

To ensure INCLUSION, FREEDOM, AND RESPECT

for all people, 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 disability labels constitute our nation’s largest minority group. It is simultaneously the most inclusive and the most diverse: both genders, all ages, all religions, all socioeconomic levels, every ethnicity, and any sexual orientation are represented. Yet people who have been labeled are all different from one another—and the only thing these individuals truly have in common with one another is dealing with 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 join in the split second of an accident, through illness, or by the aging process. If and when it happens to *you*, will you have more in common with others who have labels or with family, friends, and co-workers? How will you want to be described? And how will you want to be treated?

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

Mark Twain

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 incredibly powerful attitudinal barrier. *And this invisible, but potent, attitudinal barrier is the greatest obstacle facing individuals who have been labeled.* When we describe people by their labels (medical diagnoses), we devalue and disrespect them as individuals. Would *you* want to be known primarily by your psoriasis, gynecological history, the warts on your behind, a balding pate, or any other condition?

Worse, labels 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. When we hear a person’s label, we (mistakenly) think we know something important about him, and we give great weight to the label, 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 is often cast by others, based on the label.* Today, millions of children and adults with disability labels are effectively “incarcerated” behind the walls of “special (e.g., segregated) places:” special ed classrooms, congregate living quarters, day programs, sheltered work environments, and more—all because of the label that’s been assigned. Labels have the potential to ruin people’s lives.

Inaccurate Descriptors

“The 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 he was thought to be at a *disadvantage*. Later, “disadvantage” was equated to having a disability label. 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 labels make up one homogenous group of pitiful, needy people! Other people who all share the same medical diagnosis (or any other characteristic) are not all alike; similarly, individuals who have disability labels are not alike. *In fact, people who have been labeled are more like people who have not been labeled than different!*

Parking spaces, hotel rooms, and other structures are often labeled “handicapped”—to indicate something which is useful to people with disability labels. But most accommodations so designated are created to provide *access* for people with physical disability conditions. In general, such modifications have little or no benefit for people with other conditions, such as visual, hearing, or cognitive disability labels. 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 not an appropriate descriptor, either. Our society corrupts the meanings of words. Traffic reporters frequently use the term, “disabled vehicle.” (They once said, “stalled car.”) In that context, “disabled” means “broken down.” People with disability labels are human beings and they’re not broken!

If a new toaster doesn’t work, we say, “It’s defective!” and return it for a new one! Shall we return babies who have “birth defects”? The more accurate and respectful label is “congenital disability.”

Many parents say, “I have a child with special needs.” This descriptor typically generates *pity*, as demonstrated by an, “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 label who wants to be known as “special.”* Can’t we learn from those with real experience, and no longer inflict this pity-laden descriptor on children or adults?

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 and on and on. 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”

Society tends to view disability as a problem, so much so that “problem” seems to be the #1 word used about people with disability labels. People *without* labels, however, don’t spend a lot of time talking about their problems. They know this would not only promote an inaccurate perception of themselves, but 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.”

Let’s recognize that 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 labels begin speaking about people *with* labels in the same 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 make a child feel like, 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?

The Real Problems are Attitudinal and Environmental Barriers

If educators demonstrated the attitude that children with disability labels 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 need to advocate for inclusive education.

If employers demonstrated the attitude that adults with disability labels have (or could learn) valuable job skills, we wouldn’t need to advocate for real jobs for real pay in the real world.

If business owners demonstrated the attitude that people with disability labels are customers with money to spend, we wouldn’t need to advocate for accessibility and other accommodations.

If service providers demonstrated the attitude that the people they serve are “customers,” instead of “clients,”

If thought corrupts language,
language can also corrupt thought.

George Orwell

“consumers,” or “recipients,” perhaps individuals with disability labels would move from second-class citizenship to fully-participating members of their communities.

A New Paradigm of Disability

“Disability is a natural part of the human condition...”

*U.S. Developmental Disabilities Act
and The Bill of Rights Act, 1993*

Yes, *disability is natural*, and it can be redefined as a “body part that works differently.” A person with a physical disability label has legs (or arms) that work differently, a person with a cognitive disability label learns differently, a person with a label of autism has a brain that works differently, and so forth. And when we recognize that the body parts of people *without* disability labels are also different, we’ll also recognize that it’s the “degree of difference”—and the *way* these differences affect a person and/or the need for services, entitlements, or legal protections—that dictates the use of labels.

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 label! People can no more be defined by their disability labels than others can be defined by their gender, ethnicity, religion, sexual orientation, hair color, or anything else!

Additionally, whether a person has a label is often a *consequence of the environment*. It’s interesting to observe how many children with learning disability, attention deficit disorder, and/or other labels aren’t diagnosed until they enter public school! Life was rosy when they were youngsters at home or in daycare settings. But once within the public school, they’re thought to have one label or another. Is it possible that their learning styles simply don’t mesh with a teacher’s teaching style? Why do we “blame” the child and label him? *Why don’t we modify the environment by providing him with a variety of ways to learn that meet his needs?*

When a person is in a welcoming, accessible environment, and when he has the appropriate supports, accommodations, and tools, does he still have a disability? I think not. *Disability is not a constant state.* The medical condition may be constant, but whether or not the condition represents a “disability” at any given time is frequently more a consequence of the environment and whether a person has the accommodations and tools he needs, rather than how his “body parts” actually operate.

Using People First Language is Crucial

People first language puts the person before the disability, and it describes what a person *has*, not what 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” or “disabled”
or does she have a disability label?

If people with disability labels 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 been labeled. (Your time might be coming, especially if you live long enough!)

Children with disability labels 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 labels 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 only places where the use of disability labels is appropriate or relevant are in the service system (at those ubiquitous “I” team meetings) and in medical or legal settings. Labels have no place—and they should be irrelevant—within families, among friends, and in the community.

We often use labels 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 label can be less than desirable! A label 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 label*.

Besides, *the label is nobody’s business!* Have individuals who have been labeled 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 too many of us talk about people with

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

William James

disability labels *in front of them, as if they're not there*. We must stop this demeaning practice.

And consider this: the Civil Rights and Women's Movements changed attitudes and language. The Disability Rights Movement is following in those important footsteps, and similar changes are occurring.

My son, Benjamin, is 17 years old. More important than his disability label are his interests, strengths, and dreams. He loves *Spiderman*, *Harry Potter*, the "Terminator," fish sticks with malt vinegar, writing plays and stories on the computer, and his Pez collection. He has 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 label is only one of many characteristics of his whole persona. *He is not his diagnosis*. His potential cannot be predicted by his label.

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 saddled with disability labels 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. We have the power to create a new paradigm of disability. In doing so, we'll not only influence societal attitudes, we'll also change the lives of children and adults who have been labeled, and our own lives, as well.

**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 labels).-----	The handicapped or disabled.
He has a cognitive disability (label). -----	He's mentally retarded.
She has autism (or an autism label). -----	She's autistic.
He has a diagnosis of Down syndrome. -----	He's Down's.
She has a learning disability (label). -----	She's learning disabled.
He has a physical disability (label). -----	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 (or label). -----	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 labels. -----	Normal or healthy kids.
Communicates with her eyes/device/etc.-----	Is non-verbal.
Customer -----	Client, consumer, recipient, etc.
Congenital disability label. -----	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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