

When is a Disability Not a Disability?

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

What is a disability? Is there a universally-accepted definition? Some might say yes. But if we look beyond our own personal experiences and environments, as well as the DSM-IV and other official sources, we'll understand there is not a "one-size-fits-all" disability definition. "So what," you may be wondering. "What difference does it make?" It makes all the difference in the world to individuals on the receiving end of disability diagnoses!

Within the service system, a diagnosis is a necessary requirement before a person can receive services. Other factors may also be considered when determining eligibility, but the diagnosis is often the first and more important factor. So a disability diagnosis is "good" in the sense that it enables a person to receive services.

But diagnoses are very, very bad when they're misused, and they're misused in a variety of ways. Within the service system, a serious misuse occurs when a person's diagnosis becomes the primary guide in determining how and where services are provided. Public schools often segregate children with similar disabilities in one setting; group homes, sheltered work, and other entities often do the same with adults. Vocational-rehabilitation or other employment counselors may use a person's diagnosis to predetermine what type of job a person can or cannot do.

Life-altering decisions about people with disabilities are frequently made by others (often without the person's consent and/or against the person's will) based solely on a *one or two word characteristic* that we call a disability diagnosis. Ultimately, a person's life—where she spends her time, her relationships with others, her potential, and her hopes and dreams—may be defined by, and at the mercy of, how others use her diagnosis.

This is not only patently unfair, but it borders on the obscene. Those of us who are *not* labeled (yet) would never allow others to inflict power over us because of a personal characteristic. Thankfully, more and more people are speaking up against the practice of delivering services based primarily on a person's diagnosis instead of the real and individualized needs and wants of a human being.

But the greater misuse of disability diagnoses occurs without us even being aware of it. I'm referring to the

common practice of using a person's diagnosis across every environment of the person's life! A disability diagnosis is *only* a sociopolitical passport to services. Why, then, do we use a person's diagnosis outside of the service system? Why do we use it in our homes, with families and friends, in community activities, and other places that are far removed from the service system? And why do some of us believe (and pass on the belief) that a disability diagnosis is the most important thing about a person?

At a conference I attended, a woman who appeared to be in her 50s approached me and said, "My name is Margery. I'm a Down's person." My then sixteen-year-old daughter later asked, "Mom, how can she think of herself that way? That's *not* who she is!" Why *did* Margery think of herself that way? *You* know—because that's what she's heard from others, all her life.

This practice causes untold injuries to the hearts and minds of people with disabilities, and I believe it's one of the greatest barriers to their success and inclusion. Using diagnoses outside of the narrow confines of the service system causes people to think they

"know" someone because they know the name of the diagnosis, even before they truly know the individual!

People with other conditions—conditions that are not considered

disabilities—do not usually share *their* medical diagnoses with every Tom, Dick and Harry! I don't routinely tell others about my back pain or my husband's bunions. But many parents routinely tell others about their child's diagnosis before saying the child's name, believing every person who may have any contact with the child has some inherent "right to know." Adults with disabilities learn (from years of hearing others talk about them) to talk about their medical diagnosis more than who they are as individuals. Professionals and parents often assume the disability diagnosis is relevant in every area of a person's life, and it's used as indicator of a person's abilities, potential, or character. *But it's not!*

Let's ponder this very carefully: whether a person is considered to have a disability depends on which services, programs, or laws are accessed. In other words, what constitutes a disability differs from program to program. There's one definition for young children who

Disability is a social construct, and a diagnosis is simply a socioeconomic passport for services. That's all!

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are born with certain conditions, another for adults who are eligible for vocational-rehabilitation services, still another for soldiers who have permanent injuries, and so forth.

So what is a disability? It's whatever a given law, policy, agency, or gatekeeper says it is, within the context of disability services or laws!

In our society, disability is a *social construct*. It's a concept that's been created to fulfill our society's efforts—private and public—to (pick one or more): address the “problems” of disability, provide services and entitlements, protect people with disabilities from discrimination, and so forth.

But what if a person has a particular condition which entitles him to services, but doesn't use any? Does he still have a disability? My son, Benjamin, chose to stop receiving physical and occupational therapy when he was six. The only services he received were special ed services in an inclusive elementary school. Then from sixth grade on, he was homeschooled, and received no services or entitlements (his and our choice). During that time, did he have a disability? No. He had—and has—a diagnosis of cerebral palsy, but the diagnosis doesn't automatically mean a person has a disability. Now, as my son prepares to enter community college, he'll access accommodations from the school's disability services office. Thus, a disability status is *conferred* when a person chooses to access a particular service, entitlement, or protection of law.

Therefore, does a person *always* have a disability? I say no—it's more of a fluctuating state, based on the physical and/or social environment! Read on.

In our home—which is accessible—my son does *not* have a disability. As a student in a typical martial arts class, he did not have a disability. When performing in children's theater productions, playing the role of the Wizard in the *Wizard of Oz*, a pirate in *Treasure Island*, and more, he did not have a disability. In these and other settings, his cerebral palsy is irrelevant. Does he have differences and needs that are unique to him? Yes, *but so does everyone!*

In many societies where there is no service system, there is no such thing as disability! Yes, there are people

with cerebral palsy, Down syndrome, and other conditions. But if there is no service system and/or no laws targeting people who may share certain conditions, there is no *social construct* of disability.

Too often, we use a disability diagnosis across all environments in a person's life. In doing so, we dehumanize the person, making the medical condition the most important characteristic of her life, and we set the stage for physical exclusion and social isolation.

It's time to deconstruct the “disability status” and recognize that the social construct of disability *is not a constant state of being*. We have allowed it to become so by invoking it in environments other than the service system.

Our efforts to change will begin when we restrict the use of “disability talk” to the service system. For example, spewing disability diagnoses and jargon while attempting to get a child or an adult included in a typical activity is counterproductive. Instead, simply describe what the person *needs* to be successfully supported and included. Disability jargon can scare the pants off people who don't know what in the heck we're talking about! And we must actively dispute and resist the practice of using a disability diagnosis to define a person's character, abilities, or potential!

Let's recognize the many areas in which a person does *not* have a disability. At home, there's no reason parents should constantly think of their Emma as having a disability! She's a daughter, a sister, a girl who loves Barbie dolls, and more. A disability status should not exist in the comfort and safety of her home. In ordinary settings (preschools, community activities, jobs, and so forth), a person's disability status is not important. And yes, providing accommodations and support may be needed, but this need doesn't necessarily require invoking the disability status. I'm not considered to be a person with a disability (yet), but I have many needs and require accommodations, as we all do. No special status is required before these are provided—people around me help because they care about me. And this is the way things *can be* for people with disabilities, because at home, among friends, and in the community, *disability is irrelevant*.

Why do we use disability diagnoses outside the service system?