The Politics of Naming
by Sarah Triano

"Definitions belong to the definer, not the defined." Toni Morrison

DEFINITIONS OF DISABILITY IN THE DOMINANT CULTURE

• What is the first thing that comes to your mind when you hear the words "disability" or "disabled"?

According to The American Heritage Dictionary of the English Language, "disability" is defined as "a disadvantage or deficiency, especially a physical or mental impairment that interferes with or prevents normal achievement in a particular area, or something that hinders or incapacitates."

This definition of "disability" is paralleled in most of the civil rights laws today that protect the rights of people with disabilities, including:

Definition of "Disability" Contained in The Rehabilitation Act and The Americans with Disabilities Act: "Any individual who has a physical or mental impairment which substantially limits one or more of such person's major life activities, has a record of such impairment, or is regarded as having such an impairment."

In other words, you are limited in what you can do because of your disability.

Definition of "Disability' contained in the Individuals with Disabilities Education Act: "A physical or mental impairment that 'adversely affects a child's educational performance.'"

In other words, you can't learn because of your disability.

Definition of "Disability" contained in the Social Security Act: "Disability" means 'inability to engage in any substantial gainful activity…'

In other words, you can't work because of your disability.

Definition of "Disability' contained in the Developmental Disabilities Act: "A 'developmental disability' is a severe, chronic disability of a person five years of age or older which - is attributable to a mental or physical impairment or combination of mental or physical impairments; is manifested before the person attains age twenty-two; is likely to continue indefinitely; results in substantial functional limitations in three or more of the following areas of major life activity: A) self-care, B) receptive and expressive language, C) learning, D) mobility, E) self-direction, F) capacity for independent living, and G) economic self-sufficiency…."

In other words, you basically can't do anything because of your developmental disability.
QUESTION TO PONDER: Interestingly enough, when you go to look up the definition of "race" under the Civil Rights Act of 1964, it's not there - there is no definition of "race or ethnicity" in the entire Civil Rights Act. Why is it that "disability" is so highly prescribed and carefully defined in civil rights laws, while other human differences that are subject to protection under the law (such as race, sex, etc) are not?

Labeling people with disabilities by medical categories, and attributing the problems we experience in society to our disabilities, or to an internal "deficiency or abnormality" as disability is often perceived, is antithetical to the philosophy and goals of the disability civil rights movement.

MEDICAL VS. SOCIAL MODEL OF DISABILITY

What is the medical and social model?

According to the prominent Disability Studies scholar and activist, Carol Gill (1998), the experience of disability has been historically viewed as a "tangible flaw located within an individual's physical or mental constitution." This view comprises what has been commonly referred to as the "medical model of disability." With the passage of Section 504 of the Rehabilitation Act in 1973, however, disability rights activists and others began articulating a "social model of disability" which de-emphasizes "the significance of individual impairments (such as, paralysis, blindness or learning limitations) in causing the problems persons with disabilities face" (Gill, 1998, p.1). It focuses, instead, "on such socially constructed barriers as exclusion, blocked access and disability prejudice as the 'real' problems of disability" (Gill, 1998, p.1).

According to a social model of disability, therefore, the educational difficulties experienced by disabled children in the classroom are not necessarily caused by their individual disabilities, but are rather the result of a poorly-structured education system that is not equipped to meet the needs of a diverse student population. The barriers experienced by people with disabilities in society are not necessarily caused by our disabilities, but are rather the result of living in a society that is designed by and for non-disabled people.

In my travels as a disability activist, I have asked many people across the country what the first thing is that comes to their mind when they hear the words "disabled" or "disability." Without exception, the responses of most people (disabled and non-disabled alike) reinforce the dominant culture's views of disability - a medical model of disability: "pathetic, weak, unable, not able, a barrier, a challenge, something that prevents you from doing something, not normal, a wheelchair."

In one instance, I had a woman say, "I have a disability. I'm black." She went on to explain that because of her skin color, she has experienced many barriers and challenges in the dominant white culture.
**THE "WE ALL HAVE A DISABILITY" ARGUMENT**

The other typical response I will get is, "Well, we all have some kind of disability." In fact, the first time I heard this *we all have a disability* argument was when I was at the National Leadership Development Conference for Students with Disabilities in Washington, DC in 1998. One of the speakers made the following remark during his speech at the conference: "We all have a disability, don't we? After all, I'm not 6 foot 2 and can't dunk a basketball like Michael Jordan, so in a sense, I have a disability, right?"

I was upset when I heard him say this, but at the time I couldn't quite express why. My comrade in the National Disabled Students Union, Kathy Coleman, expressed my feelings beautifully when she said, "The 'everyone has a disability' argument doesn't sit well with me either. I had a professor in a course say her disability was that she could 'not spell when she was writing on the board in front of the classroom' as her way of making an argument for the 'everyone has a disability' viewpoint (she does not have a learning disability). There is a difference between being weak at a skill and having a disability. Everyone has strengths and weaknesses that are not a disability. You don't get denied health insurance because you make a mistake spelling on the chalk board." Similarly, I seriously doubt the speaker at the National Leadership Development Conference has ever been denied health insurance or the right to equal education because of his "disability."

**RECLAIMING THE DEFINITION OF "DISABILITY"**

Fundamentally what is at issue here, to me, is the definition of disability. The unnamed speakers of the world define "disability" as a "limitation," a "weakness," a "barrier to be overcome." If that is how you define "disability," then yes, we all have a disability because we all have barriers and challenges we must overcome in our lives, including discrimination and all the other "isms."

But I do not define disability that way. I define disability as a natural and beautiful part of human diversity that people living with disabilities can take pride in. I believe the barrier to be overcome is not my disability; it is societal oppression and discrimination based on biological differences (such as disability, sex, race, age, sexuality, etc).

Today, it would be ludicrous to define the experience of being a woman as an "impairment that substantially limits one or more major life activities." We would be outraged if the laws guaranteeing equal education for African-American children explicitly stated that these children are only protected by the laws if the children have a skin color that "adversely affects their educational performance." We would laugh if we heard a white person say, "I understand what you are going through because, after all, we're all Latino, aren't we?" How often do you hear a civil rights activist boast about the fact that they have "overcome their skin color"? Do they hold out for that "cure" for their skin color, like Christopher Reeve does with his disability? Do we try to "overcome our skin color," or understand that the primary barriers for racially and ethnically
diverse communities in our society are racism and discrimination? Why is it somehow different for disability? "When disabled people internalize the demand to ‘overcome’ rather than demand social change, they shoulder the same kind of exhausting and self-defeating 'Super-Mom' burden that feminists have analyzed" (Linton, 1998, 18).

It's time that we reclaim the definition of disability and take control over the naming of our own experience. As the Disability Studies scholar, Simi Linton, has said in her book, Claiming Disability: Knowledge and Identity, "A project of disability studies scholars and the disability rights movement has been to bring into sharp relief the processes by which disability has been imbued with the meaning(s) it has and to reassign a meaning that is consistent with a sociopolitical analysis of disability" (p.10). All disabled people must go out into the world with our heads held high, with our dignity and pride intact, vowing to take back the definition of disability with militant self-pride. Just as "Black is beautiful," Disability is beautiful and we should never let anyone tell us any differently or make us feel ashamed to be who we are. Some people may define disability as bad, but I think it's all good, and no one, not even the Extreme Court of the United States, can take that away from me.

**SELF-DEFINITION:**

**THEORIES ON THE ROLE OF DICHOTOMIES/BINARY OPPOSITIONS AND WAYS TO SUBVERT THEM**

In 1966, during his historic speech in Berkeley, Stokely Carmichael defined the concept of Black Power as a fundamental right to define oneself and to be free of the oppressive black/white opposition in society - "the lie that says anything black is bad." "People have been telling you anything all black is bad," he said, "but I'm never going to be put in that bag. I'm all black and I'm all good" (Carmichael). Carmichael's refusal to be subjected to a black/white dichotomy through a purposive reversal of values hearkens back to a strategy of inversion articulated over a century before by Frederick Douglass: "What [my master] most dreaded, that I most desired. What he most loved, that I most hated. That which to him was a great evil, to be carefully shunned, was to me a great good, to be diligently sought; and the argument which he so warmly urged, against my learning to read, only served to inspire me with a desire and determination to learn" (Douglass). In 1978, the well-known lesbian feminist, Mary Daly, employed a similar strategy of inversion in her book, Gyn/Ecology, by arguing that a woman whom the patriarch calls "evil" is in fact good, whereas a woman whom the patriarch calls "good" is in fact bad (Daly).

Uniting all three of these narratives is an attempt to subvert the cultural imperative to structure experience through false dichotomies such as white/black, man/woman, straight/gay, able/disabled, etc. According to the lesbian theorist, Judith Butler, the Western philosophical tradition is largely driven by a binary system that defines certain terms, such as masculinity, by virtue of their negative, contrasted opposite (i.e. femininity), thereby producing a series of binary oppositions that serve to solidify meaning, beliefs, and what is perceived to be reality, or the "truth" (39). Elizabeth Grosz argues that this "dichotomous thinking necessarily
hierarchizes and ranks the two polarized terms so that one becomes the privileged term and the other its suppressed, subordinated, negative counterpart:

The subordinated term is merely the negation or denial, the absence or privation of the primary term, its fall from grace; the primary term defines itself by expelling its others and in this process establishes its own boundaries and borders to create an identity for itself. Body is thus what is not mind, what is distinct from and other than the privileged term. (Grosz 3)

These oppositional terms, therefore, do not coexist on equal grounds; rather, one side of the binary opposition is privileged, while the other side is devalued (Schrift 15). In the system of signification, or representation, then, "white" becomes the privileged term -the signifier - that defines itself by its suppressed, subordinated, negative opposite: "black," the signified. As Grosz notes, this subject/object divide serves a very specific linguistic and cultural purpose, particularly in terms of establishing the boundaries necessary for the creation of a seemingly stable cultural identity. According to Rosemarie Garland Thomson, the dominant culture's identity, or "ideal self," "requires the ideological figures of the woman to confirm its masculinity and of the black to assure its whiteness," just as it also requires the disabled "to secure its able-bodiedness." "The freak, the cripple, the invalid, the disabled," she writes, "like the quadroon and the homosexual - are representational, taxonomical products that naturalize a norm comprised of accepted bodily traits and behaviors registering social power and status" (Extraordinary Bodies 44). Those who are situated in the position of the negative, subordinated "other" (i.e. the black, the woman, the disabled, etc.) are not allowed to participate in this process of representation and to offer their definition of what it means to be black, feminine, disabled. Instead, as the "constitutive outside," they are subjected to an explicit narration of their bodies that in and of itself serves to erase any "disruptive possibilities" or alternative definitions (Butler 35). As the French feminist, Luce Irigaray, notes, when these isotopical feminine figures are taken to be the feminine, the "real" feminine (i.e. femininity as defined by the "other," the woman) is fully erased by its very representation as the negative, contrasted opposite of masculinity (cited in Butler 36). This dichotomous representation then becomes a "reality" that people act upon as if it were true - a sign that supposedly references the world without any complication or ambiguity.

As many feminist theorists have shown, however, this sign is highly unstable. That which we believe to be "natural" or inherently "true" (i.e. that black is the negative opposite of white) is nothing more than an illusion of language, an imposed fiction that only appears stable and absolute because it has been repeated and reified from one generation to the next. Once it is recognized that meaning is not fixed, and that the relationship between the signifier and the signified is an arbitrary product of language, Butler argues that it is then possible to interrupt the site of signification and directly challenge the assumption that what we believe to be true is inherently true by developing alternative definitions that transgress the binary oppositions of white/black, masculine/feminine, form/matter, mind/body, etc. Grosz notes, however, that when dissolving these oppositional categories, "we cannot simply ignore them, vowing never to speak in their terms again." "This is neither historically possible nor even desirable," she writes, "insofar as these categories must be engaged with in order to be superceded" (24).
"SPECIAL NEEDS," "PHYSICALLY CHALLENGED," "disABILITY, ETC"

What is appropriate language? Many disabled people today propose that we choose a new name for ourselves and our community rather than "disability" such as "physically challenged," "disAbility," "the able disabled," and "special needs." As Grosz notes, however, these terms do not necessarily challenge the oppositional category of able/disabled." As Stokely Carmichael, Frederick Douglass, and Mary Daly all illustrate, one of the most effective ways to directly engage, and thereby supercede, this dichotomous category is to invert the subject/object divide and effectively mobilize it to its opposite by purposively valuing that which is devalued. We must, as Grosz argues, engage the language that has been historically used to stigmatize us, "disabled," and reclaim and reassign meaning to it by purposely valuing that which is devalued ("disability"). Therein lies my rationale for DISABLED AND PROUD!

GET READY FOR THE REACTION AND RESPONSE

What I am proposing - a fundamental redefinition of disability in society - is extremely radical and strikes at the deepest feelings and assumptions people have about themselves and the nature of life itself. As one of my comrades in the National Disabled Students Union, Jodi Ross, said:

"The mindset of oppression is pervasive, has a momentum of its own and takes a lot of energy to get free of. So even people who have quite a few insights and positive qualities and even care about you/me/us in some genuine ways are often still very caught up in it and very unsettled when its challenged. But unfortunately, I don't think there is a chance in hell that the ablebodied population will get this until we get it ourselves. There are MANY - I would say MOST- who are disabled who share the belief that they are lesser and that disability is by definition tragic and bad. Even disabled people who I personally consider amazing and wonderful and even people who are politicized about other oppression, still believe the lies about themselves and their disability.

This is a common problem in oppressed populations: internalized oppression. I think it's worse among disabled people because our movement is so little known and because many of us grow up in families where the folks who are supposed to love us best buy into the idea. As a lesbian, I can say that this is a common problem for other minorities who live in a situation of being "the only one" in their family, in a world that affirms the "defective" status of "people like me," as well.

But it's not hopeless. Dykes, gay men, and other sexual minorities have worked hard over ages and made considerable progress. The suicide rate for gay teens is still many times that of straight ones, but there are many more people coming out and finding self-love, community, and the respect of others than in the past.

We need to do the same in the disability movement. We need to show models of empowerment, not only for practical reasons, but also because humans are social creatures and don't like to be
alone in their thoughts any more than we like to be alone in our bodies. **We need to tell the world, starting with ourselves, who we are and what we are, and it will give others the insight and courage to open up their hearts and minds as well.**

Through this website and our emphatic stance that we are disabled and proud, we will begin the revolution of empowerment. We will:

- Change the way people think about disability
- Break down the internalized shame among people living with disabilities, and
- Promote the belief in society that disability is a natural and beautiful part of human diversity that people living with disabilities can take pride in.

**Remember: Disability Is Beautiful! Difference Is Beautiful! That Makes You Beautiful!**

---

**SOME ADDITION QUESTIONS TO PONDER:**

1. What is your personal definition of disability?
2. Is your definition of "disability" based on the oppressive, binary disabled/able opposition in society?
3. Where did your definition of "disability" come from?
4. How can you begin to personally redefine disability and value the experience of disability in your life?
5. What do you think is appropriate language to use when describing our community?

---

**A NOTE ABOUT LANGUAGE**

It's impossible to begin the process of reassigning meaning to "disability" without also discussing language and terminology, and the question of what is appropriate language. As Linton (1998), notes, "Over the past twenty years, disabled people have gained greater control over these definition issues. The disabled or the handicapped was replaced in the mid-70s by people with disabilities to maintain disability as a characteristic of the individual, as opposed to the defining variable…. Beginning in the early 90s disabled people has been increasingly used in disability studies and disability rights circles when referring to the constituency group. Rather than maintaining disability as a secondary characteristic, disabled has become a marker of the identity that the individual and group wish to highlight and call attention to" (p. 13).

Many self-advocates and people with developmental disabilities still prefer to use what is called "people-first" language (i.e. "people with disabilities"). As Jerry Kainulainen argued in his article, Why 'Handicapped' is not Cool, "In using language, we can choose to emphasize people's similarities or differences. The term 'disabled person' is a sloppy short cut to the more psychologically sound expression, 'person with a disability.' The latter places the person first, not
the disability. Placing the disability first distorts and undermines who people with disabilities are and how they want to be seen. We don't refer to people with broken legs as 'broken-leg people!"

Yes, but we also don't refer to women as "people who are women." That seems silly to me. I am a woman and proud of it. Period. Saying that I am a "person who is a woman" gives credence and authority to those who would deny me my personhood as a womyn. Even though someone uses "proper terminology" doesn't mean their internal beliefs have changed. Just because someone refrains from using the "n-word" doesn't mean they are not a racist. Just because someone uses "person-first" language doesn't mean they don't harbor internal ableism and paternalism.

For these reasons, and many more, I prefer to say "disabled person" and place my disability first because I am proud of it. Disability is beautiful and a natural part of human diversity. It is an important part of who I am and also contributes to my uniqueness. I am, therefore, Disabled and Proud, and not "A Person with a Disability and Proud."

---

**A "SPECIAL" FOOTNOTE ABOUT "SPECIAL NEEDS"**

FOR ALL YOU "SPECIAL" TEACHERS AND EDUCATORS OUT THERE:

"Special needs," in particular, is a phrase that is still used today in educational circles and really grates on my nerves. There is nothing "special" about our needs. In fact, certain things people with disabilities require to function are things that a majority of non-disabled people either need or could benefit from. For example, curb cuts were made for people in wheelchairs, but they benefit skateboarders, bike riders, and mothers using strollers. Schools are just now starting to put books on CD's because students are getting back problems as a result of their heavy backpacks, but students with learning disabilities and students who are blind have been using books on CDs and on tape for ages. These accommodations are not "special" - they are things that benefit all of humanity. And, as one of the youth in our Leadership/Organizing Training at Access Living in Chicago, recently said, "There ain't nothin' special about special education."

---

**ADDITIONAL RESOURCES:**

"Dis-Ing Definitions," by Steven E. Brown, 1997:
http://www.independentliving.org/docs3/brown97b.html

June Isaacson Kailes, a Disability policy consultant, has a great tool for sale that has a section in it on, "Language As An Element of Disability Pride and Culture." I highly recommend it!
http://www.jik.com/resource.html