

—LIFE BEYOND THE LABEL—

Revolutionary Common Sense by Kathie Snow, www.disabilityisnatural.com

We're so accustomed to using disability labels, we seldom consider using any other words to describe a person with a disability. But how important is the label? Does it *really* tell us very much about an individual with a disability? And how might life change when we choose to use other words?

Before answering these questions, let's acknowledge that in today's current system, disability descriptors represent a sociopolitical passport to most services: no label, no services. So while I wish labels would become as extinct as dinosaurs, they are a necessary evil *within certain environments*. We grievously err, however, in using these labels in the community, with friends and neighbors; in churches, employment settings, inclusive classrooms in public schools; and other every day settings. So before answering the questions posed in the first paragraph, let's look at the errors we make in our nonchalant use of labels.

Before my son, Benjamin, entered first grade in an inclusive classroom, I wanted his teacher to feel as comfortable as possible. At the end of his kindergarten year, I gave the first grade teacher a book about children with cerebral palsy (CP) and asked her to read it over the summer. When September rolled around, I asked if she had read the book. "You bet!" she replied.

"Do you have any questions?" I asked. "No, not really. I know Benjamin will . . ." (she went on to describe some symptoms of cerebral palsy). Correcting her as gently as possible, I said, "No, Benjamin doesn't do *that*." She then listed other characteristics described in the book. Again, I let her know that these did not apply to Benjamin. With great dismay, I realized the teacher had learned a great deal about *cerebral palsy*, when what she really need to know about was *Benjamin!*

Luckily, I was able to reverse the misinformation she had acquired about my son. But in too many cases, we let a disability diagnosis define a human being. This rarely happens to people who do not have disabilities. Regardless of what a person does, where he lives, or any other characteristic, we know that "Joe Blow" is a multifaceted human being. But many people who know a person's disability diagnosis believe they "know" the person. In turn, the person is usually seen as a collection of negative problems instead of positive possibilities. Our prejudices run deep. When will we realize individuals

with disabilities are multifaceted, too? And when will we realize that not every personal characteristic is *a component of the disability condition*—that a person with autism, for example, may like to be alone because that's part of his personality instead of part of the disability?

Like most mothers, I didn't know anything about people with disabilities when my son was born. When the doctor said the words "cerebral palsy," the vision of my son as an adult was him sitting in a manual wheelchair, not speaking, head hanging down, with a long string of drool reaching to his sunken chest.

Where did this image come from? I had only one conscious memory of an adult with cerebral palsy, and this was it. In my ignorance, I thought this one image represented all people with cerebral palsy. Had I not met other adults with cerebral palsy over the next several years—people whose *only similarity* was the name of their medical diagnosis and who were very different from one another—I probably would have continued to believe my *one* image of a person with cerebral palsy applied to *all* people with cerebral palsy.

I was lucky. My Partners in Policymaking training (a leadership development program for adults with disabilities and parents of children with disabilities), which put me shoulder to shoulder with adults with developmental disabilities, helped dispel the myths I had. This experience, along with continued friendships with adults with disabilities and daily interaction with my son, enabled me to see the truth: that my perceptions were wrong. *Equally important was my conscious decision to throw out the notion that knowing a person's disability diagnosis could tell me much of anything about the person.* Not having preconceived ideas based on a label has been an unbelievably freeing experience. It has truly allowed me to see the person—not the disability—first. And it's also allowed me to shed most preconceptions about "the homeless," "seniors," "special ed directors," and many others who have one label or another.

Let's look at just a few of the ways our careless use of labels can harm people with disabilities. An IEP team decides placement of a child based solely on the child's disability label. A parent doesn't believe her child could participate in [fill in the blank] because of the child's disability. A classroom teacher says, "No way!" when asked to include a child labeled with [whatever disability]

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in her regular ed classroom. A Sunday school teacher insists a child with a particular disability must be in the nursery instead of the primary grades class. A park and rec program directs a person with a disability to a “special (segregated) program.” An employer or a voc-rehab/employment counselor believes a person with this or that disability cannot be successfully employed.

These are, without a doubt, prejudicial actions: individuals have been prejudged based on a disability diagnosis. Worse than the prejudicial beliefs of others, however, is when *a child or an adult believes what others say about her, based on the diagnosis that's been assigned.* Whether, for example, it's the seemingly benign, “Girls with CP can't take ballet,” to the crueler, “Women with Down syndrome will never get married,” preconceived beliefs can become self-fulfilling prophecies. In the process, they destroy a person's hopes, dreams, and self-confidence. And these beliefs are a bigger barrier to success than the actual disability!

Most of us recognize the dangers of telling a child he's stupid, that he can't learn to do this or that, or any other soul-crushing insult. Can we not also recognize similar dangers when it comes to disability-related language and presumptions based on a label?

I'm not implying that we pretend a person doesn't have a disability. When my son was three, he learned to say, “I have cerebral palsy,” so he could speak for himself when someone asked why he used a walker. I *am* suggesting, however, that we eliminate our own prejudices based on a diagnosis, so we'll never be guilty of inflicting life-long injuries to a person's heart and mind.

There are many ways to move beyond the disability label. And the actions we take will make a difference not only in the lives of people with disabilities, but also in how they're perceived by society. We truly can—in small ways and large—change the world by helping change attitudes and perceptions!

The first step is to limit our use of disability diagnoses. Consider that people with other health conditions routinely limit the use of their diagnoses. A woman with cancer or diabetes, for example, usually doesn't feel compelled to tell every Tom, Dick, and Harry about her condition! *It's personal information that is no one's business!* Mary limits conversations about her condition to her physician, other health professionals, and a very few others on a “need to know” basis.

Mary does this to protect her privacy and her dignity—to safeguard against others expressing pity or

other negative reactions. And if Mary's condition creates a difference in her appearance which generates curiosity in others, *she is under no obligation to satisfy this curiosity.* She may, under certain circumstances, choose to educate an inquisitive person, but she is also perfectly justified in ignoring insensitive or rude comments and stares.

Pregnant women are all too familiar with this issue. Some people feel a pregnant belly is public property! These strangers feel no compunction about wanting to touch a women's abdomen, commenting about whether she's carrying the baby “high” or “low,” and expressing other personal opinions.

People with disabilities are also frequently seen as public property! And many of us feel obligated to “explain” an individual's disability to strangers or casual acquaintances in response to a stare or a comment. Our “explanations” sometimes reveal very personal details. Not only is this unnecessary, but it's a *demeaning invasion of privacy.* It is no one's business why or how a person looks, behaves, speaks, or anything else! (What has happened to good manners?) You're perfectly justified in ignoring nosey people. Alternatively, a stranger *may* ask a personal question in a very polite way. In either case—a rude or polite inquiry—you may choose to educate or use humor. If you decide to educate the curious person, do so in a way that focuses on the condition itself, not on the individual you're with. (See the “Humor to the Rescue: What Do You Say When...?” article for humorous strategies which can help diffuse uncomfortable situations.)

Limiting our use of disability labels with strangers is just the tip of the iceberg, however. The slings and arrows of strangers aren't nearly as harmful *as those delivered by family members and others who are dear to the hearts of people with disabilities.*

Think of the numerous times a person with a disability hears others talk about him and his diagnosis. Too many of us talk about a child in front of him, as if he's not even there! Parents may begin doing this when the child is very young, before he can understand. But we're unaware that at some point, a child *does* understand our words (even if he's not yet speaking himself). Sadly, this becomes such a common occurrence that when the child grows up, he continues to endure this horrific behavior when it's practiced by his parents, teachers, service providers, and others.

Do *you* routinely talk to others about your spouse's body parts in front of him or her? Would you ever talk to your neighbor about your 14-year-old daughter's breast development in front of your daughter? Do you regularly discuss your supervisor's hair loss during Monday

morning staff meetings? If you agree that these examples represent rudeness and insensitivity, then isn't doing the same thing to people with disabilities rude and insensitive? The solution to this dilemma is easy: remember the good manners your mama taught you, including, "Treat others the way you want to be treated."

We think in words: *words shape—as well as express—our feelings and beliefs*. Just as insulting words used to describe a person (such as stupid) can become a self-fulfilling prophecy, they can also reinforce and cement a belief in our own minds. Thus, if you tell a child he's stupid enough times, *your* perception becomes fixed and the child may never rise above this descriptor *in your mind*.

I believe the same thing happens with disability labels. When parents and professionals constantly use the disability label and/or routinely connect the label with the person verbally or in the mind, the perceived limitations and/or negative attributes of the disability also become fixed in our minds. A major effort must be made to erase this image—but it can be done.

Jenny was firm in her beliefs about the limitations (many) and the potential for success (minuscule) of her 14-year-old daughter with autism. After talking with me at the end of a presentation, Jenny began to see her daughter in a different light. "My gosh!" she exclaimed. "I realize that every time I looked at Kate, it was like the word 'autism' was tattooed on her forehead. I only saw her *that way!*" This painful but enlightening revelation caused Jenny to reframe Kate as a 14-year-old budding young woman. And with this revelation, Kate's life (and Jenny's) changed overnight.

Jenny began treating Kate like a 14-year-old. As a result, Kate began exhibiting many "grown-up" characteristics (being responsible, staying home alone for the first time, and more). Kate also demonstrated some typical teenage traits (wanting to get her ears pierced, highlight her hair, and more). Jenny resolved to remove the word "autism" from her vocabulary and her mind!

Jenny and many others are discovering that what's important about a person is not the label, but who the person really is! Once Jenny quit thinking about Kate's label all the time, she was able to see beyond the label to the "real girl."

When we routinely use a person's label, we frequently do so with the intention of communicating what the person's needs are. But this effort can backfire in a big way! A label can be the genesis of a range of unintended and unfortunate reactions—including (but not limited to) pity, prejudice, misinformation, and/or confusion.

**DO YOU ALLOW YOURSELF TO BE DEFINED BY A LABEL?
the blonde...the redneck...the fat lady
the Anglo...the bald guy...the working mom
the baseball player...the Methodist...the advocate
the special ed director...the dishwasher...the vegetarian
or (fill in the blank)**

How many parents have heard, "Oh, I'm so sorry," after telling someone their child's diagnosis? How many children with disabilities have been automatically rejected for placement in a regular ed classroom because of the label? And how many people have assumed (incorrectly) they knew what a person needed simply because they knew the diagnosis? There are deeply-rooted myths that accompany labels. And many parents and professionals—not to mention society-at-large—believe these. Here are just a few of these myths:

- Kids with autism don't make eye contact.
- People with Down syndrome are always happy.
- Children with mental health labels come from dysfunctional families.

A description of the person's *actual and individual needs* is far more important, more accurate, and more respectful than a label. And these needs can only be determined by knowing the person well, and by seeing the person through clear eyes, instead of looking through the lens of the diagnosis.

How do we go about changing our thinking and our language? First, stop using a person's label except in the very narrow confines of the service system (including special ed services). Even there, use the label only as the initial passport to services. In an IEP meeting, for example, use the label *only if it's absolutely necessary for paperwork*. But while talking about placement or anything else, the discussion should focus on the person's needs. It may be helpful (in a team meeting or in other circumstances) to state your intentions. I could say, "Benjamin's official diagnosis is cerebral palsy. But from here on, let's focus on his specific needs, not on the diagnosis."

What if someone persists in mentioning the label, as in, "But we know kids with cerebral palsy [blah, blah, blah]."? I could deliver a friendly reminder, such as, "What's important to remember is that Benjamin has needs that are specific to him, irrespective of the general knowledge of his medical diagnosis." If you're a person with a disability, make a similar statement about yourself to keep people focused on your needs instead of the diagnosis.

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Professionals: what changes could you make in forms, in meetings, and how you serve people, so the focus is on a person's *needs* rather than the disability diagnosis? To stay within rules and regulations, you may still need to "categorize" a person by the label on official documentation, but you can stop using the diagnosis after that point and concentrate on the person's needs. (But what *would* it take to change official policy so that people could be served based on needs instead of disability categories? Let's live on the edge!)

Change has to first take place in our hearts and minds, as in Jenny's situation. Quit thinking of your child or a person you work with in terms of the label. Just take the word out of your vocabulary altogether! Too many of us are stuck in the rut of negatives. For example, we think about what a child will never do or be, based solely on the label, as in: "Children with [fill in the blank] will never go to college." Such thinking not only clouds our minds, but also severely limits a person's opportunities for success! *How dare we do this?* And why should we believe the dire predictions we've heard? If you don't believe in the absolute accuracy of psychic hotlines, you shouldn't accept professional prognostications as absolute fact either!

What can happen when you delete disability labels from your consciousness and focus on a person's needs, as well as her gifts, talents, and dreams? You'll free yourself and people with disabilities from "negatives" and "problems," as well as perceived limitations. You'll see the real person before the disability condition.

You'll see unlimited possibilities rather than an uncertain future, for anything is possible when we open our minds! Instead of thinking a person with a disability can't do this or that; you'll consider *how* a person can do [whatever] once her needs are met and accommodations are provided. Instead of focusing on a person's perceived "deficits," you'll tune in to his interests, hopes, and dreams. And this new way of thinking will lead to dignity, freedom, and success.

In our home, we seldom mention Benjamin's disability. Instead, we focus on his dream of being an actor. This has led to Benj taking acting classes and performing in a children's theater (he was great as the Wizard in "The Wizard of Oz")!

In the real life setting of the community, focusing on a person's interests and needs, instead of the label, can lead to inclusion and community! If, for example, we get past the autism label and recognize that Tony has an interest in art, we will no longer believe he can't participate in community art classes. Instead, we'll figure out *how* Tony can participate, and we'll do *whatever it takes* to ensure his success. And as Tony's parents enroll him in the class, they won't need to tell the teacher or students, "Tony has autism," for they'll know this might result in prejudice and exclusion. Instead, they'll share Tony's strengths and interests, along with how his needs can be accommodated and supported. If someone asks "What's wrong with him?" or "Why doesn't he talk?," Tony or his parents can describe some of the symptoms of autism, while also sharing Tony's personal *similarities* with other budding artists.

In addition, thinking beyond the label will help us focus on what's really important, and our energies will be spent supporting a person's interests and needs instead of trying to remedy perceived deficits. For example, we may decide what Christine *really needs* is a power wheelchair so she can play with other kids at recess and make friends—and *get on with the business of living*—instead of endless hours of therapy focused on making her walk.

It's impossible to predict all of the many wonderful changes that can occur when we move beyond disability labels. (Let me know about the changes that occur in *your life*.) But it's happening—and all across the country people with disabilities and their families are living real lives for the first time ever! When we throw labels out the window (using them only in limited arenas, if at all), and focus on a person's interest, desires, and needs, we'll truly know that people with disabilities are more *like* people without disabilities than different. Isn't it time to embrace this belief? Isn't it time to move beyond labels? Isn't it time to free people with disabilities from the shackles of prejudice and discrimination? And isn't it time to recognize that *individuals with disabilities never asked to be labeled?*

What would you want if you were the one with a disability label? The answer to living beyond the label is as simple as that.

Words are loaded pistols.
Jean-Paul Sartre

You can stroke people
with words.
F. Scott Fitzgerald