilitation Research, have been adopted into the *Associated Press Stylebook*, a basic reference for professional journalists.

Please use the *Guideline*s when you write or report about people with disabilities. If you would like more information, additional copies of the Guidelines, or an attractive 18" x 24" poster of disability writing style do's and don'ts, contact the Research and Training Center on Independent Living at:

RTCIL Publications
1000 Sunnyside Avenue, 4089 Dole
University of Kansas
Lawrence, KS 66045-7555

You can also contact our Center by:

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Research and Training Center on Independent Living, University of Kansas. (2008). *Guidelines for reporting and writing about people with disabilities (7th Edition)*. Lawrence, KS: Author.

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Portrayal Issues

Please consider the following when writing about people with disabilities.

Do not focus on disability unless it is crucial to a story. Avoid tear-jerking human interest stories about incurable diseases, congenital impairments, or severe injury. Focus instead on issues that affect the quality of life for those same individuals, such as accessible transportation, housing, affordable health care, employment opportunities, and discrimination. People with disabilities actively participate in their communities and can participate even more when portrayed just like anyone else in the community.

Put people first, not their disability. Say *woman with arthritis, a child who has a learning disability,* or *person with a disability*. This puts the focus on the individual, not the particular functional limitation. Labeling the person as the disability (for example, a *quad*) dehumanizes the individual and equates the condition with the person. (However, note that some disability advocates use the term "disabled person" as part of a disability pride.) It is people first, too, for indicating disability groups. Say *people with cystic fibrosis* or *people who have cancer*. Terms such as "the_____ (for example, "the retarded") imply a homogenous group separate from society as a whole.

Do not portray successful people with disabilities as heroic overachievers or long suffering saints. Even though the public may find these portrayals inspirational, these stereotypes raise false expectations that all people—with and without disabilities— should be such "super humans."

Avoid sensationalizing and negative labeling. Saying *afflicted with, crippled with, victim of or suffers from* devalues individuals with disabilities by portraying them as helpless objects of pity and charity. It is more neutral to say an *individual with AIDS* than a *person who suffers from AIDS*. Similarly, do not use emotional descriptors such as *unfortunate* or *pitiful*.

Emphasize abilities, not limitations. For example, *uses leg braces* or *walks with crutches,* is more accurate than *confined to a wheelchair* or *wheelchair bound*. For, in reality, wheelchairs and crutches represent independence, not a burden. To emphasize capabilities, avoid words that start with *in, dis, un*, or *de* that imply lacking or inferiority such as *invalid* or *defective.*

Bypass condescending euphemisms. Disability groups also strongly object to the use of euphemisms to describe disabilities. Terms such as *handicapable, differently abled, special*, and *challenged* reinforce the idea that people cannot deal honestly with their disabilities.

Maintain the integrity of each individual. Do not use words or phrases regarded as offensive such as *freak, subnormal, vegetable, misshapen, feeble minded,* or *imbecile.*

Do not imply disease when discussing disabilities that result from a prior disease episode. People who had polio and experienced after effects have post-polio syndrome. They are not currently experiencing the disease. Do not imply disease with people whose disability has resulted from anatomical or physiological damage (for example, person with spina bifida or cerebral palsy). Reference to disease associated with a disability is acceptable only with chronic diseases, such as arthritis, Parkinson's disease, or multiple sclerosis. Individuals with disabilities should never be referred to as *patients* or *cases* unless their relationship with their doctor is under discussion, or if they are referenced in the context of a hospital or clinical setting.

Appropriate Terminology

Consensus-preferred terms for referring to disabilities are listed and defined below.

Accessible refers to accommodations for people who have a disability. Replace *disabled* or *handicapped* with *accessible* such as an *accessible parking space* rather than a *handicapped parking space*.

ADHD (Attention-Deficit Hyperactivity Disorder) is a syndrome of learning and behavioral problems characterized by difficulty in sustaining attention, impulsive behavior, and usually by excessive activity. Do not say *hyperactive*. Say *person with ADHD*.

Advocacy is an active process designed to make any social system more responsive to the needs of each individual participating in that sytem. Through advocacy, individuals with disabilities can communicate their needs and choices and participate in decision making that affects them.

Autism is considered to be a spectrum condition, as the symptoms may encompass a wide array of physical and behavioral anomalies. These conditions may be characterized by functional limitations in social interactions, language use and form, and repetitive actions. Effects can result in mild to severe impairment and can be mixed, that is, a person with severe limitations in one area, may have normal or even extraordinary capabilities in another. Do not say *autistic*. Say *person with autism*.

Blind describes a condition in which a person has loss of vision for ordinary life purposes. Visually impaired or living with vision loss are the generic terms used by some individuals to refer to all degrees of vision loss. Say *boy who is blind, girl who is visually impaired,* or *man who has low vision*.

Brain injury describes a condition where there is long-term or temporary disruption in brain function resulting from injury to the brain. Difficulties with cognitive, physical, emotional, and/or social functioning may occur. Do not say *brain damaged*. Say *person with a brain injury, woman who has sustained brain injury,* or *employee with an acquired brain injury*.

Chronic fatigue syndrome has been debated as the proper term to describe this specific chronic condition in which individuals experience six or more months of fatigue accompanied by physical and cognitive symptoms. *Chronic fatigue and immune dysfunction syndrome* today is currently preferred even though it does not adequately describe this condition, known as *myalgic encephalomyelitis* in Europe and by other terms, depending on region. Be sure to term this condition correctly. For example, *Yuppie Flu* implies personality disorders and is not scientifically supportable. Do not get it mixed up with overlapping or similar conditions such as *Epstein-Barr Virus Syndrome.*

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

Congenital disability describes a disability that has existed since birth but is not necessarily hereditary. The terms *birth defect* and *deformity* are inappropriate. Say *person with a congenital disability* or *disability since birth*.

Consumer has been used by many to refer to someone with a disability. The civil rights movement inspired the independent living movement of the 1970s that maintained people with disabilities were *consumers* of assistive services and had a responsibility to evaluate and control their services. On a similar note, some people prefer to be described as what they use to define themselves such as *wheelchair user, ventilator user,* or *mental health service user.*

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 term *hearing impaired*. Other terms in use include *deaf* or *hard of hearing* (which refers to a mild to moderate hearing loss that may or may not be corrected with amplification). Never use *deaf and dumb*. A person who has hearing difficulties may have speech difficulties, too, but deafness does not affect mental abilities. Say *woman who is deaf, boy who is hard of hearing,*

individuals with hearing loss, or *people who are deaf or hard of hearing*. As a group, this population typically refers to itself as *the Deaf* or *Deaf community* because it identifies with a specific community made up of those who share a common language (sign language) and culture; this is an exception to the people-first policy.

Developmental disability is any mental and/or physical disability starting before the age of 22 and continuing indefinitely. Examples include cerebral palsy, autism, sensory impairments, and intellectual disabilities.

Disability is a general term used for an attribute or 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 refer to people with disabilities as *the handicapped* or *handicapped persons* because *disability* and *handicap* are not interchangeable. *Handicap,* an archaic word, originally meant at a disadvantage and today indicates a barrier or source of limitation. So, a disability, the environment, or prejudice can be handicapping but the disability itself is not handicapping. Avoid using *the disabled* as a generic label because it has connotations of non-functioning (for example, *disabled car*); describes a condition and people are not conditions; and implies a homogenous group apart from the rest of society.

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

Down syndrome describes a chromosome disorder that causes a delay in physical, intellectual, and language development. *Mongol, mongoloid,* and *Down person* are unacceptable. Say *person with Down syndrome.*

HIV/ AIDS attacks the immune system's CD4 T-cells, which are essential to fighting off infection. Over time, HIV (human immunodeficiency virus) can weaken the immunity 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. Do not say *AIDS victim*. Say *people living with HIV, people with AIDS* or *living with AIDS.*

Independent living is a philosophy about having opportunities to make decisions that affect one's life, a civil rights movement of and for persons with disabilities for equal participation in community life, and a service system made up of centers for independent living (also known as independent living centers). These nonresidential resource centers on disability serve people with disabilities as well as the entire community. Their core services include advocacy, information and referral, independent living skills training, peer counseling, and most recently, deinstitutionalization of people with disabilities.

Learning disability describes a permanent neurological condition that affects the way individuals take in, retain, and express information. Some groups prefer *specific learning disability*, because it emphasizes that only certain learning processes are affected. Do not say *slow learner* or *retarded,* which are different from learning disabled. Say *person with a learning disability.*

Mental retardation refers to below-average intellectual functioning that requires environmental or personal supports to live independently and as a term, has fallen out of favor by those who have this condition, their families, and related organizations who prefer to use *intellectual disability* in place of *mental retardation*. *Developmental disability* has also been used to indicate *mental retardation,* but is not a precise match. Do not use *subnormal* or *the retarded.* Say *people with intellectual disabilities.*

Multiple chemical sensitivities describes a chronic condition characterized by neurological impairment, muscle pain and weakness, respiratory problems, and gastrointestinal complaints

triggered by contact with low level exposure to common substances including pesticides, new carpet, particleboard, cleaning agents, perfumes, and electromagnetic fields. Several terms have been applied to the syndromes these people with heightened reactivity to chemicals have experienced, including chemical hypersensitivity, environmental illness, chemical AIDS, 20th century disease, total allergy syndrome, sick building syndrome, chemophobia, immune dysregulation and others. People with this condition are not *neurotic* or *lazy* or experiencing a *psychosomatic* condition. Say *person with chemical intolerance* or *people with an environmental illness.*

Nondisabled is a term for people who do not have disabilities. *Normal, able-bodied, healthy*, or *whole* are inappropriate. Use *people without disabilities* to adhere to people-first language.

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

Psychiatric disability refers to a variety of psychological conditions. Use *psychotic, schizophrenic, neurotic*, and other specific terms only in proper clinical context for medical and legal accuracy. Note, too that *bipolar disorder* has replaced *manic depression*. Words such as *crazy, maniac, lunatic, demented, schizo,* and *psycho* are offensive and should never be applied to people with mental health problems. Acceptable terms include *psychiatric disabilities, psychiatric illnesses, emotional disorders,* or *mental disorders.*

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. The word *convulsion* should be used only for seizures involving contraction of the entire body. Do not use *fit, spastic,* or *attacks.* Rather than *epileptic,* say *girl with epilepsy* or *teen with a seizure disorder.*

Small/short stature describes a variety of genetic conditions causing people to grow under 4' 10" tall. Do not refer to these individuals as *midgets* because of its circus sideshow connotations. *Dwarfism* is an accepted medical term, but it should not be used as general terminology. Say *persons of short statur*e, although some consumer groups prefer *little people*.

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

Spinal cord injury describes a condition in which there has been permanent damage to the spinal cord. *Quadriplegia* denotes substantial or significant loss of function in all four extremities. *Paraplegia* refers to substantial or significant loss of function in the lower part of the body only. Say *man with paraplegia, woman who is paralyzed,* or *person with a spinal cord injury.*

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 *people who are alcohol dependent*. Individuals who have a history of dependence on alcohol and/or to drugs and are no longer using alcohol or drugs may identify themselves as *recovering* or as a *person in recovery* although this phrase may be considered a euphemism by some people.

Survivor is used by those affirming their recovery from or conquest of an adverse health condition such as *cancer survivor*, *burn survivor*, *brain injury survivor,* or *stroke survivor.*

On the cover: Original artwork by Skip Smith of Parsons, Kansas based on a photograph courtesy of the National Council on Independent Living (NCIL).
The Kansas Youth Empowerment Academy (KYEA) participates in the 2006 NCIL Annual Conference Rally on Capitol Hill. KYEA staff and supporters are: (left to right) Zach Coble, Shawn Bryant, Traci Turner, Julia Fonseca and Carrie Greenwood.

Note: Since its inception, over 1 million *Guidelines* have been distributed. The guidelines have been endorsed by hundreds of disability organizations. Endorsees for this edition include AIDS Action Council, American Cleft-Palate and Craniofacial Association, Association of Programs for Rural Independent Living, The Arc, Bazelon Center for Mental Health Law, Brain Injury Association of America, Delta Airlines, Goodwill Industries International, Institute on Independent Living, National Down Syndrome Congress, National Council on Independent Living, Post-Polio Health International, SARDI (Substance Abuse Resources and Disability Issues), TASH, Through the Looking Glass, and World Institute on Disability.

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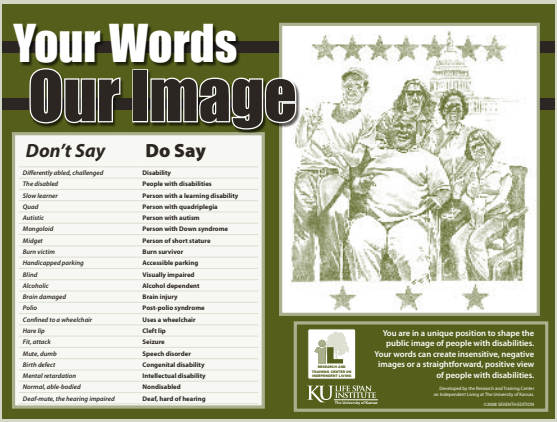

If you would like more information, additional copies of the Guidelines, or this attractive 18" x 24" poster of disability writing style do's and don'ts, contact the Research and Training Center on Independent Living at the address below.

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