People first language

- For people with disabilities, the custom once was to give the disability first: A crippled person. A deaf-mute person.
- Sometimes the person even disappeared altogether. The identifying words then were “a cripple” or “a deaf-mute.”
- We now say “A person with a disability” not “a disabled person.”
- “People first language” has been important in the civil rights movement of people with disabilities.

Language guidelines

These guidelines can help us choose words that convey positive images:

- Refer to the person first, not the disability. John is a person with learning disabilities; he is not “learning disabled.”
- Avoid grouping individuals together into categories such as “the handicapped,” “the blind,” or “the retarded.”
- “Handicapped” is an archaic term that evokes negative images of pity, fear, and more. It’s no longer used in any federal legislation.
- The term used for something that has been modified to make it usable by all is “accessible.” Say “accessible parking” not “handicapped parking.”
- When describing a person’s disability, avoid labels, abbreviations of labels, and acronyms. “He’s a quad” is disrespectful and implies that a person’s entire existence is defined by his diagnosis.
- A person “uses” a wheelchair, rather than is “confined to” or “restricted to” a wheelchair.
- Language that refers to “normal” functioning implies that a person with a disability can only be considered “abnormal.” Refer to a “person without a disability” rather than “normal” person.
- Most people would prefer not to be described by their problems, so avoid the expression “has a problem with....” It’s friendlier to say “needs help with....”

Health status disparities

- Obesity.
- Higher rate of diabetes.
- Increased risk of cardiovascular disease.
- Inadequate emotional support (correlates with poorer quality of life and mental health problems).
- Higher rate of chronic pain.
- Higher rate of osteoporosis.
- Increased risk of seizures.
- More mental illness and behavior disorders.
- More hearing and vision problems.

Healthcare disparities

- Too few primary care providers receive adequate training.
- Providers with appropriate training find few financial incentives to ensure appropriate health care.
- Less likely to receive appropriate and adequate treatment.
- Fewer routine health examinations and immunizations, less mental health care, and less oral health care.
- Lower rates of breast and cervical cancer screening.
- Those with communication difficulties at risk for overmedication.
- Communication disparities for people with vision, hearing, and intellectual disabilities.
- Primary care settings often lack adaptive equipment, such as accessible examination tables.
- Few developmentally-appropriate educational materials
- American health research often bypasses this population.
Tips for providers

Here are some tips from experienced healthcare providers:

“They need to see us as people first, with health issues like any other person” (Waisman Center, 2003).

- Realize that a clinic visit for a person with a developmental disability will take more time.
- Use your best clinical skills—and slow down.
- Don’t assume level of intellectual functioning based on appearance.
- Learn the principles of People First language and other language guidelines.
- Speak in a normal voice.
- Speak directly to the person; use simple sentences.
- Ask questions one at a time; ask a question in several different ways when you’re not sure of the answer.
- Ask the person to repeat if you don’t understand what was said.
- If you still don’t understand, go back to “yes” and “no” questions.
- Be aware that many people with developmental disabilities have not been taught anatomical names for body parts so they may not have any words to use—or they may use slang.
- Use demonstrations and repetitions in your explanations.
- Families, guardians, or support brokers may keep a comprehensive and complete health summary beginning at birth. Sometimes the medical clinic only has portions of the record.
- Introduce yourself to the person accompanying the patient, and find out their role in the patient’s life.
- Find out who knows the most about the person’s health and health history and get a signed release to speak to that person.

Tips for providers

A woman with cerebral palsy:

“There was a time when I could get on an examining table and position myself, but the older I get the more difficult it becomes.”

“I don’t think the doctor realizes what a big deal it is for someone with CP to have a CAT scan. It takes a lot of effort. In the last couple of years, holding still has become really difficult. It helps if the nurse or technician reminds me to breathe at a regular pace, or to hold my breath for something really quick. It also helps if they prop me with sandbags to stabilize me.

“On the other hand, people with CP are often denied diagnostic processes such as mammograms and pelvic exams because doctors and technicians seem to feel they wouldn’t be able to do it. They don’t even think about accommodations that could be made.”

A nurse practitioner:

- Conduct a physical examination even if your facility does not have a specialized examining table. Problem-solve with the patient and support provider about how to complete it.
- Modify the clinic physical environment. For example, install motorized examination tables that lower for wheelchair transfers.
- Train staff to assist with transfers and support people during procedures.

Involve all stakeholders in the planning and evaluation.

Encore Studio for the Performing Arts. Photographs provided by Kelsy Schoenhaar, Executive/Artistic Director. For information, go to http://www.encorestudio.org/

Phil Porter Art. To read about Phil and see his vibrant paintings, go to http://www.philporterart.com/
Health Care Tool Kit

This resource kit from the Wisconsin Council on Developmental Disabilities supports a system of communication between adult consumers, health care providers, and support personnel. The forms and materials enable the tracking of health care concerns and interventions. It prepares the individual for their visit to health care providers and prompts the provider to be more responsive to the consumer. It includes forms for emergency situations. You may purchase one copy or a camera-ready copy for duplicating. To order, go to: http://www.wcdd.org/publications2/pub_all_details.cfm?pubID=50

Nursing organizations

- Developmental Disabilities Nurses Association [www.ddna.org](http://www.ddna.org)
  A nonprofit nursing organization, founded to meet the professional needs of nurses serving individuals with developmental disabilities. Exists to provide opportunities for exploration of common issues and concerns, education and professional recognition to those nurses in the life of individuals with developmental disabilities.

- International Society of Nurses in Genetics [www.isong.org](http://www.isong.org)
  A global nursing specialty organization dedicated to fostering the scientific and professional growth of nurses in human genetics and genomics worldwide. The mission of ISONG is to foster the scientific, professional, and personal development of members in the management of genomic information.

- Association of Rehabilitation Nurses [www.rehabnurse.org](http://www.rehabnurse.org)
  ARN's mission is to promote and advance professional rehabilitation nursing practice through education, advocacy, collaboration, and research to enhance the quality of life for those affected by disability and chronic illness.

- American Psychiatric Nurses Association [www.apna.org](http://www.apna.org)
  The American Psychiatric Nurses Association, APNA, is a professional membership organization of nearly 5,000 members committed to the specialty practice of psychiatric mental health nursing, health and wellness promotion through identification of mental health issues, prevention of mental health problems and the care and treatment of persons with psychiatric disorders.

Disability Information

  This organization, formerly known as the American Association on Mental Retardation, is the oldest and largest interdisciplinary organization of professionals (and others) concerned about mental retardation and related disabilities. AAIDD promotes progressive policies, sound research, effective practices and universal human rights for people with intellectual and developmental disabilities.

- The American Council for the Blind. [www.acb.org](http://www.acb.org)
  This is a national organization established to promote independence, dignity and well being of blind and visually impaired people. The Council helps to improve the lives of people who are blind by working to enhance civil rights, employment, rehabilitation services, safe and expanded transportation, travel and recreation, accessibility and working in coalition with other disabilities groups.

- The Arc of the United States. [www.thearc.org](http://www.thearc.org)
  The Arc is the world's largest grassroots organization of and for people with intellectual and developmental disabilities. With over 140,000 members affiliated through more than 850 state and local chapters across the nation, The Arc is devoted to promoting and improving supports and services for all people with intellectual and developmental disabilities. The website offers excellent information about resources and links to other websites.

- Autism Society of America [www.autism-society.org](http://www.autism-society.org)
  This organization was founded in 1965 by Bernard Rimland, Ph.D. It continues to be dedicated to increasing public awareness about autism and the day-to-day issues faced by individuals with autism, their families and the professionals with whom they interact. The Society and its chapters share a common mission of providing information and education, and supporting research and advocating for programs and services for the autism community.
Better Hearing Institute (BHI) – www.betterhearing.org
This Institute implements national public information programs on hearing loss and available medical, surgical hearing aids and rehabilitation assistance for millions with uncorrected hearing problems. BHI maintains a toll-free “Hearing Help Line” telephone service that provides information on hearing loss and also provides materials and assistance to individuals wishing to start a local support group.

Epilepsy Foundation of America www.efa.org
The organization was founded in 1968 to provide advocacy, education and awareness for and about adults and children with seizures. Accurate and up-to-date information about epilepsy, its treatment and the impact it has on daily life is available through the web site.

Family village – www.familyvillage.wisc.edu
Search engine on various disabilities, supports, services, literature, education

United Cerebral Palsy – www.ucpa.org
Website with information and referral, legislative advocacy, technology initiatives and research for people with cerebral palsy and other disabilities. UCP has over 150 affiliates in 43 states.

The National Institute of Neurological Disorders and Stroke (NINDS). http://www.ninds.nih.gov/about_ninds
Website for NINDS has excellent information on specific neurological disorders. Staff in this institute conducts and supports research on brain and nervous system disorders. Created by the U.S. Congress in 1950, NINDS is one of the more than two dozen research institutes and centers that comprise the National Institutes of Health (NIH).

The National Organization for Rare Disorders (NORD). www.rarediseases.org
NORD is a unique federation of voluntary health organizations dedicated to helping people with rare "orphan" diseases and assisting the organizations that serve them. NORD is committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and service. Through the webpage, there is access to a rare diseases database, national organization database, medication assistance program and equipment exchange.

The National Alliance on Mental Illness (NAMI). www.nami.org
This non-for-profit agency is the nation’s largest grassroots mental health organization dedicated to improving the lives of persons living with serious mental illness and their families. The website provides families and individuals who have mental illness with information on support, court rulings, advocacy friends and links to other sites that provide useful information.

National Down Syndrome Society www.ndss.org
Started in 1979, the mission of NDSS is to benefit people with Down syndrome and their families through national leadership in education, research and advocacy. The website has excellent information related to Down Syndrome related to education, research, advocacy and history of the discovery of the syndrome.

The National Fragile X Foundation. www.nfxf.org
The website provides information to families, people who have fragile X, educator and health care providers about national policy issues, advocacy issues, support groups, medications and other issues relevant to those with fragile X syndrome and for those who support them.

The National Organization on Fetal Alcohol Syndrome (NOFAS). http://www.nofas.org
This nonprofit organization was founded in 1990 dedicated to eliminating birth defects caused by alcohol consumption during pregnancy and improving the quality of life for those individuals and families affected by FAS. NOFAS is the leading voice and resource of the Fetal Alcohol Spectrum Disorders (FASD) community. The website provides excellent information on FAS for individuals with FAS and their families, educators, health care providers and the general public.

TASH. www.tash.org. This is a civil rights organization for, and of, people with mental retardation, autism, cerebral palsy, physical disabilities and other conditions that make full integration a challenge. It is an international membership association leading the way to inclusive communities through research, education, and advocacy. TASH members are people with disabilities, family members, fellow citizens, advocates, and professionals working together to create change and build capacity so that all people, no matter their perceived level of disability, are included in all aspects of society.
References


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