To ensure Inclusion, Freedom, and Respect for all, it's time to embrace

People First Language

by Kathie Snow, www.disabilityisnatural.com

Did you know that people with disabilities constitute our nation's largest minority group (one in five Americans has a disability)? It is also the most inclusive and most diverse group: all ages, genders, religions, ethnicities, sexual orientations, and socioeconomic levels are represented.

Contrary to conventional wisdom, individuals with disabilities are not:

- People who *suffer* from the *tragedy* of *birth defects.*
- *Paraplegic heroes* who *struggle* to become *normal* again.
- *Victims* who *fight* to *overcome* their *challenges.*

Nor are they the *retarded, autistic, blind, deaf, learning disabled,* etc.—*ad nauseam!*

They are *people:* moms and dads; sons and daughters; employees and employers; friends and neighbors; students and teachers; scientists, reporters, doctors, actors, presidents, and more. People with disabilities are people, *first.*

> ***The difference between the right word and the almost right word is the difference between lightning and the lightning bug.***
> Mark Twain

They do not constitute the stereotypical perception: a homogenous sub-species called "the handicapped" or "the disabled." They are unique individuals.

The only thing they may have in common with one another is being on the receiving end of societal misunderstanding, prejudice, and discrimination. Furthermore, this largest minority group is the only one which *any person can join at any time:* at birth or later—through an accident, illness, or the aging process. When it happens to *you,* will you have more in common with others who have disability diagnoses or with family, friends, and co-workers? How will you want to be described and how will you want to be treated?

What *is* a Disability?

Is there a universally-accepted definition of disability? No! First and foremost, a disability descriptor is simply a *medical diagnosis,* which may become a *sociopolitical passport* to services or legal status. Beyond that, the definition is up for grabs, depending on which service system is accessed. The "disability criteria" for early intervention is different from early childhood, which is different from vocational-rehabilitation, which is different from special education, which is different from worker's compensation, and so on. Thus, "disability" is a *social construct,* created to identify those who may be entitled to services or legal protections due to *characteristics* related to a medical condition.

—The Power of Language and Labels—

Words are powerful. Old, inaccurate descriptors and the inappropriate use of medical diagnoses perpetuate negative stereotypes and reinforce a significant and an incredibly powerful attitudinal barrier. And this invisible, but potent, force—not the diagnosis itself—is the *greatest obstacle* facing individuals who have conditions we call disabilities.

When we see the diagnosis as the most important characteristic of a person, we devalue her as an individual. Do *you* want to be known for your psoriasis, gynecological history, the warts on your behind, or any other condition?

Unfortunately, disability diagnoses are often used to define a person's value and potential, and low expectations and a dismal future may be the predicted norm. A person's diagnosis is often used to decide how/where the person will be educated, what type of job he will/won't have, where/how he'll live, and more, including what services he is thought to need.

With the best of intentions, we work on people's bodies and brains, while paying scant attention to their hearts and minds. And far too often, the "help" provided can actually cause harm—*and can ruin people's lives.* For "special" services frequently result in the social isolation and physical segregation of children and adults: in special ed classrooms, congregate living quarters, day programs, sheltered work environments, segregated recreational activities, and more. Are other people isolated, segregated, and devalued because of *their* medical conditions?

—Inaccurate Descriptors—

"Handicapped" is an archaic term (no longer used in federal legislation) that evokes negative images of pity, fear, and more. The origin of the word is from an Old English bartering game, in which the loser was left with his "hand in his cap" and was said to be at a disadvantage. Based on this meaning, it was applied to people with certain conditions. A *legendary* origin of the word refers to a person with a disability begging with his "cap in his hand." This antiquated, derogatory term perpetuates the negative image that people with disabilities are a homogenous group of pitiful, needy people! Others who share a certain characteristic are not all alike, and individuals who happen to have disabilities are not alike. In fact, people with disabilities are more *like* people *without* disabilities than different!

"Handicapped" is often used to describe modified parking spaces, hotel rooms, restrooms, etc. But these usually provide *access* for people with physical or mobility needs—and they may provide *no benefit* for people with visual, hearing, or other conditions. This is one example of the misuse of the H-word as a *generic descriptor.* (The accurate term for modified parking spaces, hotel rooms, etc. is "accessible.")

> ***If thought corrupts language, language can also corrupt thought.***
> George Orwell

"Disabled" is also not appropriate. Traffic reporters often say, "disabled vehicle." They once said, "stalled car." Sports reporters say an athlete is on "the disabled list." They once said, "injured reserve." Other uses of this word today mean "broken/non-functioning." *People with disabilities are not broken!*

If a new toaster doesn't work, we say it's "defective" or "damaged" and return it. Shall we return babies with "birth defects" or adults with "brain damage"? The accurate and respectful descriptors are "congenital disability" or "brain injury."

Many parents say, "My child has special needs." This term generates *pity,* as demonstrated by the usual response: "Oh, I'm *so sorry*," accompanied by a sad look or a sympathetic pat on the arm. *(Gag!)* A person's needs aren't "special" to him—they're ordinary! Many adults have said they detested this descriptor as children. Let's learn from them, and *stop using this pity-laden term!*

"Suffers from," "afflicted with," "victim of," "low/high functioning," and similar descriptors are inaccurate, inappropriate, and archaic. A person simply "has" a disability/medical condition.

—Disability is *Not* the "Problem"—

We seem to spend more time talking about the "problems" of a person with a disability than anything else. People *without* disabilities, however, don't constantly talk about *their* problems. This would result in an inaccurate perception, and would also be counterproductive to creating a positive image. A person who wears glasses, for example, doesn't say, "I have a *problem* seeing." She says, "I wear [or need] glasses."

What is routinely called a "problem" actually reflects a *need.* Thus, Susan doesn't "have a problem walking," she "needs/uses a wheelchair." Ryan doesn't "have behavior problems," he "needs behavior supports." Do *you* want to be known by your "problems" or by the many positive characteristics which make you the unique individual you are? When will people *without* disabilities begin speaking about people *with* disabilities in the respectful way they speak about themselves?

Then there's the use of "wrong" as in, "We knew there was *something wrong* when…" What must it feel like when a child hears his parents repeat this over and over and over again? How would *you* feel if those who are supposed to love and support you constantly talked about what's "wrong" with you? Isn't it time to stop using the many words that cause harm?

The Real Problems are Attitudinal and Environmental Barriers!

The real problem is *never* a person's disability, but the attitudes of others! And a change in attitudes and beliefs can change everything.

If educators believed in the potential of *all* children, and if they recognized boys and girls with disabilities need a quality education so they can become successful in the adult world of work, millions of children would no longer be *segregated and undereducated* in special ed classrooms. If employers believed adults with disabilities have (or could learn) valuable job skills, we wouldn't have an estimated *(and shameful)* 75 percent unemployment rate of people with disabilities. If merchants saw people with disabilities as customers with money to spend, we wouldn't have so many inaccessible stores, theaters, restrooms, and more. If the service system identified people with disabilities as "customers," instead of "clients/consumers/recipients," perhaps it would begin to meet a person's *real* needs

(like inclusion, friendships, etc.) instead of trying to remediate his "problems."

If individuals with disabilities and family members saw *themselves* as first-class citizens who can and should be fully included in all areas of society, we might focus on what's really important: living a *Real Life in the Real World*, enjoying ordinary opportunities and experiences and dreaming big dreams (like people without disabilities), instead of living a *Special Life in Disability World,* where low expectations, segregation, poverty, and hopelessness are the norm.

—A New Paradigm—

"Disability is a natural part
of the human experience..."
U.S. Developmental Disabilities/Bill of Rights Act

Like gender, ethnicity, and other traits, a disability is simply one of many natural characteristics of being human. Are *you* defined by your gender, ethnicity, religion, age, sexual orientation, or other trait? No! So how can we define others by a characteristic which is called a "disability"?

Yes, *disability is natural,* and it can be *redefined* as "a body part that works differently." A person with spina bifida has legs that work differently, a person with Down syndrome learns differently, and so forth. And the body parts of people *without* disabilities are also different—it's the *way* these differences affect a person which creates the eligibility for services, entitlements, or legal protections.

> ***The greatest discovery of my generation is that human beings can alter their lives by altering their attitudes of mind.***
> William James

In addition, a disability is often a *consequence of the environment.* For example, most children with ADD and similar conditions are not diagnosed until they enter public school. Why is this? Could it be that as young children, their learning styles were supported by parents, preschool teachers, etc.? But once in public school, if the child's learning style doesn't mesh with an educator's teaching style, the child is said to have a "disability." Why do we blame the child, label him, and segregate him in a special ed classroom? Shouldn't we modify the regular curriculum (per special ed law) and/or provide supports to meet his needs so he can learn in ways that are best for him?

When a person is in a welcoming, accessible environment, with the appropriate supports, accommodations, and tools, does he still have a disability? No! *Disability is not a constant state.* The *diagnosis* may be constant, but whether it's a disability is more a *consequence of the environment* than what a person's body or mind can/cannot do. We don't need to change people with disabilities through therapies or interventions. We need to change the *environment,* by providing assistive technology devices, supports, and accommodations to ensure a person's success!

Using People First Language is Crucial!

People First Language puts the person before the disability, and describes what a person *has,* not who a person *is.*

Are you "myopic" or do you wear glasses?
Are you "cancerous" or do you have cancer?
Is a person "handicapped/disabled"
or does she have a disability?

If people with disabilities are to be included in all aspects of society, and if they're to be respected and valued as our fellow citizens, we must stop using language that devalues and sets them apart.

The use of disability descriptors is appropriate *only* in the service system (at those ubiquitous "I" team meetings) and in medical or legal settings. Medical diagnoses have no place—and they should be irrelevant—within families, among friends, and in the community.

Many erroneously share a diagnosis in order to convey information, as when a parent says, "My child has Down syndrome," hoping others will realize her child needs certain accommodations or supports. But the outcome of this action can be less than desirable! A diagnosis can scare people, generate pity, and/or set up exclusion ("We can't handle people *like that...*"). In these circumstances, *and when it's appropriate,* we can simply describe the person's *needs* in a respectful, dignified manner, and *omit the diagnosis.*

Besides, *the diagnosis is nobody's business!* Have individuals with disabilities given us permission to share their personal information with others? If not, how dare we violate their trust! Do *you* routinely tell every Tom, Dick, and Harry about the boil on your spouse's behind? (I hope not!) And we often talk about people with disabilities *in front of them, as if they're not there.* We must stop this demeaning practice!

My son, Benjamin, is 22 years old. His interests, strengths, and dreams are more important than his diagnosis! He loves politics, classic rock, and movies, and has earned two karate belts, performed in plays, and won a national award for his *Thumbs Down to Pity* film. Benj is attending college, where he's a member of Phi Theta Kappa national honor society, and he wants to become a writer. He has blonde hair, blue eyes, and cerebral palsy. His diagnosis is just one of many characteristics of his whole persona. *He is not his disability, and his potential cannot be predicted by his diagnosis.*

When I meet new people, I don't whine that I'll never be a prima ballerina. I focus on my strengths, not on limitations. Don't you do the same? So when speaking about my son, I don't say, "Benj can't write with a pencil." I say, "Benj writes on a computer." I don't say, "He can't walk." I say, "He uses a power chair." It's a simple, *but vitally important,* matter of perspective. If I want others to know what a great young man he is—more importantly, *if I want him to know what a great young man he is*—I must use positive and accurate descriptors that portray him as a valuable, respected, and wonderful person.

The words used to describe a person have a powerful impact on the person's self-image. For generations, the hearts and minds of people with disabilities have been crushed by negative, stereotypical words which created harmful, mythical perceptions and caused other detrimental consequences. We must stop believing and perpetuating the myths—*the lies*—of labels. Children and adults who have conditions called "disabilities" are unique individuals with unlimited potential, like everyone else!

The Civil Rights and Women's Movements prompted changes in language and attitudes. The Disability Rights Movement is following in those important footsteps. People First Language was created by individuals who said, "We are *not* our disabilities." It's not "political correctness," but good manners and respect.

We can create a new paradigm of disability. In the process, we'll change ourselves and our world—as well as the lives of millions of children and adults. It's time to care about the *feelings* of the *people we're talking about* and to carefully consider what *perceptions* we create about people with disabilities with our words.

Isn't it time to make this change? If not now, when? If not you, who?
Using People First Language is the right thing to do, so let's do it!

Examples of People First Language

Say:	Instead of:
People with disabilities.	The handicapped or disabled.
Paul has a cognitive disability (diagnosis).	He's mentally retarded.
Kate has autism (or a diagnosis of...)	She's autistic.
Ryan has Down syndrome (or a diagnosis of...)	He's Down's; a Down's person; mongoloid.
Sara has a learning disability (diagnosis).	She's learning disabled.
Bob has a physical disability (diagnosis).	He's a quadriplegic/is crippled.
Mary is of short stature/Mary's a little person.	She's a dwarf/midget.
Tom has a mental health condition	He's emotionally disturbed/mentally ill.
Nora uses a wheelchair/mobility chair	She's confined to/is wheelchair bound.
Steve receives special ed services	He's in special ed; is a sped student/inclusion student.
Tonya has a developmental delay	She's developmentally delayed.
Children without disabilities	Normal/healthy/typical kids.
Communicates with her eyes/device/etc.	Is non-verbal.
Customer.	Client, consumer, recipient, etc.
Congenital disability	Birth defect.
Brain injury	Brain damaged.
Accessible parking, hotel room, etc.	Handicapped parking, hotel room, etc.
She needs . . . or she uses	She has a problem with. . . /She has special needs.

Keep thinking—there are many other descriptors we need to change!