

IDENTITY THEFT

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

Identity theft hasn't happened to me yet—knock on wood. I hope it hasn't happened to you. According to the Better Business Bureau website, identity fraud volume for 2004 was \$52.6 billion, involving 9.3 million victims. A variety of companies now offer tips and products to help us protect ourselves from thieves who would steal our names, personal information, and more.

But there's another form of identity theft that's been occurring since time began; it's affected millions of men, women, and children; and the loss to individuals and our society seems to be immeasurable. It can happen in an instant and last a lifetime, but there are no companies or government agencies to help "victims" regain their identities. In far too many cases, the individual and her family don't even realize the theft has occurred. And sadly, family members and others close to the person may be unwitting co-conspirators of the crime.

This form of identity theft occurs when a disability diagnosis is used in ways that robs an individual of the right to define himself. His identity, along with opportunities, experiences, potential, and hopes and dreams, are stolen. This theft might occur when a physician makes the diagnosis, or it can take place at home, in a school, a human services agency, a therapy clinic, or any other location at the moment those in power decide the diagnosis is the most important characteristic of the individual.

When my now 19-year-old son was very young, I was a guilty perpetrator of this crime. At the time he was diagnosed with cerebral palsy at four months of age, our family joined in a conspiracy with physicians, therapists, and early intervention personnel. We allowed "cerebral palsy" to take over the life of Benjamin. Fortunately, some adults with

developmental disabilities and a few others who knew the potential dangers of conventional wisdom came to my aid and helped me learn new ways of thinking, which enabled our family to see the real Benjamin. Our son's identity was restored. He emerged from the black hole relatively unscathed. My husband and I are on parole and in rehab—monitoring our attitudes and actions daily. But it's a vigilant parole (and our son helps us), for there are still people and systems that would once again steal Benjamin's identity and turn him into a client, a consumer, a recipient, a "CP," a "special needs" person, or something similar.

We may not be aware that our attitudes, words, and actions can rob a person of his identity. It's easy to commit this crime—and it's done unintentionally all the time. In many cases, it occurs *even when people have the best of intentions!*

The power of labels to stigmatize, create self-fulfilling prophecies and reduce or enhance self-images is awesome.

J. Dan Rothwell
Telling It Like It Isn't

Many physicians, parents, therapists, and early childhood specialists have the best of intentions, and this puts them in a high-risk category. I know; been there, done that. It's far too easy to embrace the-earlier-the-better mentality and attempt to do everything possible to remediate

the disability in a baby or very young child. In the process, intensive services, therapies, treatments, and special programs take over a child's life and he's robbed of his childhood. (The family's life is stolen, too!)

School-aged children may have their identities stolen by the special education system. Many are no longer "Ryan" or "Melissa"—they become the "sped student," the "Down's kid," or even the benign-sounding, but ultimately demeaning "inclusion student." Placement in a segregated special ed classroom, being pulled out of class for "special help," and/or being identified by some

2 - Identity Theft

“educational status” can rob a child of opportunities to be a fourth-grader, a choir member, or other typical roles assumed by the majority of children in public schools. Throughout their school careers, most students proudly enjoy the ever-changing roles they assume, like being Sarah, a second-grader; then later, Sarah, a sixth-grader; and still later, Sarah, a senior. Students with disabilities who spend years in ungraded classrooms are denied this rite of identity passage.

Many adults—whose identities were stolen as children—may continue to exist in this black hole. To the identity thieves within the human services system, disability descriptors are more relevant than an individual’s name, and perceived deficits are more important than abilities. As a result, far too many adults are denied opportunities to assume the identities of employee, wife or husband, volunteer, taxpayer, and other ordinary roles.

There are many ways to end this form of identity theft. First, recognize that disability descriptors are just words that denote the medical condition a person has, and they cannot be used to judge a person, his value, his potential, or anything else that’s important!

In our society, some words seem to immediately confer respect or elevated status. Physician, teacher, professional initials behind the name, and others come to mind. But as I read in an Ann Landers column many years ago, “Fifty percent of all doctors graduated in the lower half of their class.” (And the same is true for other college-educated professionals.) So the second step is to rethink *all* the different words and labels we use for people, and question the assumptions that go with those descriptors.

The third step depends on your role in the lives of people who happen to have disabilities. When issuing the diagnosis, doctors can reduce the rhetoric

about the prognosis, acknowledging that they’re not fortune tellers and cannot predict the future of a person based on a medical diagnosis! Most pediatric specialists (who do much of the diagnosing) have little or no experience with successful adults with developmental disabilities, so how do they know what’s really possible?

Staff in the public school system and human service agencies, along with therapists and service providers of all kinds, may need to use a person’s diagnosis as eligibility criteria for services, but they can leave the diagnosis at the door of the IFSP/IEP/IPP meeting, and spend more time focused on the individual and his abilities, and on what assistive technology, supports, and accommodations he needs

to make his hopes and dreams come true.

Imagine what it might feel like if your parents, teachers, and others (including some who hardly know you) spent years trying to change you into their definition of “normal”—under that seemingly altruistic mantra:

“For your own good.” This is identity theft! Now imagine what it feels like to never be able to meet that artificial standard: to feel that you’re a failure, that *who you are* isn’t good enough and what you *can do* isn’t good enough—and *never will be in the eyes of those who are supposed to care for you*. Who you are is not acceptable to others, so they attempt to remake you, stealing your unique identity in the process. Many struggle against this theft of spirit, individuality, and potential. In response, we may add “non-compliant” and “inappropriate” to their identities!

If you’re guilty of this form of identity theft, rehabilitate your attitudes, words, and actions. Put yourself on vigilant parole, and ask others to help keep you on the straight and narrow. And make amends to those you’ve hurt. Would you hope for anything less if *your* identity had been stolen?

***A judgment ...is a conclusion...
Premature judgment often
prevents us from seeing what
is directly in front of us.***

Hayakawa and Hayakawa
Language in Thought and Action