To ensure INCLUSION, FREEDOM, AND RESPECT for all, it's time to embrace

People First Language

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Did you know that people with disabilities constitute our nation's largest minority group (one in five Americans has a disability)? It's 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* represent the stereotypical perception: a homogenous sub-species called "the handicapped" or "the disabled." Each person is a unique individual.

The only thing they may have in common with one another is being on the receiving end of societal ignorance, prejudice, and discrimination. Furthermore, this largest minority group is the only one that *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 special education, which is different from vocational-rehabilitation, which is different from worker's compensation, which is different from the military, and so on. Thus, "disability" is a governmental *sociopolitical construct*, created to identify those entitled to specific services or legal protections.

—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 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, arthritis, diabetes, sexual dysfunction, or any other condition?

Disability diagnoses are, unfortunately, often used to define a person's value and potential, and low expectations and a dismal future are the predicted norm. Too often, we make decisions about how/where the person will be educated, whether he'll work or not, where/how he'll live, and what services are offered, based on the person's *medical diagnosis,* instead of the person's unique and individual strengths and needs.

With the best of intentions, we work on people's bodies and brains, while paying scant attention to their hearts and minds. Far too often, the "help" provided can actually cause harm—*and can ruin people's lives*—for "special" services usually result in lifelong social isolation and physical segregation: in special ed classrooms, residential facilities, day programs, sheltered work environments, segregated recreational activities, and more. Are other people isolated, segregated, and devalued because of *their* medical conditions? No.

—INACCURATE DESCRIPTORS—

"Handicapped" is an archaic term (no longer used in federal legislation) that evokes negative images of pity, fear, and worse. 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. It was later applied to other people who were thought to be "disadvantaged." A *legendary* origin of the word refers to a person with a disability begging with his "cap in his hand." Regardless of origin, this antiquated term perpetuates the negative perception that people with disabilities are a homogenous group of pitiful, needy people! But others who share a certain characteristic are not all alike, and individuals who happen to have disabilities are not all 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 either return it or throw it away. Shall we do the same to babies with "birth defects" or adults with "brain damage"? The accurate and respectful descriptors are "congenital disability" and "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 or a medical diagnosis.

—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 that 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* because..." 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 talk about what's "wrong" with you? Isn't it time to stop using 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! A change in our attitudes leads to changes in our actions. Attitudes drive actions.

If educators believed in the potential of *all* children, and if they recognized that 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 "people we serve," instead of "clients, consumers, recipients," perhaps those employed in the field would realize *they* are dependent on people with disabilities for their livelihoods, and would, therefore, treat people with disabilities with greater respect and deference.

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 relationships and experiences, and dreaming big dreams (like people without disabilities), instead of living a *Special, Segregated Life in Disability World,* where services, low expectations, poverty, dependence, 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 that is known as a "disability"?

Yes, *disability is natural,* and it can be *redefined* as "a body part that works differently." A person with spina bifida may have legs that work differently, a person with Down syndrome may learn differently, and so forth. And the body parts of people *without* disabilities are also different—it's the *way* these differences impact a person that 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, many children with attention-deficit disorder (ADD) and similar conditions are not diagnosed until they enter public school. Why then? Perhaps when they were younger, their learning styles were *supported* by parents and preschool teachers. But once in public school, if the child's learning style doesn't match an educator's teaching style, the child is said to have a "disability," and is shipped off to the special ed department. Why do we blame the child, label him, and segregate him in a special classroom? Shouldn't we, per special ed law, modify the regular curriculum and/or provide supports so he can learn in ways that are best for him? It seems that ADD and other conditions may be "environmentally-induced disabilities"!

When a person is in a welcoming, accessible environment, with appropriate supports, accommodations, and tools, where she can be successful, does she 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 brain 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 marginalizes and sets them apart. Numerous historical examples of horrific treatment by the "majority" toward a "minority" demonstrate that the process *begins* with language that devalues and makes others "less than."

The use of disability descriptors is appropriate *only* in the service system, at IFSP, IEP, ISP meetings, and/or in medical or legal settings. Medical diagnoses have no place—*and they should be irrelevant*—within families, among friends, and in the community.

Many people share a person's diagnosis in an attempt to provide helpful information, as when a parent says, "My child has Down syndrome," hoping others will understand what the child needs. But this can lead to disastrous outcomes! The diagnosis can scare people, generate pity, and/or set up exclusion ("We can't handle people *like that...*"). Thus, in certain circumstances, *and when it's appropriate,* we can simply share information about what the person *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.* Let's stop this demeaning practice.

My son, Benjamin, is 28 years old. His interests, strengths, and dreams are more important than his diagnosis. He loves politics, American history, classic rock, and movies; he's earned two karate belts, performed in plays, and won a national award for his *Thumbs Down to Pity* film. Benj has earned his Master's degree and is on the job hunt. 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 what I *can* do, not what I *can't.* 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 his 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 wonderful, valuable, and respected person.

The words used *about* a person have a powerful impact *on* the person. For generations, the hearts and minds of people with disabilities have been crushed by negative, stereotypical descriptors that, in turn, led to segregation, abuse, devaluation, forced sterilization, and worse. 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, attitudes, and actions. The Disability Rights Movement is following in those important footsteps. People First Language was created by individuals who said, "We are *not* our disabilities; we are people, first." 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—and also generate positive change in the lives of people with disabilities. It's time to care about how our words impact the people we're talking *about,* and to be mindful of the *attitudes and actions* generated by the words we use.

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.
Jose 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.
Maria uses a wheelchair/mobility chair	She's confined to/is wheelchair bound.
Tom has a mental health condition	He's emotionally disturbed/mentally ill.
Ryan receives special ed services	He's in special ed; is a sped student/inclusion student.
LaToya has a developmental delay	She's developmentally delayed.
Children without disabilities	Normal/healthy/typical kids.
Communicates with her eyes/device/etc.	Is non-verbal.
People we serve/provide services to.	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!