Words of Respect: Speaking of Disability

Val Alexander Renault
May 1, 2015
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
Guidelines:
How to Write and Report About People with Disabilities

Based on a national survey of disability organizations

8th Edition

Promoting Person-First Language


Do say
Disability
Person with disabilities
Person with spinal cord injury
Person with autism, on the autism spectrum
Person with Down syndrome
Person of short stature
Uses a wheelchair
Has a learning disability
Has chemical or environmental sensitivities
Has a brain injury
Blind, low vision
Deaf, hard of hearing
Intellectual disability
Amputee, has limb loss
Congenital disability
Burn survivor
Post-polio syndrome
Service animal or dog
Psychiatric disability, mental illness
How should I describe you or your disability?
Accessible parking or restroom

Don’t say
Differently abled, challenged
The disabled, handicapped
Cripple
Autistic
Mongoloid
Midget, dwarf
Confined to a wheelchair
SLOW learner
Chemophobic
Brain damaged
Visually handicapped, blind as a bat
Deaf-mute, deaf and dumb
Retarded, mental retardation
Gimp, lame
Birth defect
Burn victim
Suffers from polio
Seeing eye dog
Crazy, psycho, schizo
What happened to you?
Handicapped parking, disabled restroom

Want more information?
Download our brochure Guidelines: How to Write and Report About People with Disabilities at www.rtcil.org/guidelines

Research and Training Center on Independent Living
The University of Kansas
4800 Evergreen
Lawrence, KS 66045-1060
E-mail: rtcil@ku.edu
Phone: 785-864-0500
Toll free: 800-864-0765
Web: www.rtcil.org

©2013 KU Research and Training Center 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

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

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.

New York Times, 1973

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 and

too self-evident and there-

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 Metcalf
Sam .............. Bruce Weltz
Football Player .......... Richard Fancy
Astronaut .......... Stefan Peters
Girl ............... Ronni Richards
Master of Ceremonies: Phillip C. MacKenzie
Jim ................... Richard DeFaebees
Shriners .......... Philip C. MacKenzie
Sauders ............ Phillip Nolan
Puffo the Clown Franklin C. MacKenzie
Shrinkers .......... Stefan Peters, Ronald Corallian
Barker ............. Phillip Charles MacKenzie
Carson ............. Peter Vogt
Voice of Thelma ........... Robin Nolan

New York Times, 1973
A Civil Rights Movement

- The “Capitol Crawl” in March 1990 - seeking passage of the Americans with Disabilities Act

  - 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.
"Our editors are sufficiently sensitive to exercise good taste in their characterizations of disabled people."
“I am circulating the project prospectus and guidelines among AP science and medical writers and others.”
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 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

FOR EXCELLENCE IN CARING FOR PEOPLE WITH DISABILITIES

We recognize

for your responsiveness, effective communication methods and positive attitude toward people with disabilities.

Presented by:

[Your name or logo here]
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”
“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
  Val Alexander Renault
  Communications Coordinator
  Research and Training Center on Independent Living (RTC/IL)
  The University of Kansas
  4089 Dole Center
  1000 Sunnyside Ave.
  Lawrence, KS 66045
  785-864-0575
  vrenault@ku.edu

- 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”
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