Guidelines for Reporting and Writing about People with Disabilities



<u>APPROPRIATE TERMINOLOGY</u>: An alphabetical list arranged by appropriate terminology and usage

<u>PORTRAYAL ISSUES</u>: Overall do's and don'ts for writing about people with disabilities

Introduction

As professional communicators, educators, and human service providers, you are in a unique position to shape the public image of people with disabilities. The words and images you use can create either a straightforward, positive view of people with disabilities or an insensitive portrayal that reinforces common myths and is a form of

discrimination.

Here is a set of clear guidelines to help you make better choices in terms of language and portrayal. The *Guidelines* explain preferred terminology and offer suggestions for appropriate ways to describe people with disabilities. The *Guidelines* reflect input from over 100 national disability organizations and has been reviewed and endorsed by media and disability experts throughout the country.

Although opinions may differ on some terms, the *Guidelines* represent the current consensus among disability organizations. Portions of the *Guidelines* have been adopted into the *Associated Press Stylebook*, a basic reference for professional journalists.

Please use the *Guidelines* when you write or report about people with disabilities. If you would like more information, print copies of the *Guidelines*, or an attractive 18" x 24" poster of disability writing style do's and don'ts, contact:
Publications, Research and Training Center on Independent Living, 1000 Sunnyside Avenue, Room 4089 Dole, University of Kansas, Lawrence, KS 66045-7555. You can also contact

our Center by email at rtcil@ku.edu, phone: 785.864.4095, TTY: 785.864.0706, or by fax: 785-864-5063.

Information about the *Guidelines* is also listed in our free catalog (available by contacting the RTC/IL at the address above) and on the World Wide Web under http://www.rtcil.org

The RTC/IL acknowledges the National Institute on Disability Rehabilitation Research for providing funds to develop the first edition of the *Guidelines*. ©2001, SIXTH EDITION

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Appropriate Terminology

Reflecting input from more than 100 disability organizations, the preferred terms for referring to disabilities are listed and defined below.

ADHD (Attention Deficit Hyperactivity Disorder) is a syndrome of learning and behavioral problems that is not caused by any serious underlying physical or mental disorder and is characterized especially by difficulty in sustaining attention, impulsive behavior, and usually by excessive activity. Do not say hyperactive. Say person with ADHD.

Autism is a mental disorder originating in infancy that is characterized by absorption in self-centered subjective mental activity, especially when accompanied by marked withdrawal from reality, inability to interact socially, repetitive behavior, and language dysfunction. **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 is the generic term 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 boy with an acquired brain injury.**

Chronic Fatigue syndrome, also called chronic fatigue and immune dysfunction syndrome, describes a serious chronic condition in which individuals experience six or more months of fatigue accompanied by physical and cognitive symptoms. Do not use terms such as Yuppie Flu, malingering, and hypochondriasis as they are pejorative, imply personality disorders, and are not scientifically supportable. Say person with chronic fatigue 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 a 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.

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. These terms include people who are hard of hearing and deaf. However, some individuals completely disfavor the term hearing impaired. Others prefer to use deaf or hard of hearing. Hard of hearing refers to a mild to moderate hearing loss that may or may not be corrected with amplification. Say woman who is deaf, boy who is hard of hearing, individuals with hearing losses, people who are deaf or hard of hearing.

Developmental disability is any mental and/or physical disability starting before the age of 22 and continuing indefinitely. It limits one or more major life activities such as self-care, language, learning, mobility, self-direction, independent living, and economic self-sufficiency. This includes individuals with mental retardation, cerebral palsy, autism, epilepsy and other seizure disorders, sensory impairments, congenital disabilities, traumatic injuries, or

conditions caused by disease (polio, muscular dystrophy, etc.). It may also be the result of multiple disabilities. **Say person** with a developmental disability.

Disability is a general term used for a functional limitation that interferes with a person's ability, for example, to walk, lift, heal, or learn. It may refer to a physical, sensory, or mental condition. Do not refer to people with disabilities as the handicapped, handicapped persons, or special. Handicap can be used when citing laws and situations, but should never be used to describe a person or disability. **Say as a descriptive noun or adjective, such as person living with AIDS, woman who is blind, or man with a disability.**

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

Down syndrome describes a chromosome disorder that usually causes a delay in physical, intellectual, and language development. Usually results in mental retardation. Mongol, Mongoloid, and Downs child/person are unacceptable. **Say person with Down syndrome.**

HIV/AIDS acquired immunodeficiency syndrome is an infectious disease resulting in the loss of the body's immune system to ward off infections. The disease is caused by the human immunodeficiency virus (HIV). A positive test for HIV can occur without symptoms of the illnesses that usually develop up to 10 years later including tuberculosis, recurring pneumonia, cancer, recurrent vaginal yeast infections, intestinal ailments, chronic weakness and fever, and profound weight loss. Don't say AIDS victim. Say people living with HIV, people with AIDS or living with AIDS.

Learning disability describes a permanent 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, retarded, etc., which are different from learning disabilities. Say person with a learning disability.

Mental disability The Federal Rehabilitation Act (Section 504) lists four categories under mental disability: psychiatric disability, retardation, learning disability, or cognitive impairment as acceptable terms. Always precede these terms with, "person with..."

Mental retardation refers to substantial intellectual delay that requires environmental or personal supports to live independently. Mental retardation is manifested by belowaverage intellectual functioning in two or more life areas (work, education, daily living, etc.) and is present before the age of 18. Don't use subnormal or the retarded. Say people with mental retardation.

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, and perfumes. Some people react to foods and electromagnetic fields. Do not use psychosomatic or 20th Century disease. Say person with chemical intolerance or environmental illness.

Nondisabled is the appropriate term for people without disabilities. **Normal, able-bodied, temporarily able-bodied, healthy, or whole are inappropriate.**

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

Psychiatric disability psychotic, schizophrenic, neurotic, and other specific terms should be used only in proper clinical context and should be checked carefully for medical and legal accuracy. Words such as crazy, maniac, lunatic, demented, schizo, and psycho are offensive and should never be applied to people with mental health problems or anyone else. Acceptable terms are people with psychiatric disabilities, psychiatric illnesses, emotional disorders, or mental disorders.

Seizure describes an involuntary muscular contraction, a brief impairment or loss of consciousness, etc., resulting from a neurological condition such as epilepsy or from an acquired brain injury. The term 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 boy with a seizure disorder.**

Small/short stature describes people under 4'10" tall. Do not refer to these individuals as dwarfs or midgets, which implies a less than full adult status in society. Dwarfism is an accepted medical term, but it should not be used as general terminology. **Say persons of small (or short) stature. Some groups prefer the term "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 with no verbal speech capability, **say woman 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.

Stroke is caused by interruption of blood to the brain. Hemiplegia (paralysis on one side) may result. Stroke survivor or person who has had a stroke is preferred over stroke victim.

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. Substance dependence is generally characterized by impaired control over consumption, preoccupation with the substance, and denial of impairment in life areas. Substance dependence may include physiological dependence/tolerance withdrawal. 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. An individual who has

a history of dependence on alcohol and/or other drugs and is no longer using alcohol or drugs may identify themselves as recovering or as a person in recovery.

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.

DO NOT PORTRAY SUCCESSFUL PEOPLE WITH DISABILITIES AS SUPERHUMAN OR HEROES. Even though the public may admire superachievers, portraying people with disabilities as superstars raises false expectations that all people with disabilities should achieve this level.

DO NOT SENSATIONALIZE A DISABILITY by saying afflicted with, crippled with, suffers from, victim of, and so on. Instead, say person who has multiple sclerosis.

DO NOT USE GENERIC LABELS for disability groups, such as "the retarded," "the deaf." Emphasize people, not labels. Say people with mental retardation or people who are deaf.

PUT PEOPLE FIRST, not their disability. Say woman with arthritis, children who are deaf, people with disabilities. This puts the focus on the individual, not the particular functional limitation. Because of editorial pressures to be succinct, we know it is not always possible to put people first. If the portrayal is positive and accurate, consider the following variations: disabled citizens, nondisabled people, wheelchairuser, deaf girl, paralyzed child, and so on. Crippled, deformed, suffers from, victim of, the retarded, infirmed, the deaf and dumb, etc. are never acceptable under any circumstances.

Also, do not use nouns to describe people, such as epileptic, diabetic, etc.

EMPHASIZE ABILITIES, not limitations. For example: uses a wheelchair/braces, walks with crutches, rather than confined to a wheelchair, wheelchair-bound, differently-abled, birth difference, or crippled. Similarly, do not use emotional descriptors such as unfortunate, pitiful, and so forth.

DO NOT USE CONDESCENDING EUPHEMISMS.

Disability groups also strongly object to using euphemisms to describe disabilities. Terms such as handicapable, mentally different, physically inconvenienced, and physically challenged are considered condescending. They reinforce the idea that disabilities cannot be dealt with up front.

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 (e.g., 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. People with disabilities should never be referred to as patients or cases unless their relationship with their doctor is under discussion.

SHOW PEOPLE WITH DISABILITIES AS ACTIVE

participants of society. Portraying persons with disabilities interacting with nondisabled people in social and work environments helps break down barriers and open lines of communications.

Partial List of Endorsees

ACCENT ON LIVING MAGAZINE BLOOMINGTON, IL

ADVOCATES FOR CHILDREN NEW YORK, NY

ADVOCATES FOR PERSONS WITH DISABLING CONDITIONS IN ALLIED HEALTH CHICAGO, IL

	AIDS A	ACTION	COUNCIL	WASHINGTON,	DC
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AMERICAN ASSOCIATION FOR THE ADVANCEMENT OF SCIENCE WASHINGTON, DC

AMERICAN CLEFT PALATE-CRANIOFACIALASSOCIATION PITTSBURGH, PA

AMERICAN COUNCIL OF THE BLIND WASHINGTON, DC

 $\frac{\text{AMERICAN SPINAL INJURY ASSOCIATION CHICAGO,}}{\text{IL}}$

ARTHRITIS FOUNDATION ATLANTA, GA

COUNCIL FOR ADVANCEMENT & SUPPORT OF EDUCATION WASHINGTON, DC

DISABILITIES RESOURCES, INC. CENTEREACH, NY

DISABILITY RIGHTS EDUCATION AND DEFENSE FUND BERKELEY, CA

EPILEPSY FOUNDATION OF AMERICA LANDOVER, MD

GALLAUDET UNIVERSITY WASHINGTON, DC

GAZETTE INTERNATIONAL NETWORKING INSTITUTE (G.I.N.I.) ST. LOUIS, MO

GOODWILL INDUSTRIES INTERNATIONAL, INC. BETHESDA MD

HUNTINGTON'S DISEASE SOCIETY OF AMERICA, INC. NEW YORK, NY

JOSEPH P. KENNEDY, JR. FOUNDATION WASHINGTON, DC

LEARNING DISABILITIES ASSOCIATION OF AMERICA PITTSBURGH, PA

NATIONAL AMPUTATION FOUNDATION, I	NC.
MALVERNE, NY	

NATIONAL ATAXIA FOUNDATION MINNEAPOLIS, MN

NATIONAL BRAIN INJURY ASSOCIATION WASHINGTON, DC

NATIONAL CENTER FOR ENVIRONMENTAL HEALTH STRATEGIES, INC. VOORHEES, NJ

NATIONAL DOWN SYNDROME CONGRESS ATLANTA, GA

NATIONAL DOWN SYNDROME SOCIETY NEW YORK, NY

NATIONAL EMPOWERMENT CENTER, INC. LAWRENCE, MA

NATIONAL INFORMATION CENTER ON DEAFNESS WASHINGTON, DC

NATIONAL MENTAL HEALTH ASSOCIATION ALEXANDRIA, VA

NATIONAL ORGANIZATION ON DISABILITY WASHINGTON, DC

NATIONAL SPINAL CORD INJURY ASSOCIATION BETHESDA, MD

RRTC ON DRUGS AND DISABILITY WRIGHT STATE UNIVERSITY DAYTON,OH

THE Arc OF THE U.S. SILVER SPRING, MD

THE ASSOCIATION FOR PERSONS WITH SEVERE HANDICAPS (TASH) BALTIMORE, MD

THE CFIDS ASSOCIATION OF AMERICA CHARLOTTE, NC

RAGGED EDGE MAGAZINE (FORMERLY THE DISABILITY RAG & RESOURCE) LOUISVILLE, KY

THE KIDS ON THE BLOCK COLUMBIA, MD

VOLAR CENTER FOR INDEPENDENT LIVING EL PASO, TX

VSA arts WASHINGTON, DC

WORLD INSTITUTE ON DISABILITY OAKLAND, CA

For further information on disability research, training, dissemination, and utilization go to: http://www.getriil.org, http://www.getriil.org