# To ensure Inclusion, Freedom, and Respect for people with disabilities, we must use

## PEOPLE FIRST LANGUAGE

by Kathie Snow

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

Mark Twain

## Who are "the handicapped" or "the disabled?"

According to stereotypical myths, 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 naseum!

#### Who are they, really?

Moms & Dads . . . Sons & Daughters
Employees & Employers . . . Friends & Neighbors
Students & Teachers . . . Leaders & Followers
Scientists (Stephen Hawking)
Movie Stars (Marlee Matlin)
They are people.
They are people, first.

People with disabilities constitute our nation's largest minority group, which is simultaneously the most inclusive and the most diverse! Everyone's represented: people of both genders and of all ages, as well as individuals from all religions, ethnic backgrounds, and socioeconomic levels. Yet the only thing people with disabilities truly have in common with one another is dealing with societal misunderstanding, prejudice, and discrimination. Furthermore, the "disability community" is the only minority group which any one can join, 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 disabilities or with family, friends, and co-workers? And how will you want to be described? How will you want to be treated? Disability issues affect all Americans!

#### 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. A legendary origin refers to a person with a disability begging with his "cap in his hand." This antiquated, pejorative term perpetuates the stereotypical perception that people with disabilities are a homogenous group of pitiful, needy people! People who have brown hair (or those who share any other characteristic) are not all alike; similarly, individuals who have disabilities are not alike. In fact, people with disabilities are more like people without disabilities than different!

We've all seen parking spaces, hotel rooms, and other structures labeled "handicapped"—as a reference that something is useful to all people with disabilities. But these particular accommodations are designed to improve access for people with physical disabilities. In general, these modifications have no benefit for people with other types of disabilities. 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." In that context, "disabled" means "broken down." People with disabilities are human beings and they're not broken!

If a new toaster doesn't work, we say, "It's defective!" and we return it for a new one! Shall we return babies who have "birth defects?" The respectful term is "congenital disability."

Many parents say, "I have a child with special needs." This frequently provokes 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 disability who wants to be known as "special." Will we learn from those with real experience and no longer inflict this pity-laden descriptor on children?

#### The Power of Language & Labels

Words are powerful. Old, inaccurate, and inappropriate descriptors perpetuate negative stereotypes and attitudinal barriers. When we describe people by their labels or medical diagnoses, we devalue and disrespect them as individuals. What is the purpose of a disability label? It's a sociopolitical passport for services! But we mistakenly use labels to determine how/ where people with disabilities will be educated, what type of job they will/won't have, where/how they'll live, and more. 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.

#### 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 disabilities. People without disabilities, however, don't spend a lot of time talking about their "problems." They realize this would

be counterproductive to one's image, as well as inaccurate. A person who wears glasses doesn't say, "I have a problem seeing." She says, "I wear [or need] glasses."

Let's recognize that what we call 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." When will people without disabilities begin speaking about people with disabilities in the same respectful way they speak about themselves? Do you want to be known by your "problems" or by the multitude of positive characteristics which make you the unique individual you are?

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 again, throughout his childhood? How would you feel?

### The real problems are attitudinal and environmental barriers.

If educators held the attitude that children with disabilities 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 held the attitude that adults with disabilities have valuable job skills and can contribute to the success of a business, we wouldn't need to advocate for real jobs for real pay in the community.

If business owners held the attitude that people with disabilities are consumers with money to spend, we wouldn't need to advocate for accessible entrances and other accommodations.

#### What Is a Disability?

Is there a universally-accepted definition of disability? No! What constitutes a disability depends on who you ask and what type of services a person receives. In its most basic form, a disability label is a medical diagnosis or a legal status. Beyond that, the definition is up for grabs! The disability criteria for early childhood services is different from vocational-rehabilitation services; these are different from special

ed or worker's compensation criteria, and on and on and on. Thus, disability is a *social construct*, created to identify people who may be the beneficiaries of services, entitlements, or legal protections.

#### 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 has legs or arms that work differently, a person with a cognitive disability learns differently, a person with autism has a brain that works differently, and so forth. And when we recognize that the body parts of people *without* disabilities are different, we'll also recognize that it's the "degree of difference"—the *way* these differences affect them and/or the need for services, entitlements, or legal protections—which creates the need for labels.

A disability, like gender and ethnicity, is simply one of many natural characteristics of being human. One in five Americans is a person with a disability! People with disabilities cannot be defined by this one characteristic, any more than others can be defined by their gender, ethnicity, religion, sexual orientation, hair color, or anything else!

Additionally, a disability is often a *consequence* of the environment. It's interesting to observe how many kids with learning disabilities, attention deficit disorder, and other conditions aren't diagnosed until they enter public school! Life was fine when they were young children at home or in daycare settings. But within the structure of public school, they're deemed to have a disability. Is it possible that their learning styles simply don't mesh with the teaching style at school? 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" and how it affects a person at any given time is frequently more a consequence of the environment than how the person's "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?

If people with disabilities are to be included in all aspects of our communities—in the ordinary, wonderful, and typical activities most people take for granted—we must use the ordinary, wonderful, typical language used about people who don't have disabilities.

Children with disabilities 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 (medical diagnosis: myopia) doesn't say, "My daughter is myopic," so why does the parent of a child who has a medical diagnosis of autism say, "My daughter is autistic."?

Adults with disabilities 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 our families, among friends, and within 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 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 also 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 16 years old. More important than his disability label are his interests, strengths, and dreams. He loves *Star Wars*, anything "Harry Potter," fish sticks with malt vinegar, writing plays and stories on the computer, and his Pez collection. He earned two karate belts and has been in four children's theater productions. Benj wants to be a movie critic when he grows up. He has blonde hair, blue eyes, and cerebral palsy. His disability is only one of many characteristics of his whole persona. He is not his diagnosis. His potential cannot be defined by his disability label.

When I meet new people, I don't tell them 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.

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

We have the power to create a new paradigm of disability. In doing so, we'll not only influence societal attitudes—we'll also be changing the lives of children and adults with disabilities, 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:

People with disabilities.

He has a cognitive disability.

She has autism.

He has Down Syndrome.

She has a learning disability.

He has a physical disability.

She's of short stature/she's a little person.

He has an emotional/mental health disability.

She uses a wheelchair/mobility chair.

He receives special ed services.

Typical kids or kids without disabilities.

Congenital disability.

Brain injury.

Accessible parking, hotel room, etc.

She needs . . . or she uses . . .

Instead of:

The handicapped or disabled.

He's mentally retarded.

She's autistic.

He's Down's.

She's learning disabled.

He's a quadriplegic/crippled.

She's a dwarf/midget.

He's emotionally disturbed.

She's wheelchair bound/confined to a wheelchair.

He's in special ed.

Normal or healthy kids.

Birth defect.

Brain damaged.

Handicapped parking, hotel room, etc.

She has a problem with . . .

And no more "special needs!" That term evokes pity, and a person's needs aren't special to him, they're normal and ordinary! Keep thinking—there are many descriptors we need to change.

This document may be copied and shared with others. As a courtesy, please let me know you're using it. Kathie Snow, 250 Sunnywood Lane, Woodland Park, CO 80863 -719-687-8194 - kathie@disabilityisnatural.com

Please visit www.disabilityisnatural.com for other new ways of thinking!

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