

+ Words of Respect: Speaking of Disability

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Heartland Genetics Services Collaborative
Annual Conference





Research & Training Center on Independent Living, KU

Since 1980, enhancing the independence of people with disabilities through research and training. Cross-disability lines of focus:

- Community living and participation
- Emergency preparedness
- Media portrayal/advocacy



Promoting Person-First Language

8th Edition, 2013



You are in a unique position to shape the public image of people with disabilities. By putting the person first and using these suggested words, you can convey a positive, objective view of an individual instead of a negative, insensitive image.

Do say

Don't say

Disability	Differently abled, challenged
People with disabilities	The disabled, handicapped
Person with spinal cord injury	Cripple
Person with autism, on the autism spectrum	Autistic
Person with Down syndrome	Mongoloid
Person of short stature	Midget, dwarf
Uses a wheelchair, wheelchair user	Confined to a wheelchair, wheelchair-bound
Has a learning disability	Slow learner
Has chemical or environmental sensitivities	Chemophobic
Has a brain injury	Brain damaged
Blind, low vision	Visually handicapped, blind as a bat
Deaf, hard of hearing	Deaf-mute, deaf and dumb
Intellectual disability	Retarded, mental retardation
Amputee, has limb loss	Gimp, lame
Congenital disability	Birth defect
Burn survivor	Burn victim
Post-polio syndrome	Suffers from polio
Service animal or dog	Seeing eye dog
Psychiatric disability, mental illness	Crazy, psych, schizo
How should I describe you or your disability?	What happened to you?
Accessible parking or restroom	Handicapped parking, disabled restroom

Want more information?

Download our brochure *Guidelines: How to Write and Report About People with Disabilities* at www.totf.org/guidelines

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ON INDEPENDENT LIVING
Life Span Institute



How Should I Describe a Person with a Disability?

- As a person
- With respect
- In an objective manner





The Back Story: Words & Attitudes

pg. 25
**CRIPPLE A SUICIDE
BY FIRE IN QUEENS**

A crippled Queens woman, who neighbors said had been despondent recently, committed suicide by igniting her turpentine-soaked body yesterday morning, the police said.

Cripple, Using Cane To Drive Car, Kills Florida Policeman

ORMOND BEACH, Fla., March 28 (UPI)—A Daytona Beach policeman burned to death early today when his car was rammed by a vehicle driven by a crippled man who was using a cane to operate the gas and brake pedals.

New York Times, 1970

The Theater: 'Creeps'

Cripples' Plight Shown in Documentary Play

By CLIVE BARNES

The agonized impotence of cripples and their hopes for heroism and survival are the subject matter of a documentary-style play called "Creeps," which opened last night at Playhouse 2 on West 48th Street.

It has been written by David E. Freeman and is set in the men's washroom of a sheltered workshop for cerebral palsy victims in a large Canadian city. Mr. Freeman

The Cast

CREEPS, a play by David E. Freeman. Directed by Louis W. Scheeder; setting by David Chapman; movement consultant, Virginia Freeman; production stage manager, Bud Coffey. Presented by Orin Lehman, in association with the Folger Theater Group, Louis W. Scheeder, producer, Richmond Crinkley, founder. At Playhouse 2, West 48th Street.

Pete	Steven Gilborn
Michael	Philip Charles MacKenzie
Tom	Mark Melcalf
Sam	Bruce Weitz
Football Player	Richard Fancy
Astronaut	Stefan Peters
Girl	Ronni Richards
Master of Ceremonies	Philip C. MacKenzie
Jim	Richard DeFabees
Saunders	Robin Nolan
Puffo the Clown	Philip C. MacKenzie
Shriners	Stefan Peters, Ronald Corallian
Barker	Philip Charles MacKenzie
Carson	Peter Vogt
Voice of Thelma	Robin Nolan

too self-evident and there.

New York Times, 1973

+ A Civil Rights Movement



- The “Capitol Crawl” in March 1990 - seeking passage of the Americans with Disabilities Act
- The ADA became law in 1990, signed by Pres. George H.W. Bush.
 - Defines disability as a physical or mental impairment that substantially limits one or more major life activities.



Who Are People with Disabilities?

- The largest minority group in the United States (19%) – congenital or acquired.
- The only minority group that any person can join at any time.

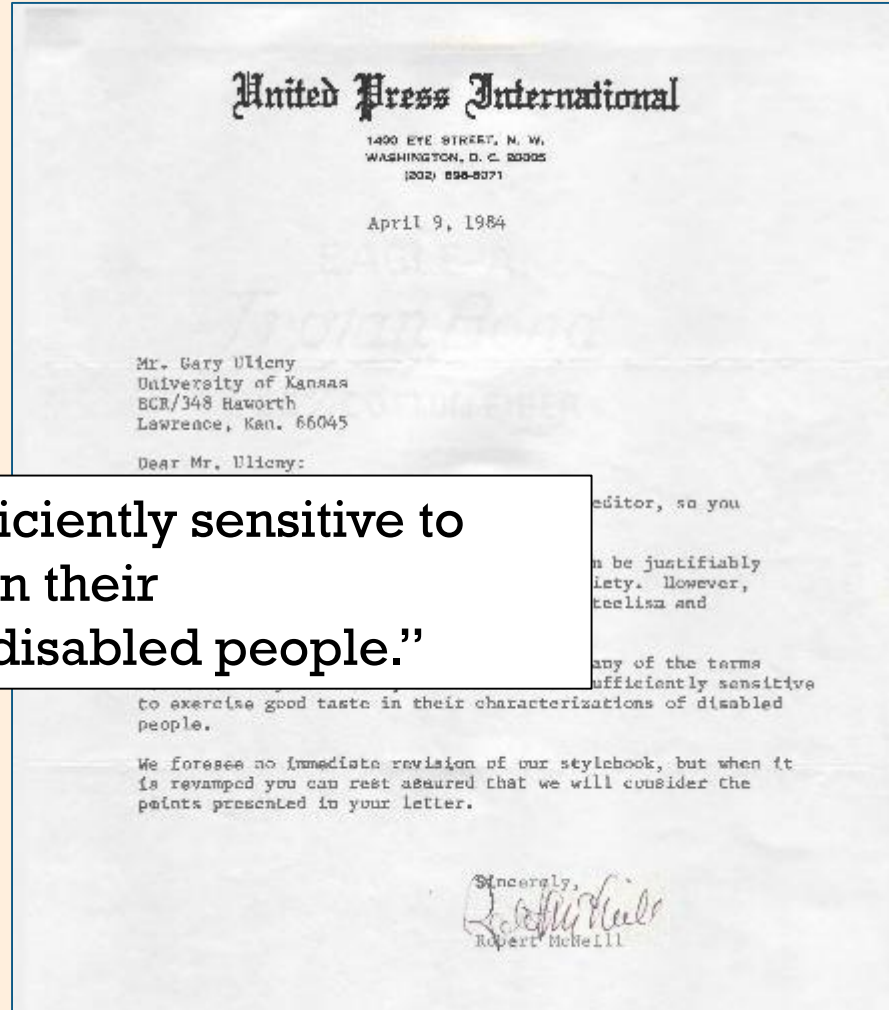




Changing the Language of Disability

- In the pre-ADA environment, media becomes a target
 - 1984 - first edition of *Guidelines for Reporting and Writing About People with Disabilities*”
- The Premise: Language influences perceptions and attitudes.
 - Writers, reporters and communicators in all fields have the power to shape the perceptions of their readers and listeners.
 - Objectivity is a key tenet of journalism.
 - Much of the language used to describe disability promotes negative images based in pity.

+ Politically Correct . . .



“Our editors are sufficiently sensitive to exercise good taste in their characterizations of disabled people.”

+ . . . Versus Just Correct

- Objective
- Fair
- Non-judgmental

AP Associated Press

Chris French
Stylebook Editor
April 27, 1984

Mr. Gary Olney
The Research & Training Center on Independent Living
University of Kansas
BCR/343 Haworth
Lawrence, Kansas 66045-2935

Dear Mr. Olney:

Thank you for letting The Associated Press look at your preliminary proposals on style in dealing with persons with disabilities.

I am circulating the project prospectus and guidelines among AP science and medical writers and others who are consulted in putting together the AP Stylebook.

The basic rule for editors and writers at AP is one which is cited at the beginning of the guidelines which you are considering. It is to use a reference to a person's race, religion, sex, politics, marital status or by extension disability only if it is necessary to the meaning of the story.

I will get back to you as soon as possible with the AP review and recommendations.

Sincerely,



/cfl

“I am circulating the project prospectus and guidelines among AP science and medical writers and others.”

50 Rockefeller Plaza, New York, N.Y. 10020 212 621-1615

THE ASSOCIATED PRESS
STYLEBOOK
AND LIBEL MANUAL

handicaps Use figures, hypercorrecting adjectival forms before a noun: *He has a 2 handicap; he is a 3-handicap golfer; a handicap of 2 strokes; a 3-stroke handicap.*

handicapped, disabled, impaired In general do not describe an individual as disabled or handicapped unless it is clearly pertinent to a story. If such a description must be used, make it clear what the handicap is and how much the person's physical or mental performance is affected.

Some terms include:

disabled A general term used for a condition that interferes with an individual's ability to do something independently.

Handicap It should be avoided in describing a disability.

blind Describes a person with complete loss of sight. For others use terms such as partially blind.

deaf Describes a person with total hearing loss. For others use partial hearing loss or partially deaf.

mute Describes a person who physically cannot speak. Others with speaking difficulties are speech impaired.

wheelchair-bound Do not use this or variations. A person may use a wheelchair occasionally or may have to use it for mobility. If it is needed, say why.

TER
T LIVING



Low hanging fruit –
victim language:
“Wheelchair-bound,”
“confined to a
wheelchair”

+ Objective description:
“Wheelchair user,”
“uses a wheelchair”



“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.’”

- Dot Nary, Ph.D.

+ A Change of Perspective



+ Portrayal Issues

- Put the person first
- Emphasize abilities
- Do not focus on disability
- Bypass condescending euphemisms
- Do not portray successful people with disabilities as heroic over-achievers or long-suffering saints
- Avoid sensationalizing and negative labeling
- Do not equate disability with illness
- Respect the person





“Beware the Scare Tactics: Stop Negative Portrayals of Disability in PSAs”

“Beware the Chair has it all wrong. Wheelchairs are not the enemy. Osteoporosis is the real enemy. But the problem is that even though Beware the Chair is supposedly trying to warn against neglecting bone health, its messaging is muddled and unclear. It portrays wheelchair use as the problem rather than osteoporosis.”

+ Person-first Language

- Puts the person before his or her disability
- Provides an objective description instead of a label
- Results in sentences that read:
 - A person with ...
or
 - S/he has ...



+ Change Takes Time

**Moron,
imbecile**



**Mentally
retarded**



**Intellectual
disability**

Parents welcomed
this change.

Advocates created
“Spread the Word
to End the Word”
campaign

+

Visual Language Is Changing, Too



New 'Handicapped' Symbol Featured At Museum Of Modern Art

+ As Is Visibility of PWD: Inclusion



+ One Key Concept in Disability Community

The Medical Model

- Disability needs to be fixed by expert
- Problem resides in the person
- Focus on the disability

The Social/IL Model

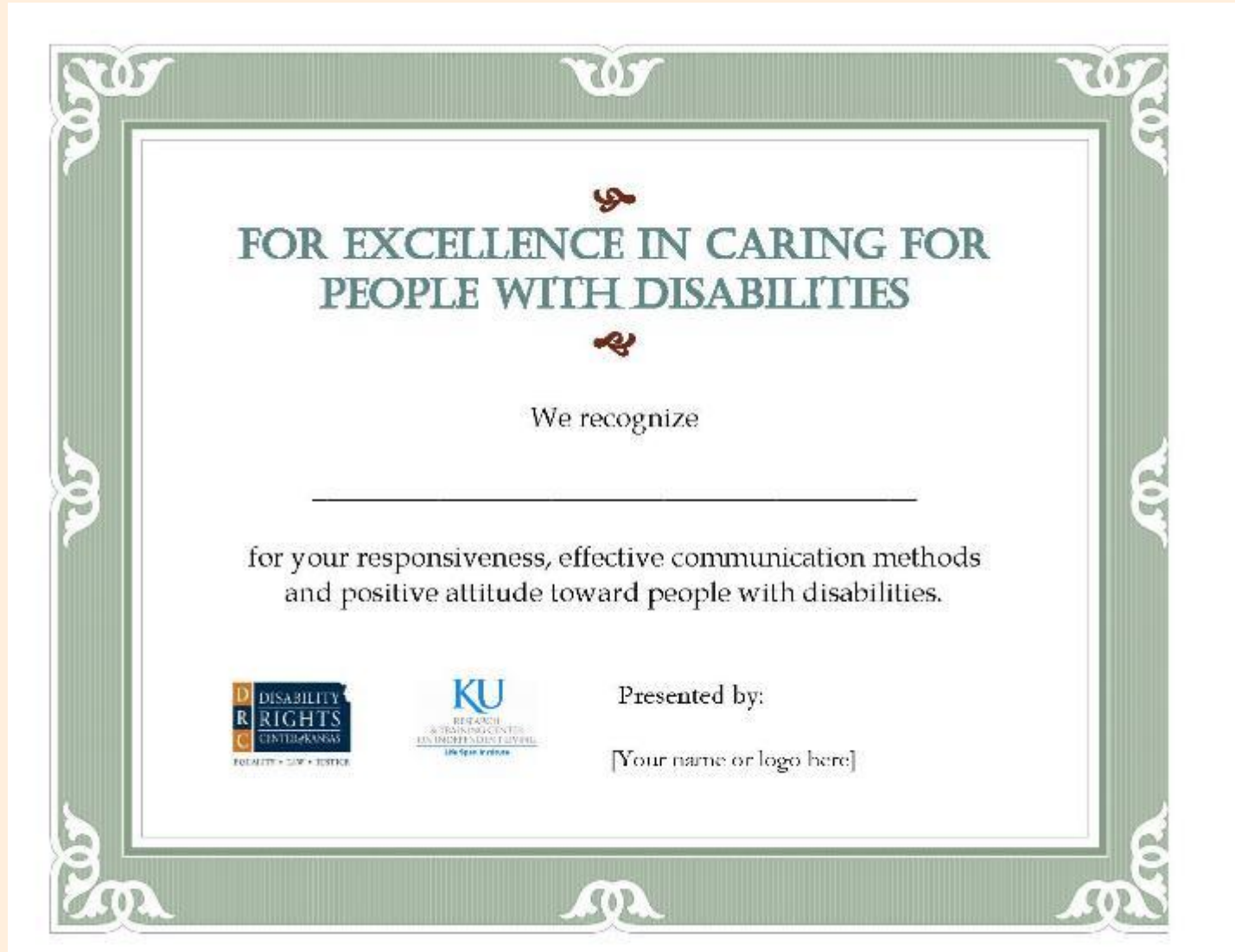
- Disability is a normal part of life
- Problems/barriers reside in the environment
- Focus on all aspects of health

+ Partnering with Health Care Providers

- People with disabilities (PWD) can be healthy(exercise, eating)
- Access – both physical and programmatic
- Communication – respect is all
 - Listening sessions with IDD and TBI populations



Resources for Health Care Access



+ Disability Training for Health Care Providers

- Kansas TRAIN: “Health Care Access for Persons with Disabilities” (ks.train.org, Course #1025624, free or \$10 for one CEU/CNE)
- KU School of Nursing online graduate-level course: “Caring for People with Disabilities”

+ The Wisdom of Youth

“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.”

– Nick Marcellino, age 9

+ For More Information:

- rtcil.org/guidelines *and* resources for health care providers

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- National Center on Disability and Journalism - <http://ncdj.org/style-guide/>
- Reporting on Mental Health – <http://www.eiconline.org/teamup/for-journalists/>
- “Stop Saying 'Wheelchair-Bound' And Other Outdated And Offensive Terms To People With Disabilities”
http://www.huffingtonpost.com/2013/11/01/how-to-talk-to-person-with-disability_n_4191830.html?ncid=edlinkusaolp00000003

+ What Do You See?



+ Rosa's Law and the Language of Bullying





A Few Exceptions (I HAVE said something wrong!)

- Deaf/deaf
- Disability humor
- Identity language and disability pride:
“I am autistic!”



+ People with Disabilities CAN Be Healthy

- Ways health care providers can improve communication with PWD
 - Speak to the patient/PWD, not the support person
 - Use alternate formats for patient education: large print, audio discs, video relay for ASL
 - Customize messages. Brain injury survivors appreciate text and phone messages to confirm appointments, information that is clearly broken into small segments, slow speech with clear enunciation
- Ways to improve facility/service access
 - Height-adjustable exam tables
 - Accessible scales