

## Appendix D

# 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 nauseam!**

## 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 and 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 with disabilities.** 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. **A person's future may be determined—based on his diagnosis—by those with authority over him!** Today, millions of children and adults with disability diagnoses are essentially "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.**

## Inaccurate descriptors

"Handicapped" is an archaic term (it's no longer used in any 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 this "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 disabilities make up one homogenous group of pitiful, needy people! Other people who share a certain characteristic are not all alike; similarly, individuals who happen to have disabilities are not alike. **In fact, people who have disabilities are more like people who don't have disabilities than different!**

"Handicapped" is often used to describe parking spaces, hotel rooms, restrooms, etc. But these generally 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 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." Sports reporters say, "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" and return it. Shall we return babies with "birth defects"? The accurate and respectful descriptor is "congenital disability."

Many parents say, "I have a child with special needs." This term 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 who wanted to be called "special."** Let's learn from those with real experience, and **stop inflicting this pity-laden descriptor on others.**

"Suffers from," "afflicted with," "victim of," and similar descriptors are inaccurate, inappropriate, and archaic. A person simply "has" a condition, period!

## What is a disability?

Is there a universally accepted definition of disability? No! 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! What constitutes a disability depends 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 because of **certain characteristics** related to a medical diagnosis.

## 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 disabilities. 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." **So 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** disabilities 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 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? 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 disabilities are boys and girls with 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 under-educated** 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 perceived 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."

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** (like people with disabilities) instead of a **Special Life** under the authority of others in the system, which often results in the social isolation and physical segregation of the "disability welfare state."

## 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, as person with Down Syndrome learns differently, and so forth. Yet the body parts of people **without** disabilities are also different. It's the **way** these differences affect a person (or how a person is **perceived**) which qualifies him as eligible for services, entitlements, or legal protections, and this mandates the use of a disability descriptor in the service or legal system. One in five Americans is a person with a condition we call a disability!

**A disability, like gender, ethnicity, and other traits, is simply one of many natural characteristics of being human.** People can no more be defined by their medical conditions than others can be defined by their gender, ethnicity, religion, sexual orientation, or anything else!

In addition, a disability is often a **consequence of the environment**. Why are many children not diagnosed until they enter public school? Is it because physicians are ignorant or parents are "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, he's said to have a "disability." Why do we blame the child, label him, and segregate him in a special ed classroom? Why don't we modify the regular curriculum (per special ed laws) 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? No! **Disability is not a constant state**. The medical diagnosis may be constant, but whether the condition represents a "disability" is 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 describes that 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 sets them apart and devalues them.

Children with disabilities are **children, first**. The only labels they need are their names! Parents must not talk about their children using the medical terms used by professionals. Educators must not use terms like "sped kids," "LD students," and other demeaning descriptors. Children in school are **students** and some **receive special ed services**.

Adults with disabilities are **adults, first**. The only labels they need are their names! They must not talk about themselves using professional lingo. Service providers must not use terms like "MR client," "quads," and other diagnostic terms.

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 labels have no place—and they should be irrelevant—within families, among friends, and in the community.

We often use a diagnosis 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? (I hope not!) And too many of us talk about people with disabilities **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 Right 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 interest, 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 has earned two karate belts, has taken drama classes, and performs in five children's theater productions. Benj is attending college and wants to be a film 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 strength, 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, **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 I think he is**—I must use positive and accurate descriptors that portray him as a whole, real, wonderful person, instead of 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 perceptions. We must stop believing (and perpetuating) the myths— **the lies**—of labels. We must believe children and adults who have been diagnosed with conditions called "disabilities" are unique individuals with unlimited potential, 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

<b>Say:</b>	<b>Instead of:</b>
People with disabilities	The handicapped or disabled
He has a cognitive disability (diagnosis)	He's mentally retarded
She has autism (or a diagnosis of . . .)	She's autistic
He has Down Syndrome (or a diagnosis of . . .)	He's Down's; a Down's person
She has a learning disability (diagnosis)	He's learning disabled
He has a physical disability (diagnosis)	He's a quadriplegic/is 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 confined to/is wheelchair bound
He receives special ed services	He's in special ed
She has a developmental delay	She's developmentally delayed
Children without disabilities	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.

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She needs . . . or she uses	She has a problem with . . . She has special needs
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Keep thinking—there are many other descriptors we need to change!

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