

To ensure INCLUSION, FREEDOM, AND RESPECT
for all, we must use
PEOPLE FIRST LANGUAGE

by Kathie Snow

Who are the so-called
"handicapped" or "disabled"?

According to stereotypical perceptions, they are:

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

Categorically, they are called *retarded, autistic, blind, deaf, learning disabled, etc., etc., etc.—ad nauseum!*

Who are they, really?

Moms and Dads • Sons and Daughters
Employees and Employers • Friends and Neighbors
Students and Teachers • Leaders and Followers
Scientists, Doctors, Actors, Presidents, and More
They are people. *They are people, first.*

People with disabilities constitute our nation's largest minority group. It is also the most inclusive and most diverse: both genders, any sexual orientation, and all ages, religions, socioeconomic levels, and ethnicities are represented. Yet people who have been diagnosed with disabilities are all different from one another. The only thing they have in common 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 become part of, at any time!* Some join at birth—others in the split second of an accident, through illness, or during the aging process. If and 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?

The Power of Language & Labels

Words are powerful. Old and inaccurate descriptors, and the inappropriate *use* of these descriptors, perpetuate negative stereotypes and reinforce an incred-

ibly powerful attitudinal barrier. *And this invisible, but potent, attitudinal barrier is the greatest obstacle facing individuals who have disability diagnoses.* When we describe people by their medical diagnoses, we devalue and disrespect them as individuals. Do you want to be known primarily by your psoriasis, gynecological history, the warts on your behind, or any other condition?

Worse, medical diagnoses are frequently used to define a person's potential and value! In the process, we crush people's hopes and dreams, and relegate them to the margins of society. If we know about (or see) a person's diagnosis, we (mistakenly) think we *know something important about him*, and we give great weight to this information, using it to determine how/where a person will be educated, what type of job he will/won't have, where/how he'll live, and more. *In effect, a person's future may be determined by those with authority over him, based on the diagnosis.* Today, millions of children and adults with disability diagnoses are effectively "incarcerated" behind the walls of "special (segregated) places:" special ed classrooms, congregate living quarters, day programs, sheltered work environments, and more—all because of the diagnosis that's been assigned. *When incorrectly used as a measure of a person's abilities or potential, medical diagnoses can ruin people's lives.*

The difference between the right word
and the almost right word is the
difference between lightning
and the lightning bug.

Mark Twain

Inaccurate Descriptors

"Handicapped" is an archaic term—it's no longer used in any federal legislation—that evokes negative images (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 thought to be at a disadvantage. A legendary origin of the "H-word" refers to a person with a disability begging with his "cap in his hand." This antiquated, derogatory term perpetuates the stereotypical perception that people with disability diagnoses make up one homogenous group of pitiful, needy people! Other people who share a certain

characteristic are not all alike; similarly, individuals who have disability diagnoses are not alike. *In fact, people who have disabilities are more like people who don't have disabilities than different!*

The "handicapped" descriptor is often used for parking spaces, hotel rooms, restrooms, etc. But most accommodations so designated provide *access* for people with physical or mobility needs. These modifications may provide little or no benefit for people with visual, hearing, or cognitive diagnoses. This is just one example of the inaccuracy and misuse of the H-word as a *generic descriptor*. (The accurate term for modified parking spaces, hotel rooms, etc. is "accessible.")

"Disabled" is also not appropriate. Traffic reporters frequently say, "disabled vehicle." (They once said, "stalled car.") In that context, "disabled" means "broken down." People with disabilities are not broken!

If a new toaster doesn't work, we call it "defective" and return it for a new one! Shall we return babies who have "birth defects"? The more accurate and respectful descriptor is "congenital disability."

Many parents say, "I have a child with special needs." This term typically generates *pity*, as demonstrated by the, "Oh, I'm *so sorry*," response, a sad look, or a sympathetic pat on the arm. (*Gag!*) A person's needs aren't "special" to him—they're ordinary! *I've never met an adult with a disability diagnosis who wants to be called "special."* Let's learn from those with real experience, and stop inflicting this pity-laden descriptor on others.

What is a Disability?

Is there a universally-accepted definition of disability? No! What constitutes a disability depends on who you ask and what services a person receives. First and foremost, a disability label is a medical diagnosis, which becomes a *sociopolitical passport* to services or legal status. Beyond that, the definition is up for grabs! The "disability criteria" for early childhood services is different from vocational-rehabilitation which is different from special ed which is different from worker's compensation, etc. Thus, disability is a *social construct*, created to identify people who may be entitled to specific services or legal protections *because of certain characteristics*.

Disability is Not the "Problem"

Because society tends to view disability as a "problem," this seems to be the #1 word used about people with disability diagnoses. People *without* disabilities,

however, don't spend a lot of time talking about *their* problems. They know this would promote an inaccurate perception of themselves, and it would also be counter-productive 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 multitude of positive characteristics which make you the unique individual you are? When will people without dis-

abilities begin speaking about people *with* disabilities in the respectful way they speak about themselves?

Then there's the "something wrong" descriptor, as in, "We knew there was something wrong when..." What must it feel like, to a child, to hear his parents repeat this over and over and over again, throughout his childhood? How would *you* feel if those who are supposed to love and support you constantly talked about what's "wrong" with you? Let's stop talking this way!

The Real Problems are Attitudinal and Environmental Barriers

A change in attitude can change everything. If educators believed children with disability diagnoses are boys and girls who have the potential to learn, who need the same quality of education as their brothers and sisters, and who have a future in the adult world of work, we wouldn't have millions of children being segregated and undereducated in special ed rooms.

If employers believed adults with disability diagnoses have (or could learn) valuable job skills, we wouldn't have an estimated 75% 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 saw people with disabilities as "customers," instead of "clients," "consumers," or "recipients," perhaps it would focus on meeting a person's real needs (like inclusion, friendships, etc.) instead of trying to remediate a person's "problems."

And if individuals with disabilities and family members saw *themselves* as first-class citizens who can and should be fully included in all areas of life, we might also focus on what's really important (living a Real Life),

If thought corrupts language,
language can also corrupt thought.

George Orwell

instead of a Special Life governed by services that often result in social isolation and physical segregation.

A New Paradigm

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

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 when we recognize that the body parts of people *without* disability diagnoses are also different, we'll know it's the *way* these differences affect a person and/or her qualifying for services, entitlements, or legal protections which mandates the use of a disability descriptor.

A disability, like gender, ethnicity, and other traits, is simply one of many natural characteristics of being human. One in five Americans is a person with a disability diagnosis! People can no more be defined by their diagnoses than others can be defined by their gender, ethnicity, religion, sexual orientation, or anything else!

Additionally, whether a person has a disability is often a *consequence of the environment*. Why are many children not diagnosed until they enter public school? Is it because their parents or physicians were ignorant or "in denial"? Or is it because as toddlers, they were in environments that supported their learning styles? But once in public school, if a child's learning style doesn't mesh with an educator's teaching style, we may say he has a "disability." Why do we "blame" the child, label him, and segregate him in "special ed"? *Why don't we simply modify the regular ed curriculum (per Special Ed law) to meet his individual needs?*

When a person is in a welcoming, accessible environment, with the appropriate supports, accommodations, and tools, does he still have a disability? I think not. *Disability is not a constant state.* The medical diagnosis may be constant, but whether or not the condition represents a "disability" is often more a consequence of the environment than what a person's body or mind can or cannot do.

Using People First Language is Crucial

People First Language puts the person before the disability, and it 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?
Are you "freckled" or do you have freckles?
Is a person "handicapped/disabled"
or does she have a disability?

If people with disability diagnoses are to be included in all aspects of our communities—in the ordinary, wonderful, and typical activities most people take for granted—and if they're to be respected and valued, we must use the ordinary, wonderful, typical language used about people who have not yet acquired a disability diagnosis. (If you live long enough, *your* time is coming!)

Children with disability diagnoses are children, first. The only labels they need are their names! Parents must not talk about their children in the clinical terms used by professionals. The parent of a child who wears glasses (diagnosis: myopia) doesn't say, "My daughter is myopic," so why does the parent of a child who has a diagnosis of autism say, "My daughter is autistic."?

Adults with disability diagnoses are adults, first. The only labels they need are their names! They must not talk about themselves the way professionals talk about them. An adult with a medical diagnosis of cancer doesn't say, "I'm cancerous," so why does an adult with a diagnosis of cerebral palsy say, "I'm disabled."?

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

We often use diagnoses 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 sharing the diagnosis 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?

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

William James

(I hope not!) And too many of us talk about people with disability diagnoses *in front of them, as if they're not there.* We must stop this demeaning practice.

Attitudes and language changed as a result of the Civil Rights and Women's Movements. The Disability Rights Movement is following in those important footsteps, and similar changes are occurring.

My son, Benjamin, is 18 years old. More important than his diagnosis are his interests, strengths, and dreams. He loves history, burned fish sticks, classic rock, and writing movie reviews, and he's great at mimicking actors and politicians! He's earned two karate belts, taken drama classes, and performed in five children's theater productions. Benj wants to major in journalism and be a movie critic. He has blonde hair, blue eyes, and cerebral palsy. His diagnosis is only one of many characteristics of his whole persona. *He is not his disability.* His potential cannot be predicted by his diagnosis.

When I meet new people, I don't disclose that I'll never be a prima ballerina. I focus on my strengths, not on what I cannot do. 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 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 I think he is*—I must use positive and accurate descriptors that portray him as a whole, real, wonderful person, instead of as a collection of "defects," "problems," or "body parts."

A person's self-image is strongly tied to the words used to describe him. For generations, people with disabilities have been described by negative, stereotypical words which have created harmful, mythical portrayals. We must stop believing (and perpetuating) the myths—the *lies*—of labels. We must believe children and adults who have been diagnosed with conditions we call disabilities are unique individuals with unlimited potential to achieve their dreams, just like all Americans.

People First Language isn't about being "politically correct." It is, instead, about good manners and respect (and it was begun by individuals who said, "We are not our disabilities!"). We have the power to create a new paradigm of disability. In doing so, we'll change the lives of children and adults who have disability diagnoses—and we'll also change ourselves and our world.

Isn't it time to make this change?
If not now, when? If not you, who?
People First Language is right.
Just do it—*NOW!*

EXAMPLES OF PEOPLE FIRST LANGUAGE

Say:	Instead of:
People with disabilities (or disability diagnoses)	The handicapped or disabled.
He has a cognitive disability (diagnosis)	He's mentally retarded.
She has autism (or an autism diagnosis)	She's autistic.
He has a diagnosis of Down syndrome	He's Down's.
She has a learning disability (diagnosis)	She's learning disabled.
He has a physical disability (diagnosis)	He's a quadriplegic/crippled.
She's of short stature/she's a little person	She's a dwarf/midget.
He has a mental health diagnosis	He's emotionally disturbed/mentally ill.
She uses a wheelchair/mobility chair	She's wheelchair bound/confined to/in a wheelchair.
He receives special ed services	He's in special ed.
She has a developmental delay	She's developmentally delayed.
Typical kids or kids without disability diagnoses	Normal or healthy 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!

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