# SELF, IDENTITY AND THE NAMING QUESTION: REFLECTIONS ON THE LANGUAGE OF DISABILITY

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**Abstract**—With all the emphasis on 'political correctness', it is especially important to delineate the functions of naming. People with disabilities are facing issues quite similar to minority groups which have preceded them in attempting to enter 'mainstream' America. Their similarities and differences with these groups are traced as well as their own unique path (with all its implications) and some possible analytic and political solutions.

*Key words* self, identify, language, disability

"When I use the word, it means just what I choose it to mean—neither more nor less."

Humpty Dumpty

## I. THE POWER OF NAMING

Language ... has as much to do with the philosophical and political conditioning of a society as geography or climate ... people do not realize the extent to which their attitudes have been conditioned to ennoble or condemn, augment or detract, glorify or demean. Negative language inflicts the subconscious of most ... people from the time they first learn to speak. Prejudice is not merely imparted or superimposed. It is metabolized in the bloodstream of society. What is needed is not so much a change in language as an awareness of the power of words to condition attitudes [1].

A step in this awareness is the recognition of how deep is the power of naming in Western culture. According to the Old Testament, God's first act after saying "Let there be light" was to call the light "Day" and the darkness "Night". Moreover, God's first act after the creation of Adam was to bring in every beast of the field so that Adam could give them names; and "whatsoever Adam called every living creature, that was the name thereof" (Genesis 2:20). Thus what one is called tends 'to stick' and any unnaming process is not without its difficulties and consequences [2].

While a name has always connoted some aspect of one's status (e.g. job, location, gender, social class, ethnicity, kinship), the mid-twentieth century seems to be a time when the issue of naming has assumed a certain primacy [3, 4]. In the post-World War II era Erik Erikson [5] and Alan Wheelis [6] noted that "Who am I" or the issue of identity had become a major psychological concern of the U.S. population. The writings of C. Wright Mills [7] as well as the Women's Movement [8], however, called attention to the danger of individualizing any issue as only a "personal problem".

The power of naming was thus recognized not only as a personal issue but a political one as well. While social scientists focused more on the general 'labelling' process [9–13] and the measurement of attitudes toward people with various chronic diseases and disabilities [14, 15], a number of 'liberation' or 'rights' movements focused on the practical implications. They claimed that language was one of the mechanisms by which dominant groups kept others 'in place' [16, 17]. Thus, as minority groups sought to gain more control over their lives, the issue of naming—what they are called—was one of the first battlegrounds. The resolution of this was not always clear-cut. For some, the original stigmas became the banner: Negroes and coloreds become Blacks. For others, only a completely new designation would suffice—'Ms' has caught on as a form of address but 'womyn', 'wimmin' have not been so successful in severing the vocabulary connection to 'men'.

People with disabilities are in the midst of a similar struggle. The struggle is confounded by some special circumstances which mitigate against the easy development of either a disability pride or culture [18, 19]. While most minority group members grow up in a recognized subculture and thus develop certain norms and expectations, people with chronic diseases and disabilities are not similarly prepared. The nature of their experience has been toward isolation. The vast majority of people who are born with or acquire such conditions do so within families who neither have these conditions nor associate with others who do. They are socialized into the world of the 'normal' with all its values, prejudices, and vocabulary. As one generally attempts to rise out of one's status, there is always an attempt to put this status in some perspective. The statements that one is more than just a Black or a woman, etc., are commonplace. On the other hand, where chronic illness and disability are concerned, this negation is almost total and is tantamount to denial. Proof of successful integration is embodied in such statements as "I *never* think of myself as handicapped" or the supreme compliment, "I *never* think of you as handicapped".

What then of the institutions where too many spend too much of their time the long-term hospitals, sanitoria, convalescent and nu sing homes? These are aptly labelled 'total institutions' [20], but 'total' refers to their control over our lives, not to the potential fullness they offer. The subcultures formed within such places are largely defensive and designed to make life viable within the institution. Often this viability is achieved at such a cost that it cannot be transferred to the non-institutional world.

For most of their history, organizations of people with disabilities were not much more successful in their efforts to produce a viable subculture. Their memberships have been small in comparison to the potential disabled population, and they have been regarded more as social groups rather than serious places to gain technical knowledge or emotional support. And though there are some self-help groups which are becoming increasingly visible, militant and independent of medical influence, the movement is still in its infancy [21]. Long ago, Talcott Parsons articulated the basic dilemma facing such groups:

The sick role is . . . a mechanism which . . . channels deviance so that the two most dangerous potentialities, namely group formation and successful establishment of the claim of legitimacy, are avoided. The sick are tied up, not with other deviants to form a 'subculture' of the sick but each with a group of nonsick, his personal circle, and, above all, physicians. The sick thus become a statistical status and are deprived of the possibility of forming a solidary collectivity. Furthermore, to be sick is by definition to be in an undesirable state, so that it simply does not 'make sense' to assert a claim that the way to deal with the frustrating aspects of the social system is for everyone to get sick [22, p.477].

A mundane but dramatic way of characterizing this phenomenon can be seen in the rallying cries of current liberation movements. As the 'melting pot' theory of America was finally buried, people could once again say, even though they were three generations removed from the immigrants, that they were proud to be Greek, Italian, Hungarian, or Polish. With the rise of black power, a derogatory label became a rallying cry, "Black is beautiful" And when women saw their strength in numbers, they shouted "Sisterhood is powerful" But what about those with a chronic illness or disability? Could they yell, "Long live cancer" "Up with multiple sclerosis" "I'm glad I had polio!" "Don't you wish you were blind?" Thus the traditional reversing of the stigma will not so easily provide a basis for a common positive identity.

## 2. SOME NEGATIVE FUNCTIONS OF LABELLING

The struggle over labels often follows a pattern. It is far easier to agree on terms that should *not* be used than the designations that should replace them [23-25]. As with the racial, ethnic [26] and gender groups [27, 28] before them, many had begun to note the negative qualities of certain 'disability references' [29, 30]. Others created quite useful glossaries [31].

Since, as Phillips [32] notes, the names one calls oneself reflect differing political strategies, we must go beyond a list of 'do's' and 'don'ts' to an analysis of the functions of such labelling [33-36]. As long ago as 1651, Thomas Hobbes—in setting his own social agenda—saw the importance of such clarifications, "seeing then that truth consists in the right ordering of names in our affirmations, a man that seeks precise truth has need to remember what every name he uses stands for; and to place it accordingly; or else he will find himself entangled in words as a bird in lime twigs; the more he struggles the more belimed" [37, p.26].

There are at least two separate implications of such naming which have practical and political consequences. The first is connotational and associational. As Kenneth Burke [38, p.4] wrote "Call a man a villain and you have the choice of either attacking or avenging. Call him mistaken and you invite yourself to attempt to set him right". I would add, "Call a person sick or crazy and all their behavior becomes dismissable". Because someone has been labelled ill, all their activity and beliefs—past, present, and future become related to and explainable in terms of their illness [20, 39]. Once this occurs, society can deny the validity of anything which they might say, do, or stand for. Being seen as the object of medical treatment evokes the image of many ascribed traits, such as weakness, helplessness, dependency, regressiveness, abnormality of appearance and depreciation of every mode of physical and mental functioning [17, 40, 41]. In the case of a person with a chronic illness and/or a permanent disability, these traits, once perceived to be temporary accompaniments of an illness, become indelible characteristics. "The individual is trapped in a state of suspended animation socially, is perpetually a patient, is chronically viewed as helpless and dependent, in need of cure but incurable" [17, p.420].

A second function of labelling is its potential for spread, pervasiveness, generalization. An example of such inappropriate generalizing was provided in a study by Conant and Budoff [42]. They found that a group of sighted children and adults interpreted the labels 'blind' and 'legally blind' as meaning that the person was totally without vision—something which is true for only a small segment of people with that designation. What was problematic became a given. Another example of this process occurs when disability and person are equated. While it is commonplace to hear of doctors referring to people as "the appendicitis in Room 306" or "the amputee down the hall", such labelling is more common in popular culture than one might believe. My own analysis of the crime-mystery genre [43], noted that after an introductory description of characters with a disability, they are often referred to by their disability—e.g. 'the dwarf', 'the blind man', 'the one-armed', 'the one-legged'. This is usually done by some third person observer or where the person with the disability is the

speaker. The disability is emphasized—e.g. "said the blind man". No other physical or social descriptor appears with such frequency.

Perhaps not unexpectedly, such stand-in appellations are most commonly applied to villains. They were commonplace during the heyday of the pulp magazines, where the disability was incorporated into their names—"One-Eyed Joe", "Scarface Kelly" a tradition enshrined in the Dick Tracy comic strips. It is a tradition that continues, though with more subtlety. Today we may no longer have "Clubfoot the Avenger", a mad German master-criminal who crossed swords for 25 years with the British Secret Service [44–51], but we do have "The Deaf Man", the recurring thorn in the side of Ed McBain's long-running (over 30 years) 87th Precinct novels [52–54]. All such instances can reinforce an association between disability, evil, and abnormality [55].

A very old joke illustrates the pervasiveness of such labelling:

A man is changing a flat tyre outside a mental hospital when the bolts from his wheel roll down a nearby sewer. Distraught, he is confronted by a patient watching him who suggests. 'Why don't you take one bolt off each of the other wheels, and place it on the spare?' Surprised when it works, the driver says. 'How come you of all people would think of that?' Replies the patient, 'I may be crazy, but I'm not stupid'.

This anecdote demonstrates the flaw in thinking that a person who is mad is therefore stupid or incapable of being insightful. As the social psychological literature has long noted, this is how stigma comes about—from a process of generalizing from a single experience, people are treated categorically rather than individually and are devalued in the process. devalued [56–58]. As Longmore so eloquently concludes, a "spoiling process" [59] results whereby "they obscure all other characteristics behind that one and swallow up the social identity of the individual within that restrictive category" [17, p.419]. Peters puts it most concretely: "The label that's used to describe us is often far more important in shaping our view of ourselves—and the way others view us—than whether we sign, use a cane, sit in a wheelchair, or use a communication board" [23, p.25].

While many have offered vocabulary suggestions to combat the above problems of connotation and pervasiveness, few have analytically delineated what is at stake in such name changes [17, 60, 61]. The most provocative and historically-rooted analysis is an unpublished paper by Phillips [32], who delineates four distinct strategies which underly the renaming. While she carefully notes that further investigation may change or expand her categorization, the very idea of her schema and the historical data describing the genesis of each 'recoding' remain timely.

'Cripple' and 'handicapped', as nouns or adjectives, she sees as primarily 'names of acquiescence and accommodation', reflecting an acceptance of society's oppressive institutions. Terms such as 'physically challenged' by so personalizing the disability run the risk of fostering a 'blaming the victim' stance [62]. Such terms, as well as 'physically different', 'physically inconvenienced', not only may be so euphemistic that they confound the public as to who is being discussed but also contribute strongly to the denial of existing realities [33]. Two other strategies represent a more activist philosophy. 'Handicapper' and 'differently-abled' are 'names of reaction and reflection' whose purpose is to emphasize 'the can-do' aspects of having a disability. To the group of Michigan advocates who coined the term [63], a 'Handicapper' determines the degree to which one's own physical or mental characteristics direct life's activities. Anger, says Phillips, is basic to "names of renegotiation and inversion" where the context sets the meaning. Perhaps the best examples occur when disability activists, in the privacy of their own circles, 'talk dirty', referring to themselves as 'blinks', 'gimps', or telling 'crip' jokes and expounding on the intricacies of 'crip' time. More controversy arises however, when people publicly proclaim such terms as a matter of pride. Recently, for example, many have written about the positive aspects of 'being deaf' [64, 65] or, even more dramatically of being a 'cripple' [66]. Kriegel [60, 61] says that 'cripple' describes "an essential reality", a way of keeping what needs to be dealt with socially and politically in full view. Nancy Mairs [67], a prize-winning poet who has multiple sclerosis, clearly agrees; and in the opening remarks of her essay, "On Being a Cripple", states it most vividly:

The other day I was thinking of writing an essay on being a cripple. I was thinking hard in one of the stalls of the women's room in my office building, as I was shoving my shirt into my jeans and tugging up my zipper. Preoccupied, I flushed, picked up my book bag, took my cane down from the hook, and unlatched the door. So many movements unbalanced me, and as I pulled the door open, I fell over backwards, landing fully clothed on the toilet seat with legs splayed in front of me: the old beetle-on-its-back routine. Saturday afternoon, the building deserted, I was free to laugh aloud as I wriggled back to my feet, my voice bouncing off the yellowish tiles from all directions. Had anyone been there with me, I'd have been still and faint and hot with chagrin.

I decided that it was high time to write the essay.

First, the matter of semantics. I am a cripple. I choose this word to name me. I choose from among several possibilities, the most common of which are handicapped and disabled. I made the choice a number of years ago, without thinking, unaware of my motives for doing so. Even now, I'm not sure what those motives are, but I recognize that they are complex and not entirely flattering. People—crippled or not—wince at the word cripple, as they do not at handicapped or disabled. Perhaps I want them to wince. I want them to see me as a tough customer, one to whom the fates/gods/viruses have not been kind, but who can face the brutal truth of her existence squarely. As a cripple, I swagger [67, p.9].

When Phillips' very titles may imply an evaluation of the particular strategies, it is clear from her own

caveats that while many may try to impose their terminology as "the correct language". "None feel really right" [23, p.25].

## 3. RECONTEXTUALIZING NAMES

The ultimate question, of course, is whether any of these renaming procedures, singly and alone, can deal with the connotational and generalization issues discussed previously. I would argue that the context of usage may be every bit as important (as Phillips implies) as the specific terminology. Thus one of the reasons for all the negative associations to many terms is a result of such contexts. Here social scientists, researchers and clinicians are particularly at fault in their medicalizing of disability [55, 68, 69]. In their writings and in the transmission of these writings by the popular press and media, people with varying diseases and disabilities are inevitably refered to as 'patients', a term which describes a role, a relationship and a location (i.e. an institution or hospital) from which many connotations, as previously noted, flow. For the 43 million people now designated as having a physical, mental or biological disability, only a tiny proportion are continually resident in and under medical supervision and are thus truly patients. Similarly, the terms 'suffering from', 'afflicted with' are projections and evaluations of an outside world. No person with a disability is automatically 'suffering' or 'afflicted' except in specific situations where they do indeed 'hurt' are 'in pain' or 'feel victimized'.

I am not arguing, however, for the complete elimination of medical or physical terminology. As DeFelice cautions. "The disabled movement has purchased political visibility at the price of physical invisibility. The crippled and lame had bodies, but the handicapped, or so the social workers say, are just a little late at the starting gate. I don't like that; it's banal. When we speak in metaphorical terms, we deny physical reality. The farther we get from our bodies, the more removed we are from the body politic. . ." [70].

One meaning I derive from his caution is that we must seek a change in the connotations and the pervasiveness of our names without denying the essential reality of our conditions. Thus biology may not determine our destiny; but, as with women, our physical, mental and biological differences are certainly part of that destiny [71, 72].

A way of contextualizing our relationship to our bodies and our disabilities may not be in changing terms but in changing grammars. Our continual use of nouns and adjectives can only perpetuate the equation of the individual equalling the disability. No matter what noun we use, it substitutes one categorical definition for another. An adjective, colors and thus connotes the essential quality of the noun it modifies. Such adjectives as 'misshapen', 'deformed',

'defective', 'invalid'—far from connoting a specific quality of the individual—tend to taint the whole person.

The same is true with less charged terms. Thus 'a disabled car' is one which has totally broken down. Could 'a disabled person' be perceived as anything less? Prepositions, on the other hand, imply both 'a relationship to' and 'a separation from'. At this historical juncture the awkwardness in phrasing that often results may be all to the good, for it makes both user and hearer stop and think about what is meant, as in the phrases 'people of color' and 'persons with disabilities'.

Distance and relationship are also at the heart of some very common verb usages. The first is between the active and passive tense. Note the two dictionary meanings:

Active—asserting that the person or thing represented by the grammatical subjects performs the action represented by the verb [73, p.12].

passive—asserting that the grammatical subject to a verb is subjected to or affected by the action represented by that verb [73, p.838].

Thus in describing an individual's relationship to an assistive device such as a wheelchair, the difference between 'being confined to a wheelchair' and 'using' one is a difference not only of terminology but of control. Medical language has long perpetuated this 'disabled passivity' by its emphasis on what medicine continually *does to* its 'patients' rather than *with* them [74, 75].

Similarly the issues of 'connotation' and 'pervasiveness' may be perpetuated by the differential use of the verbs 'be' and 'have'. The French language makes careful distinctions between when to use 'etre' (be) and when to use 'avoir' (have). English daily usage is blurry, but another look at Webster's does show the possibilities.

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be  = to equal in meaning
      to have same connotation as
      to have identity with
      to constitute the same class as [73, p.96].
have = to hold in possession
      to hold in one's use
      to consist of
      to stand in relationship to
      to be marked or characterized by
      to experience
      SYN—to keep, control, retain, or experience
      [73, p.526].
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Like the issue of nouns vs prepositions, verbs can also code people in terms of categories (e.g. *x* is a redhead) instead of specific attributes (e.g. *x* has red hair), allowing people to feel that the stigmatized persons are fundamentally different and establishing greater psychological and social

distance [76]. Thus, as between the active and passive tense, so it is between 'I am ...' Both specify a difference in distance and control in relation to whatever it is one 'is' or 'has'. And since renaming relates to alternative images of distance and control, grammar, which tends to be normative, concise, shared and long-lasting, may serve us better then sheer name change. Though I personally may have a generic preference (e.g. for 'disability' over 'handicap'), I am not arguing for any 'politically correct' usage but rather examining the political advantages and disadvantages of each [36].

For example, there may be stages in the coping with a particular condition or in the perceived efficacy of a particular 'therapy' (e.g. the 12 steps in Alcoholics Anonymous) when 'ownership' and thus the use of 'I am' is deemed essential. Those old enough to remember President Kennedy's words at the Berlin Wall, "*Ich bin ein Berliner*" (I am a Berliner), will recall the power of its message of kinship. Similarly, when we politically strategize as a minority group [77] and seek a kinship across disease and disability groups [78], the political coming-out may require a personal ownership best conveyed in terms of 'I am ...'

On the other hand, there are times when the political goals involve groups for whom disease and disability is not a permanent or central issue. On my university campus, for a myriad of reasons, people with mobility impairments are virtually non-existent. Yet we are gradually retrofitting old buildings and guaranteeing accessibility in new ones. The alliance here is among women who are or may become pregnant, parents with small children, people with injuries or time-limited diseases, and others who perceive themselves at risk, such as aging staff or faculty. They rarely see themselves as disabled but often admit to having a temporary disability or sharing a part of 'the disabled experience' (e.g. "Now I know what it's like to try to climb all those stairs"). Thus where coalition politics is needed, the concept of 'having' vs 'being' may be a more effective way of acknowledging multiple identities and kinship, as in our use of hyphenated personal and social lineages— e.g. Afro-American.

### 4. A FINAL CAVEAT

One of the sad findings in Phillips' study [32] is how divisive this struggle over names has become. People thus begin to chastize 'non true-believers' and emphasize to others 'politically correct' usage. In so doing, we may not only damage the unity so necessary to the cause of disability rights but also fail to see the forest for the trees. Our struggle is necessary because we live in a society which devalues, discriminates against and disparages people with disabilities [77, 79]. It is not our task to prove that we are worthy of the full resources and integration of our society. The fault is

not in us, not in our diseases and disabilities [41, 62, 80, 81] but in mythical denials, social arrangements, political priorities and prejudices [82].

Here too, a renaming can be of service not of us but of our oppressors [83]. As Hughes and Hughes [84] note, when we turn the tables and create epithets for our oppressors, this may be a sign of a beginning cohesiveness. Thus the growing popularity of terms like TAB's and MAB's (temporarily or momentarily able-bodied) to describe the general population breaks down the separateness of 'us' and 'them' and emphasizes the continuity and inevitability of 'the disability experience'. Thus, too, those who have created the terms 'handicappism' [85] and 'healthism' [68, 86, 87] equate these with all the structural '-isms' in a society which operates to continue segregation and discrimination. To return finally to the issue of naming, the words of Philip Dunne reflect well the choices and consequences of language:

If we hope to survive in this terrifying age, we must choose our words as we choose our actions. We should think how what we say might sound to other ears as well as to our own. Above all, we should strive for clarity ...
... if clarity [is] the essence of style, it is also the heart and soul of truth, and it is for want of truth that human freedom could perish [88, p.14].

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