

**CE** 1.5  
HOURS



# Communicating Respectfully

## With People Who Have Disabilities

*Respectful communication with people who have disabilities is essential to providing superior care. Knowing exactly how to do this, however, can be confusing for some healthcare providers. The purpose of this article is to provide the clinician with resources using a case scenario.*



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Sally, a registered nurse with 20 years of home care experience, visits the home of Jake, a 15-year-old teenager with multiple pressure ulcers caused by complications from spina bifida. For the first 10 minutes of her visit, Sally speaks only to Jake's mother. Jake's mother then asks Sally if she has any experience caring for people with disabilities. Sally replies, "Oh, sure. I have taken care of many paras, quads, and cerebral palsy children throughout the years. I have also cared for stroke victims and many other handicapped patients." Moments after her answer, Sally accidentally drops her notebook and spills papers on the floor. Embarrassed, Sally states, "Oh, I am so sorry, I am just so retarded sometimes." Jake's mother then abruptly asks Sally to leave their home. Within minutes after Sally's departure, Jake's mother calls the agency to request that Sally never return.

What could Sally have done differently?

What Sally did not realize is that much of her communication was not only outdated but also offensive. According to the 2005 U.S. Surgeon General Call to Action to Improve the Health and Wellness of Persons with Disabilities (U.S. Department of Health and Human Services, Office of the Surgeon General, 2005), the educational preparation of healthcare providers like Sally is insufficient. With more than 18.7% of noninstitutionalized civilian Americans with a disability, the importance of adequate training for home healthcare clinicians is clear (Brault, 2010; U.S. Department of Health and Human Services, Office of the Surgeon General, 2005). Fortunately, there are several resources available to clinicians to guide respectful communication with individuals with disabilities. These resources, commonly used by journalists, researchers, educators, and lawmakers, can be used by all healthcare providers to guide respectful communication.

### Guidelines: How to Write and Report About People With Disabilities

A resource commonly used by journalists is *Guidelines: How to Write and Report About People With Disabilities*, also known as, *Guidelines* (University of Kansas, Research and Training Center on Independent Living, 2013a). Currently in its eighth edition, it's an easy-to-read 13-page pamphlet that assists members of the media to provide unbiased reporting. Written by the University of Kansas, Research and Training Center on Independent Living, *Guidelines* was first published in 1984 with the approval from more than 100 disability advocacy groups.

The current edition of *Guidelines* includes a description of people-first language. The premise of people-first language is that the person should be described first and any disability or diagnosis second. For example, instead of saying "cerebral palsy children," it would be more respectful to say "children with cerebral palsy." The same is true for terms such as "paras" and "quads." Describing people in this way devalues their existence. Certainly, saying "people with paraplegia" or "people with quadriplegia" would be more professional and respectful (Box 1). The idea behind the language choice is that a person should not be defined by his or her disability or diagnosis. The person is a valued individual first whose disability is only a part of their identity.

The *Guidelines* also contain information on how to avoid referring to a group of people in a way that implies that the group is excluded from society. For example, it is better to say "people with disabilities" instead of "the disabled." Similarly, it is better to say "people with mental illness" instead of "the mentally ill."

### American Psychological Association Guidelines

Another resource available to clinicians is the sixth edition of the *Publication Manual of the American Psychological Association*, also known as APA guidelines (American Psychological Association, 2010). Because avoiding negative bias is essential to professional writing, APA guidelines contain specific instructions about how to avoid this when writing about people with disabilities. In addition to recommending people-first language, these guidelines provide guidance on avoiding negative tone. For example, writing "stroke victim" can evoke unnecessary negativity and pity for an individual. A more straightforward and professional option would be to say, "a person who had a stroke."

### Holistic Nursing Theory

Clinicians can also turn to nursing theory to assist in guiding respectful communication with individuals who have disabilities. Although there are many nursing theorists who describe care of the "whole person," Madeline Leininger's theory of culture care states that the person's culture should be respected and integrated into care. If care is provided without regard to a patient's or family's values, health can be impeded (Leininger, 1985). Considering those with disability as a cultural group can assist clinicians to incorporate the communication

## Box 1. Tips for Respectful Communication

Less Respectful	More Respectful
The disabled.	People with disabilities.
She is a para.	She has paraplegia.
He is a quad.	He has quadriplegia.
He is down's. He is a down's baby.	He has down syndrome.
She is a diabetic.	She has diabetes.
He is a schizophrenic.	He has schizophrenia.
She suffers from depression.	She has depression.
He is afflicted with ALS.	He has ALS.
He is a stroke victim.	He is a stroke survivor. He had a stroke.
The boy suffers from spina bifida.	The boy has spina bifida.
He is wheelchair bound.	He uses a wheelchair.
Normal/healthy.	Typical.
The girl is mentally retarded.	The girl has an intellectual disability. The girl has a developmental disability. The girl has a learning disability.
He is handicapped.	He has a disability.
Congenital deformity or birth defect.	Congenital disability.
Handicapped parking.	Accessible parking.

ALS = amyotrophic lateral sclerosis.

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patterns that are considered respectful by disability advocacy groups. For example, most disability advocates encourage asking a person or family member regarding preferred language (United Spinal Association, 2009).

## Disability Etiquette: Tips on Interacting With People With Disabilities

Published by the United Spinal Association in 2009, *Disability Etiquette: Tips On Interacting With People With Disabilities* contains several recommendations that clinicians can incorporate into care. For example, when speaking to an individual with a disability, it is important to speak directly with the individual and not a caregiver, a family member, or an interpreter. The publication also describes several outdated terms such as “handicapped” and “crippled.” Use of these terms conveys a negative tone, which can be perceived as disrespectful.

## The R-Word Campaign

The R-Word Campaign, started in 2004 by Special Olympics, was created “at the request of athletes with intellectual disabilities who were uncomfortable being called mentally retarded” (History of the R-Word Campaign, n.d.). In recent years, the connotation attached to the term “retarded” has become negative because it undermines individuals with intellectual and developmental disabilities. The campaign includes public service announcements and publicity via the Special Olympics network of athletes, families, and volunteers.

## Rosa’s Law

On October 5, 2010, President Barack Obama signed S2781, Rosa’s Law, which removed the phrases “mentally retarded” and “mental retardation” from federal law language. Rosa’s Law replaced these terms with “intellectual disability” and “intellectual disabilities.” This affects several previously passed federal laws including the Individuals with Disabilities Education Act and the Rehabilitation Act of 1973. The premise behind the law is that negative terms in laws can affect how individuals with disability are perceived and treated. Medical coding standards were also updated during this time. For example, in the October 2011 revision of the *International Classification of Diseases* (ICD-9), the description of *mental retardation* was changed to *intellectual disability* (U.S. Department of Health and Human Services, National Center for Health Statistics, National Centers for Disease Control and Prevention, and Centers for Medicare & Medicaid Services, 2011). Similar changes occurred with the recent release of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-V). New diagnosis code descriptions of *intellectual developmental disorder* and *intellectual disability* replace *mental retardation* (American Psychiatric Association DSM-V Development, 2012). (American Psychiatric Association DSM-5 Development, 2012).

## Implications for Practice

It is important for home healthcare clinicians to remain current in understanding what people with disabilities and their families expect and deserve in terms of respectful communication. Educating clinicians about professional and respectful communication is an essential component of patient satisfaction. Managers and educators can assist in this effort by taking a proactive approach by incorporating these expectations into orientation programs. Use of short and easy-to-read written mate-

## Box 2. Suggested Online Resources

### **Guidelines: How to Write and Report About People With Disabilities, 8th edition**

<http://rtcil.org/documents/Guidelines%208th%20ed.pdf>

### **Disability Etiquette**

<http://www.unitedspinal.org/pdf/DisabilityEtiquette.pdf>

### **Leininger's Culture Care Theory**

<http://nursing-theory.org/theories-and-models/leininger-culture-care-theory.php>

### **The R-Word Campaign**

<http://www.r-word.org/>

### **Rosa's Law**

<http://abcnews.go.com/WN/person-week-marcellinos-celebrate-signing-rosas-law/story?id=11823803>

rials supplemented by the additional resources listed in Box 2 can provide the clinician with effective tools that promote superior patient care.

*In response to the concerns voiced by Jake's mother, Sally received training on how to respectfully communicate with individuals with disabilities. Today, she is visiting the home of Mark, a 17-year-old teenager with multiple pressure ulcers caused by complications from a previous spinal cord injury. Throughout the visit, Sally speaks directly to Mark when she has questions regarding his health history. During the visit, Mark's mother asks Sally if she has any experience caring for people with disabilities. Sally replies, "Oh, sure. I have taken care of people with quadriplegia, paraplegia, and cerebral palsy throughout the years. I have also helped many people recover after having a stroke. Moments after her answer, Sally accidentally drops her notebook and spills papers on the floor. Embarrassed, Sally states, "Oh, I am so sorry, I am just so clumsy sometimes." ■*

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The author and planners have disclosed that they have no financial relationships related to this article.

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DOI:10.1097/01.NHH.0000436219.02714.3a

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