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"TRY HARDER": THE EXPERIENCE OF DISABILITY AND THE DILEMMA OF NORMALIZATION*

ABSTRACT

In American culture, individuals with disabilities continue to be beset by contradictory notions of what for them is meant by success. Increasingly, however, there is an ideological shifting away from traditional and stereotyped definitions of success, such as acquiescence and normalization, to individual and context-specific definitions of success, such as adaptation, renegotiation, and inversion. Service providers, particularly rehabilitation practitioners, may need to reassess and to better accommodate these new ideological underpinnings, a process which may entail their further retreating from the medical model, and their individualizing of the rehabilitation process.

Over an eighteen-month period, during my residence in a midwestern university town, I documented oral narratives from twenty females and thirteen males with various physical disabilities.[1] Informants range in age from twenty-one to early sixties. Two-thirds have been disabled since early childhood. All except two are Caucasian, these two being racially mixed but reared in predominantly Caucasian environments. My informants share other demographic characteristics, having higher than average educational levels though lower than average socio-economic levels in comparison with their able-bodied peers.[2] (All informants cited are referred to by pseudonym and their identities disguised to preserve their privacy.)

DILEMMA

For persons with disabilities, the dilemma of "trying harder to succeed" involves, first and foremost, a determination of what is meant by success. Does success mean the pursuit of normalization, or even the illusion of normality, at all costs? Or does success mean, as one informant quipped, "becoming a professional handicapper," that is, becoming an individual known primarily by his or her disability?[3] At what point can the disabled person shed the social stereotypes and be accepted as an individual who is also physiologically different? And at what point can those with disabilities relinquish the stereotyped handicapped roles, sometimes as secure as they are suffocating, in their pursuit of uniqueness and individuality?[4]

For many of my informants, their own ambivalence about the cultural value of perseverance is further complicated by rehabilitation practitioners' objectives of normalization, particularly when informants perceive such objectives to be inconsistent with their personal expectations and goals. It is true that the explicit objective of the rehabilitation paradigm is that the client "attain his maximal potential for normal living," with an emphasis on potentiation and not necessarily on normalization.[5] However, informants report that in their rehabilitation experiences it was normalization, and not necessarily potentiation, that was emphasized. Informants indicate that for the most part they respected their practitioners as individuals; yet, they also express their ambivalence toward what they perceive to be an implicit goal of the rehabilitation process, namely normalization. I say "ambivalence" because informants did discuss their own desires to achieve normality while claiming distrust for those practitioners who emphasize normalization.

A significant variable in informants' determination of success is an ideological shift—away from absolute belief in the rehabilitation paradigm and towards a perception of their minority status, this latter consciousness apparently wrought by the disability rights movement. This factor of ideology appears to affect whether and to what degree informants define success in terms of social or personal accomplishment. Their narratives identify five major kinds of success: acquiescence, normalization, adaptation, renegotiation, and inversion. The first two are invoked for social success, and the last three for personal success. No informant subscribed solely to one or another of these definitions; in fact, most vacillated among the five. Such vacillation suggests that theirs are not static, but dynamic approaches to definitions of success. That is, their definitions vary according to context-specific situations and to accomplishment (social or personal) desired. These definitions of success are part of a dynamic, and even transformational process by which the individual attempts to assert control over his or her unique disability-related experiences.[6]

First to be considered are three ideological frameworks which provide the basis for the informants' ambivalence, and influence their selection of a particular success definition: the cultural notion of perseverance, the rehabilitation model, and the social minority model. Following these are analyses of the five definitions of success given by informants in their oral narratives.

THE CULTURAL NOTION OF PERSEVERANCE

Americans are enjoined to succeed in all undertakings. As Ortner observes, the traditional Horatio Alger story remains a key scenario in American culture, promising even those of a lowly birth the opportunity, if they try hard enough, to achieve success. Although the more sophisticated twentieth-century poor-boy-makes-good premise can be disputed, the popular media are replete with stories about Americans who persevere, who believe that hard work pays off. Surely a notion so ingrained in the American psyche influences the manner in which individuals with disabilities are expected to "overcome" all obstacles in their pursuit of a higher station, in their pursuit of normality.[8]

From the perspective of the American ethos, "if you try hard enough, you will succeed," and even beyond its manifestations in the popular images of a Franklin Delano Roosevelt or a Helen Keller, there continue to be cultural exaltations of disabled persons who "try harder" in their pursuit of normalization.[9] Such lauding of the perseverance of disabled persons most recently was demonstrated in the extensive media coverage of spinal cord-injured Nan Davis's working-to-walk campaigning.[10] Indeed, slogans modeled on such an American ideal have facilitated fund-raising for, among others, the Sister Kenny movement in the 1940's and 1950's, for which the motto "They shall walk again" promised the American people that contributions would inspire "crippled" children to try harder.[11] More modern campaigns, particularly the controversial Jerry Lewis Telethon for Muscular Dystrophy, assure the public that their financial contributions will permit medical researchers to work ever diligently to find cures, while those already "afflicted" will continue to persevere. Implicit in such pronouncements is a belief that perseverance will result in the defeat of disability (although "overcoming" a disability is a viable symbolic alternative); also, such perseverance presumes the individual's goal of the resumption of physiological normality and, ideally, of the return to societal responsibilities.[12]

THE REHABILITATION MODEL

In American culture, it is primarily the rehabilitation process which assists the disabled individual to recoup those American virtues, independence and self-reliance, supposedly lost due to disablement. In cases of those disabled since birth or childhood, such attributes are presumed not even to have been instilled through "normal" socialization processes.[13] This medical model approach increasingly is refuted by practitioners who recommend instead the individualizing of the rehabilitation process to identify specific needs and goals of each client, rather than to subsume the client to the social goals of normalization and physical restoration.[14]

The problem of individualizing the rehabilitation process had been addressed by some practitioners even before the advent of the disability rights movement. For example, in her classic work, Wright decries the "overriding potency" of "normal behavior" used as the standard by many rehabilitation practitioners. She concedes, however, that the standard of achieving normality might be abided when (1) increasing the disabled person's awareness of physiological potential helps to avoid the internalization of the notion of spread; (2) permitting the individual to cling to the normal ideal serves as a transition to recognition of real limitations; (3) normalizing interactional mannerisms (social etiquette) enhances the disabled individual's sociability; and (4) permitting the disabled individual to undergo even painful physiological restoration affects positively the psychological adjustment to the disability.[15]

Wright also cautions practitioners to avoid the deification of normality and suggests that instead they guide the disabled individual, particularly the newly disabled individual, through the predictable phases of mourning, learning to subordinate physique, and containing disability effects.[16] Although Wright allows that normalization might be abided, she counsels the practitioner nevertheless to try to effect changes in the disabled individual's belief systems, for requisite to self-acceptance the disabled individual must retreat from negative social images and accept the "difference as nondevaluating." Less than such acceptance (including denial) Wright believes to result in maladjustment. In addition, although Wright is cognizant of the many negative societal reactions to physical disability, she still contends that American cultural attitudes toward "atypical physique" are conflicting, that is, "viewing [it] on the one hand as a sign of inferiority, and on the other hand as neutral or even as an indication of virtue and goodness meriting special reverence." She concludes with a telling question: "Why is it [then] that the person with a disability focuses on the personally more devastating side of the conflict?"[17]

Thus, Wright's classic work clearly, though unintentionally, illustrates the cultural preconceptions toward disability ingrained even in advocate professionals. On the one hand, Wright vehemently rejects the notion that physically disabled persons collectively are psychologically different from their able-bodied peers. On the other hand, she suggests that disabled individuals are psychologically similar, perhaps even pathologically so, in that they often choose to focus "on the devastating side of disability" rather than on their "superior status."[18] Significantly, other scholars in the field of the psychology of disability make assumptions of maladjustment even as they argue for clients' rights to be treated as individuals. Notably an exception, DeLoach and Greer attribute more to the social dimension of adjustment and argue for the practitioner's responsibility to advocate social reform, and Vash concludes that activism is for the disabled individual the culmination to any personal "transcendence."[19] Still, in effect these analyses of the social and psychological contexts for disabled persons are an accurate portrayal of the quixotic interpersonal environment in which disabled persons must self-determine their social and personal goals, and, therefore, their own definitions, of success.[20]

Indeed, informants report that the rehabilitation model, even in its modern meliorative orientation, still orients both practitioner and client to "try harder" to effect personal adjustment *to* society. As Hey and Willoughby point out, such a posture of adjustment to society may reinforce among clients and society stereotypic notions about the helplessness of disabled persons, resulting in a perpetuation of their social and economic segregation.[21] Moreover, Hahn notes, out of an amalgam of admiration and sympathy and pity has grown a cultural paternalism which guides the development of a welfare-oriented, rather than a work ethic-oriented, public policy for the disabled.[22] Roth as well cautions that "like motherhood and apple pie" disabled people often are free from overt attack, particularly since their physical characteristics may elicit sympathy; but covertly this "aura of paternalism" continues to "permeate relations between disabled and nondisabled segments of the population," perhaps reinforcing rather than eradicating the social and self-perceptions of disabled individuals' inferiority, and consequently their predilection for failure.[23]

THE SOCIAL MINORITY MODEL

What concerns the informants who are active in disability rights is that the rehabilitation model, even as liberalized by Wright and others, continues to focus on their victim status and their problems as stigmatized persons, rather than assisting disabled persons in redefining criteria by which success (or normality) is measured. As informant Jacob Lind retorts, "There is nothing

wrong with me!"—a position in accordance with Goffman's contention that normal and stigma are not qualities inherent in persons but rather social perspectives.[24]

Regional and national disability rights movements have engendered in persons with disabilities a belief in their social minority status and a rejection of their culturally assigned anomalous status. Indeed, the notion of "normal" is mocked by those who remind able-bodied of their own vulnerability, taunting them with the label t.a.b. (temporarily able-bodied); and many disabled persons seek to be regarded as a distinct group which functions to enhance the physiological diversity of the larger culture.[25] In decades past, disabled role models included not only the famous among the perseverant, but also common men and women, and often children, whose perseverance against the odds was captured in inspirational stories of their lives.[26] In stark contrast, role models during the apex of the disability rights movement were abstractions of the "radical cripple," whose countenance and rhetoric generated a sense of extended community among diverse and divergent groups of disabled persons.[27] Indeed, even those disabled perceived to have been smothered by social exclusion and segregation, such as those living in institutions, often heeded the rhetoric calling for independence and self-reliance. Now, in the eighties, disabled role models may have become abstractions *not* of a personality type, but once again of traditional American ideals. That is, many disabled individuals, like their able-bodied peers, desire success, not necessarily within the social isolation of their group, but rather, "in the real world."

In the past there have been numerous success stories about those who have overcome handicaps.[28] The newer notion of "real world" success appears to be different from what Roth describes to be (former) acquiescent notions of overcoming and adjusting.[29] The current variant, influenced greatly by the disability rights movement but also by traditional American virtues and values, is a composite of accommodation and potentiation: assimilation *sans* denial. Someone, like informant Jacob Lind, who desires a hiatus from involvement in the disability rights movement in order to achieve success in the "real world," does not deny his disability, nor does he feel that he must adjust to society, nor abandon the cause, nor reject his social minority status. Rather, he believes that he has a contract with society, an expectation that society will act responsibly by accommodating his physiological differences and needs (primarily through the removal of architectural barriers) and that he will act responsibly by striving to be self-reliant and independent. For Jacob, the social minority model is the means by which consciousness is raised for socio-political action not only for collective gains, but also for individual success. Although the disability rights movement professes an ideology of activism, as Roth notes, it also affirms an "overwhelmingly and classically literal [ideology] . . . to be included in the social contact that has been part of this nation since its foundation.[30] The narratives of informants are replete with speculations about a new status quo, a new society, and a new social structure—a radical rhetoric. But, by and large, these informants demonstrate the ideals of a liberal ideology in their pursuit of success. The conflict they feel, the dilemma that they have, is how to maintain a positive self-image and achieve personal success, while striving for a successful social image in a society which is reluctant to accommodate, for social, political, and economic reasons, their physiological differences.[31]

DEFINITIONS OF SUCCESS IN THE NARRATIVES

Many of my informants feel caught in this dilemma. It is reasonable that they desire to maximize and/or restore their physiological abilities, yet some feel ambivalent about capitulating to societal pressure to achieve form and function normality. To illustrate, some informants have elected *not* to spend time and energy learning how to walk again. Frank Congress, for example, rejects ambulation with the same intensity of conviction that popular media's Nan Davis exhibits in her working-to-walk campaign. Robert Bell admits that he "would like to be able to stand up long enough to lift his wheelchair over the curbs," but acknowledges that he is unwilling to expend his energy indefinitely in the pursuit of becoming ambulatory once again, especially in lieu of furthering his professional career. Jonathan Webb reveals that he "doesn't really mind" using a wheelchair the rest of his life, if "only [he] could use [his] arms again." In contrast, Bonnie Anderson indicates why she perseveres, through numerous surgical procedures and continuous physical therapy, to achieve ambulation: "Because they respect you more if you can 'stand up' to them!" But perhaps even Bonnie's extensive surgical experiences have resulted in more than physical restoration. As Macgregor infers, the process itself of restorative surgery can be a positive factor in the individual's self-esteem, providing for self and for others evidence of one's social success in maximizing form and function capabilities and of one's personal success in determining the fate of his or her own body, a body perceived to be "out of control."[32] As informants relate in their narratives, each disabled person individually must negotiate the parameters of these definitions of success.

Success-as-normalization is marked by affiliation with "normals," distinctiveness as a handicapped person (overcoming), and disaffiliation from those perceived to *acquiesce* to the "cripple role." Others define success as a continuous *adaptation* of the environment to individuals' physiological needs. Some recount other strategies, including *renegotiating* social definitions of normality, or *inverting* the social stereotypes associated with disability. The majority evidence a complex approach to their selecting appropriate strategies for social interaction and personal satisfaction. For example, one disabled individual alternately may invoke success-as-normalization and success-as-adaptation to achieve social goals, yet acquiesce to the "cripple role" in order to manage, or to manipulate, one discrete situation. It is notable that I have *not* found any direct correlation between approaches selected and personality or physiological types. It does appear, however, that the disability rights movement has influenced individuals to retreat from acquiescence and normalization, and instead to define success in terms of adaptation, renegotiation, and, perhaps indirectly, inversion. My informants describe myriad contexts in which they define success, each definition according to a specific social or personal accomplishment desired. Following are cases illustrating such context-specific approaches to their definitions of success.

The Case of Jessica Howard

In a 1955 essay on the circular problems and double standards confronting ethnic minorities, Riesman makes an analogy to the "cripple [making use of] his misery . . . for fragmentary purposes."[33] Inadvertently, Riesman affirms the then-prevalent cultural assumption of the "cripple's" role. Unfortunately, the stereotype of the disabled person as dependent, helpless, weak and passive still is prevalent, particularly among the nondisabled public but also among persons with disabilities.[34] To be associated with the "cripple role" is tantamount to being assigned permanent child status. However, among my informants, it is rarely financial or physiological dependency that defines such acquiescence. They, like Riesman, define the "cripple role" as the manipulation of disability to achieve success, however "fragmentary." Yet, unlike Riesman, the informants do *not* believe that the majority of disabled persons play such a role.

Not surprisingly, none of the informants define their own behavior in terms of acquiescence, although some mention suspicious strategies used by others. And, on occasion, some reveal in amusement, or in guilt, a "cripple" behavior to which they capitulated in order to accomplish a short-range goal. Most adamantly resent society's perception of an individual's ability to be independent and productive solely in terms of physiological abilities. Certainly, several of my informants may be perceived to be dependent and nonproductive, yet through their labor they in fact do contribute to the community.

Jessica Howard, who has multiple sclerosis (MS), relies on Social Security Insurance benefits; she also works as a volunteer at a community outreach center. She reciprocates in this way in order to retain her independence to think and to choose for herself. Although Jessica may appear to acquiesce because she requires financial and physical assistance, she does take responsibility for her own destiny, a responsibility hard won after her last MS exacerbation. It was then, after being institutionalized because rehabilitation practitioners presumed her to be dependent and helpless, that Jessica reassessed her own definitions of normality. She determined that "health was not all there is to being alive," and independence is taking responsibility for her own survival. Although Jessica physically may appear to be acquiescent, she defines success as a renegotiation of society's notions of independence and self-reliance, indeed, of normality itself.

The Cases of David Simmons and Rebecca Johnson

One problem with success-as-normalization is its ambivalent message, a message which entreats disabled individuals to reform not only society but also to transform themselves by simultaneously rejecting and affirming the ideal of normality. Success-as-normalization requires the individual to transcend human frailties (including the cultural valuation of normal physique), ameliorate those social ills which beset disabled persons, and appear and behave as normally as possible without deifying normality. Adaptation, on the other hand, means the conversion of the environment to the specifications of diverse physiologies, as in the application of new technologies.

That success definitions also are related to personal and even ideological perspectives is illustrated in the cases of two individuals whose cerebral palsy greatly impedes their speech patterns. David Simmons is in his mid-twenties and is active in social functions held by the regional Center for Independent Living. A chair user, David is also physically limited to the extent that he requires assistance with virtually all activities of daily living (ADL). In addition, he is unable to speak in a manner comprehensible to most individuals with whom he interacts. David has few options in meeting his desire to communicate with others. He might elect to continue speech therapy and struggle to pronounce, albeit slowly and laboriously, a few words at a time. Instead, he opts to use a communication board, a system replete with deficiencies in that his vocabulary is limited by the constraints of space, but a system which does increase the numbers of persons with whom he can, at least potentially, communicate.[35]

Rebecca Johnson, on the other hand, rejects such devices. She, too, has cerebral palsy and is a chair user. She has more mobility than David, as she is able to use her feet to push around a manual wheelchair and her hand to operate a battery-run wheelchair. An attractive woman in her late twenties, who insists on being well-groomed and expertly made-up, Rebecca has extended her strong sense of public presentation to her attempt to speak normally.[36] In spite of her efforts, those who know Rebecca well still have some difficulty understanding her particular style of speech. Others, however, find her way of speaking extremely difficult to comprehend, straining to listen to each syllable and then piecing together words they do understand with phrases that they do not.[37] Because Rebecca has some control over her speech, she attempts to potentiate whatever ability she has. On the other hand, in her struggle for what appears to be normalization, an independence from nonconventional methods and devices, she restricts the number of those with whom she can interact. The key to the difference between the approaches selected by David and Rebecca is not either's resistance to "trying harder" to achieve success, but rather their individual definitions of success.

Regarding their use of wheelchairs, both David and Rebecca define success as adaptation, the conversion of environment or mechanical devices to accommodate unique physiological characteristics. Yet, each approaches success at communication from different perspectives and with different goals. David accommodates others as well as himself, for although communicating with the board takes time for both David and reader, the reader's patience is not overly taxed. After observing David at length, however, I began to realize that he is assertive and in control of the communication process. First, he has immediate access to interactions with strangers. It is true that many may react negatively to his disability and his physique. Yet, because of the communication board, he is approachable to the extent that his "speech" is universalized, and can be understood even by strangers. Second, he adapts these aids not only to his own physiological limitations, but also to others' limitations (tolerance and time). Perhaps his is not a radical approach, but he achieves success by accomplishing social interaction otherwise unavailable to him, as well as easing some of the personal isolation resulting from his physiological limitations.

In contrast, Rebecca appears to choose as close an approximation to normality as possible, even though the result is that she communicates with only a few. It is also plausible that Rebecca, a gregarious person, resists using any devices which might impede her expressive non-verbal communication, an important aspect of body image (form maximization).[38] What is notable about Rebecca is her activism; she has participated in picketing and campaigned for disability rights. What appears to be her desire to achieve normality may, in fact, be her renegotiation of the definition of what is normal speech. Her decision to speak, rather than to use aids or mechanical devices, is an assertion of her right to control the means by which she communicates with others. For some, Rebecca's stance is stubborn and self-defeating. Yet Rebecca is challenging the tradition of disabled persons' accommodating to the nondisabled world.

Defining Mobility as Personal or Social Success

Each of the informants approaches function restoration and maximization differently, as is illustrated in their choices of mobility devices. Increasingly, battery-run wheelchairs are used not only by those for whom manual wheelchairs are inoperable, but also by those for whom the operation of manual wheelchairs requires an extraordinary and sometimes wasteful output of energy.[39] For Jacob Lind, the motorized wheelchair allows mobility independence and is a symbol of his freedom: "[When I went to college] voc rehab provided me with a motorized wheelchair, and so I was experiencing things for the first time in my life, being alone, and being forced to deal with the outside world, and forcing *them* to deal with me. I loved it!" Jacob adapts technology and a new environment (architectural accessibility) to his physiological needs. He is also, however, renegotiating definitions of the "appropriate place" for persons with disabilities.

On the other hand, other informants consider the use of mechanical devices indicative of a loss of control over the disability. Len Richardson, who has multiple sclerosis, uses a wheelchair only at work to facilitate his mobility there, although he is ambulatory at home and outside. He expresses a reluctance to "capitulate" to a more permanent use of a wheelchair, although he is unable to walk more than fifty feet. Yet Len feels that he must resist using devices which not only mark, but also may exacerbate the progressive nature of his disability. He believes he is able to monitor his physiological changes by alternating his modes of mobility. In addition, because of his even limited ambulation, he feels less isolated in a society which remains wheelchair inaccessible.

In contrast, Frank Congress regards his sportschair as an asset to his mobility. Frank, who lost both legs in an industrial accident, at first accepted the notion that to look and to act "normal" he would have to wear artificial legs. As he began to determine his own mobility needs, he rejected the physiological normalization afforded by prostheses. He chooses instead to adapt a mechanical aid, a sports wheelchair, to his needs, including his participation in wheelchair basketball. Also, to invert (and spoof) some of the social stereotypes about appropriate disability-related behavior, Frank relishes dramatizing his freedom from prostheses—unabashedly performing handstands on his sportschair, leg stumps jutting skyward.[40]

Some informants do continue to work toward physiological restoration. Bonnie Anderson uses a wheelchair, yet she continues to undergo corrective surgery so that one day whe will be able to walk. Bonnie defines success pragmatically, hoping to increase her employment prospectives by being ambulatory. Although she rigorously supports architectural accessibility, she also affirms both the personal and the political importance, for her, of the restorative process: She quite literally desires to "stand up to" the able-bodied. Bonnie's ideological stance is that persons with disabilities must renegotiate definitions of normality: "We have 'physical characteristics,' *not* disabilities." Still, she is pragmatic about restoring her function to as close to "normal" as is possible. Bonnie defines success as a personal evolution: First, a retreat from the deification of normality; second, an identification with the disabled collective (the social minority model); third, an acceptance of social responsibility to maximize physiological capabilities; and, fourth, an assertion of the right to control all decisions regarding one's body and one's life goals.

CONCLUSION

Of the informants cited here, Bonnie Anderson is perhaps the most reflective about the transformational process resulting from her disability-related experiences. The concept of transformation does not necessarily imply a progression through predictable stages or phases, although Bonnie does describe hers as a personal evolution. Nor does transformation denote what Vash calls transcendence, a deification of disability, and a kind of inversion of the cultural obsession with normality.[41] Transformation is akin to a new individualism arising from the achievements of the disability rights movement. Ironically, out of this collective movement and out of disability kinship emerges an assertion of uniqueness and the right to individuality. Primarily it involves the disregarding of deviant status and inferior roles associated with the acquiescent "cripple role." Of course, such disavowal of deviance is not a new concept but traditionally was associated with the normalization process.[42] What is new is that the former ideal of normalization now is perceived to have been but a grand deception.[43] Certainly, my informants express that as a result of the movement they have a new belief in their ability to control their own destinies without capitulating totally to normalization. They have disregarded the old strategies of defining social or personal success solely in terms of acquiescence and normalization, and have embraced new strategies of adaptation and renegotiation, even of inversion.[44] Still, the new definitions are strongly influenced by the liberal ideologies of American notions of trying harder to achieve independence and self-reliance. Yet, they are not merely new packaging for old liberal philosophies. They are different conceptual frames, different perceptions of self and of society.[45]

The oral narratives of my informants reveal all these ideological underpinnings of their definitions of success. My findings indicate that for my informants defining success is a complex and dynamic process, and specific to each context and each new situation. They resist acquiescence, but acknowledge the social benefits that may accrue from playing the "cripple role." They have ambivalent feelings about normalization, resenting socially-imposed criteria; but they do identify personal criteria for the potentiation of their physiologies. These personal criteria may involve renegotiation of cultural notions of normality, although at times the physiological outcome may be the same. However, it is the process which is most meaningful to them, as it is based on the new ideological perspective of their social minority status: They believe, or portend to believe, in their difference, not deviance.[46]

Perhaps the most significant social implication of these findings involves a reassessment of the rehabilitation process. Although for many disabled individuals the rehabilitation experience is relatively short, its effects on individuals may be far-reaching. Certainly there is a cultural perception that persons with disabilities perpetually engage in rehabilitation, "trying hard" to achieve normalization. Newly disabled individuals particularly are affected by what may become for them an unending pursuit of form and function restoration. If they do not succeed at defeating their disability, they may presume that they have failed. As Scott reports, the rehabilitation process may accommodate, rather than defuse, such perceptions.[47]

One aspect of this problem which was expressed in my informants' narratives is an over-emphasis on the value of protheses and cosmeses. They claim that the message too often is normalization through technology, rather than the adaptation by the individual of those devices relevant not only to physiological needs, but, also, and perhaps more importantly, to ideological perspectives. The rehabilitation model may need to accommodate these new perspectives and these non-traditional strategies, including the rejection by disabled persons of notions of "disability-appropriate behavior," another concept anathema to the new ideology.[48] This involves not only individualizing rehabilitation, but also a commitment to and respect for diverse definitions of success which may be inconsistent with the traditional goals of rehabilitation, or with the cultural notions of the meaning of success for persons with disabilities.

NOTES

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1. Marilynn J. Phillips, "Oral Narratives of the Experience of Disability in American Culture," Diss., University of Pennsylvania, 1984. See also, Sandra K. D. Stahl, "The Personal Narrative as Folklore," *Journal of the Folklore Institute,* vol. 14 (1977), pp. 9–30.
2. See Michelle Fine and Adrienne Asch, "Disabled Women: Sexism Without the Pedestal," *Journal of Sociology and Social Welfare,* vol. 8 (1981), pp. 233–248, for data on low socio-economic status of disabled women and men.

3. The term "handicapper" was used regionally where I did my fieldwork. This term illustrates the concept of "master status" in the sociology of deviance. See H. Becker, *Outsiders* (New York: Free Press, 1963).

4. See Alan Gartner, "Images of the Disabled: Disabling Images," *Social Policy* (Fall, 1982), pp. 14–15, on destructiveness of "handicapped roles."

5. Frank H. Krusen, "The Scope of Physical Medicine and Rehabilitation," in *Handbook of Physical Medicine and Rehabilitation* (2nd ed.), edited by F. Krusen, F. Kottke, and P. Ellwood (pp. 1–12) (Philadelphia: W. B. Saunders, 1971).

6. See Marilynn J. Phillips, "Disability and Ethnicity in Conflict: A Study in Transformation," in *Disabled Women: Psychology from the Margins*, edited by A. Asch and M. Fine (Philadelphia: Temple University Press, forthcoming 1985), for elaboration on transformation as a form of personal success.

7. Sherry B. Ortner, "On Key Symbols," *American Anthropologist*, vol. 75 (1973), pp. 1338–1446.

8. See John Gliedman and William Rother, *The Unexpected Minority* (New York: Harcourt Brace Jovanovich, 1980), on disabled as a social minority.

9. See E. Looker, *The American Way: Franklin Roosevelt in Action* (New York: John Day, 1933); Joseph Alsop, "Roosevelt Remembered," *Smithsonian Magazine* (January, 1982), pp. 45ff.; Joseph P. Lash, *Helen and Teacher* (U.S.A.: Delcorte Press, 1980).

10. Reported on *C.B.S. 60 Minutes*, 14 November 1982.

11. See Victor Cohn, *Sister Kenny* (Minneapolis: University of Minnesota Press, 1975), and Sister Elizabeth Kenny and Martha Ostenso, *And They Shall Walk Again* (New York: Dodd, Mead, 1943).

12. See Talcot Parsons, *The Social System* [1951] (New York: The Free Press, 1967), on the social responsibility of the "sick" to get well.

13. See Carolyn Vash, *The Psychology of Disability* (New York: Springer, 1981), on "habilitation" of born disabled.

14. Charlene DeLoach and Bobby G. Greer, *Adjustment to Severe Physical Disability* (New York: McGraw-Hill, 1981).

15. Beatrice Wright, *Physical Disability: A Psychological Approach* (New York: Harper & Row, 1960), pp. 13ff.

16. See also Nancy Kerr, "Understanding the Process of Adjustment to Disability," in *Social and Psychological Aspects of Disability*, edited by J. Stubbins (Baltimore, MD: University Park, 1977), on the stages of psychological adjustment to disability.

17. Wright, *op. cit.*, p. 106.

18. In contrast, Vash notes that such "special reverence" categorically accorded those with disabilities may be merely a form of latent hostility toward the disabled, and not necessarily an expression of a positive cultural attitude.

19. See DeLoach and Greef, *op. cit.*, and Vash, *op. cit.*, p. 133, on the influence of Jung on her theories, particularly his essay, "The Problems of Modern Psychotherapy."

20. See Erving Goffman, *Interaction Ritual* (Garden City, N.Y.: Doubleday Anchor, 1967), on predictable interactions in culture.

21. Stephen C. Hey and Gary Willoughby, "Emerging Trends Among Rehabilitation Workers for the Blind," in *Social Aspects of Chronic Illness, Impairment and Disability*, edited by S. Hey, G. Kiger, and J. Seidel, pp. 4–14 (Salem, Oregon: Society for the Study of Chronic Illness, Impairment and Disability and Willamette University, 1984).

22. Harlan Hahn, "Paternalism and Public Policy," *Society*, vol. 20 (1983), pp. 36–46.

23. William Roth, "Handicap as a Social Construct," *Society*, vol. 20 (1983), pp. 59–60.

24. Erving Goffman, *Stigma* (Englewood Cliffs, N.J.: Prentice-Hall, 1963).

25. McCay Vernon and Bernard Makowsky, "Deafness and Minority Group Dynamics," *The Deaf American*, vol. 21 (July–August, 1969), pp. 3–6.

26. See, among others, Marie Killilea, *Karen* (New York: Prentice-Hall, 1952).

27. See Judy Heumann, "Consumer Perspective," in *Proceedings of an International Symposium: What Ever Happened to the Polio Patient?*, edited by D. Olsen and E. Henig, pp. 141145 (Chicago: The Education and Training Center, Rehabilitation Institute of Chicago, n.d.), for notion of cross-disability unity.

28. See Andrienne Asch and Lawrence H. Sacks, "Lives Without, Lives Within: Autobiographies of Blind Women and Men," *Journal of Visual Impairment and Blindness* (June, 1983), pp. 242–247.

29. Roth, *op. cit.*, pp. 56–61.

30. *Ibid.*, p. 59.

31. See Gerben DeJong and Raymond Lifchez, "Physical Disability and Public Policy," *Scientific American*, vol. 248 (1963), pp. 40–47, on society's failure to accommodate disabled persons.

32. Francis Cooke Macgregor, *Transformation and Identity* (New York: Quadrangle, 1974); see also Mary Douglas, *Purity and Danger* (London: Routledge & Kegan Paul, 1978), on the body as a symbol of order/disorder.

33. David Riesman, "A Philosophy for 'Minority' Living," in his *Individualism Reconsidered* (Garden City, N.Y.: Doubleday Anchor, 1955), p. 57.

34. See Fine and Asch, *op. cit.*

35. See Elizabeth Helfman, *Blissymbolics* (New York: Elsevier/Nelson, 1980), on communication boards; and "Computers and the Disabled," Special Issue, *Byte*, vol. 7 (September, 1982), on voice synthesizers.

36. See Erving Goffman, *The Presentation of Self in Everyday Life* (Garden City, N.Y.: Doubleday Anchor, 1959).

37. Such speech patterns may be like "speech styles" discussed by socio-linguists; see Dell Hymes, "Ways of Speaking," in *Explorations in the Ethnography of Speaking*, edited by Bauman and Sherzer, pp. 425–432 (London: Cambridge University Press, 1977).

38. Ray L. Birdwhistell, *Kinesics and Context* (Philadelphia: University of Pennsylvania Press, 1970), on body movement as communication.

39. See Raymond Lifchez and Barbara Winslow, *Design for Independent Living* (New York: Watson-Guptill, 1979), on "liberating" mechanical aids.

40. See Mary Douglas, *Natural Symbols* (New York: Vintage, 1973), on the body as a social symbol.

41. Vash, *op. cit.*

42. See Fred Davis, "Deviance Disavowal: The Management of Strained Interaction by the Visibly Disabled," *Social Problems*, vol. 22 (1975), pp. 548–557.

43. See Hugh Gallagher, *FDR's Splendid Deception* (New York: Dodd, Mead, 1985), on the former President's denial of his disability and his pursuit of normalization.

44. See Bruce Jackson, "Deviance as Success: The Double Inversion of Stigmatized Role," in *The Reversible World*, edited by B. A. Babcock, pp. 258–275 (Ithaca, N.Y.: Cornell University Press, 1978).

45. See Gregory Bateson, *Steps to an Ecology of Mind* (New York: Ballantine Books, 1978).

46. See Peter L. Berger, *A Rumor of Angels* (Garden City, N.Y.: Doubleday, 1969), on the concept of the cognitive minority.

47. Robert A. Scott, *The Making of Blind Men* (New York: Sage Foundation, 1969).

48. See Wilbert E. Fordyce, "Psychological Assessment and Management," in *Handbook of Physical Medicine and Rehabilitation* (2nd ed.), edited by F. Krusen, F. Kottke, and P. Ellwood, pp. 168–195 (Philadelphia: W. B. Saunders, 1971), on rehabilitation practitioners' need to instill in the newly disabled person a disability-appropriate behavior.