

Best Practices in Disability Studies

Not Just Academic: How Sociologists and Anthropologists Promoted Inclusion in the Community for Individuals with Disabilities

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Abstract: My aim in this essay is to renew interest among new generations of leaders in the field in the contribution of Erving Goffman and his disciples to understanding their impact on the promotion of inclusion in the community for individuals with disabilities. Goffman's focus on interaction, where identities are arrived at, or where strong status differences establishes identities, was a foundation for disability studies and the development of new policies contributing to the transformation of government-directed program responses to disabilities in the second half of the twentieth century in many countries. I follow this remarkable change in approach via the work of sociologists and anthropologists who adopted Goffman's conceptualization of total institutions and stigma, through to contemporary studies of inclusion.

Keywords: Goffman, Disability, Sociology

Until the 1970s, the practice of placing people with intellectual and developmental disabilities (IDD) in large and isolated settings was regarded as both humane and legally correct. Then, some community-based voluntary associations sought legal redress for patterns of abuse, neglect and deprivation in such facilities. A noted challenge to keeping individuals with IDD in state schools is found in *Halderman v. Pennhurst State School & Hospital*, 446 F.Supp. 1295 (E.D. Pa., 1977). This litigation encouraged the development of new community options and the close of facilities in a number of states.

It may be hard for students in disability studies programs to understand how American society could simply put away this population. Nevertheless, separation and isolation was the public policy in all the states, with these qualities considered to be a way of making society a better place and a form of protection for those who could not fully take care of themselves.

A reversal of thinking and practice took place. As in the Pennhurst decision, courts often upheld the rights of individuals with IDD who lived in large and isolated state schools, also known as asylums, to active treatment and return to the community. The practice of "warehousing," as it became known, was replaced by new policies of community care. Reformers in the United States learned about established humane policies and practices in the United Kingdom and the Scandinavian countries that could serve as models for change (Wolfensberg, 1969; Kushlick, 1975; Tizard, 1964, Kugel and Wolfensberger, 1969).

Change in disability practice came from diverse sources, including social science concepts and research. My aim in this essay is to renew interest among new generations of leaders in the field in the contribution of sociologist Erving Goffman and his disciples to the understanding of how the self emerges via social interaction. His dramaturgical, or performance-based approach to the study of social situations and how society is constructed is useful for understanding how the self emerges. For budding sociologists interested in answering the big question, "How is social order maintained, modified or dissolved?," Goffman's work was inspiring. His concepts were readily applied to the study of disability starting in the 1960s.

Goffman's focus on interaction, where identities are arrived at, or where strong status differences establish identities, was a foundation for disability studies and the development of new policies contributing to the transformation of American and European government-directed program responses to disabilities in the second half of the twentieth century.

The most profound changes in response came with regard to people with IDD, who had often been removed from the dangers of society, as well as to limit parental burdens. While some scholarly observers may regard the change in thinking about services for people with IDD as an evolutionary process, starting with the politics of the civil rights movement and the subsequent actions of families seeking better care and advocating for educational programs for their children, the new approach came from conceptualization that questioned the widely held Social Darwinian beliefs that the "normal" should be freed from the burden of caring for the "mentally retarded" in the community, and that the "mentally retarded" should be protected by living in restricted settings.

Not everyone supported this approach. Some parents worried about whether their children could survive in a less protected environment. Some parents did not want their adult children with IDD living either at home or in community residences because they chose not to reveal their existence to their colleagues or neighbors. In addition, some professionals, who had a vested interest in keeping state institutions open, opposed community care.

The Theoretical Model for the Study of Total Institutions

Following the end of World War II, a number of diaries and memoirs of people who were incarcerated in European concentration camps and prison-of-war camps were studied closely by sociologists and anthropologists to determine the impact on the self of these experiences.

Criticism of American mental hospitals by psychiatrists and psychologists emerged in the 1950s and prompted participant observation studies of these facilities by sociologists and anthropologists. Erving Goffman adopted a role as a participant observer within a mental hospital in Washington, D.C. to study how behavior was influenced by organizational constraints

and opportunities, and wrote about it in his classic study, *Asylums*. The way the self is constructed by the environment became central to understanding human development and interaction.

In turn, Goffman was very influential on later generations of sociologists and anthropologists who explored what happens when former inmates are returned to the community and live in group homes and other settings. Goffman's brilliant work on "total institutions" continues to resonate more than a half century after it was published. In the following quote, Goffman identifies characteristics of total institutions:

"Every institution captures something of the time and interests of its members and provides something of a world for them; in brief, every institution has encompassing tendencies. When we review the different institutions in Western society, we find some that are encompassing to a degree discontinuously greater than the ones next in line. Their encompassing or total character is symbolized by the barriers to social intercourse with the outside and to departure that is often built right into the physical plant, such as locked doors, high walls, barbed wire, cliffs, water, forests, or moors. These establishments I am calling total institutions, and it is their general character I want to explore" (Goffman, 1961, p.4).

In the 1970s, when large and isolated institutions were being closed because the quality of care was poor, and residents, often known to the employees of these programs as "inmates," were being resettled in the community, Goffman's intellectual leadership was recognized by sociologists such as Sam Seiffer and myself. In our monograph, *Resettling Mentally Retarded Adults in a Managed Community*, we studied what happened when people with IDD were returned to community settings. We reported on the process and outcome of this major shift in public policy in Goffman's language. Court decisions, while setting in motion deinstitutionalization, did not capture the transformations that were anticipated when return to the community took place.

The meaning of social institutions and their impact on the way we live and particularly on those who are considered incapable of caring for themselves may be illuminated by the findings reported here. Special-purpose organizations have often been given complete control over the fate of large numbers of persons deemed incapable of caring for themselves and/or thought to be a danger to themselves and others. Central to such "caretaker" organizations are three tasks: (1) the need to maintain internal order and coordination; (2) continued reaffirmation of the rightness of the initial judgments made about persons designated as convicts, mental patients, and residents (some of the popular labels applied to inmates); and (3) safeguarding the public from the inmates. Sometimes it may be conceived that such organizations through their practices,

confirm the need for their existence by calling forth in their wards evidence of “personal maladjustment” and “social incompetency.” Alternatively, sheer neglect and under-stimulation may produce behaviors which are regarded as bizarre and inappropriate but may, in actuality, be the only possible way for inmates to express their unfulfilled needs. Organizationally, these behaviors operate in a self-serving and self-fulfilling way to justify the need for tight control over inmates’ lives (Birenbaum and Seiffer, 1976, p.6).

From Total Institutions to Stigma

In *Asylums*, Goffman examined a variety of settings he characterized as total institutions, including many where mental patients and other inmates lived. Coming out of a total institution left a mark on former inmates, and sometimes, after release into the community, they preferred not to disclose where they had been. In other words, former patients as well as ex-convicts, regarded this information about themselves as potentially stigmatizing. Managing information about their history was a way to avoid being considered less than fully deserving of respect. Sociologists, under Goffman's influence, began to recognize the importance of "the other" in determining one's behavior and how social identity is shaped.

Origins of the Concept of Stigma

New encounters were based on social diversity. With ethnic and racial minorities migrating to northern cities during and after World War II to take jobs in an expanding economy, social scientists saw opportunities to study what happens when minority group members come into the presence of dominant, or “ordinary,” people. Diaries and memoirs published by people with physical disabilities described the indignities to which they were subjected by “normals,” who treated them as less than fully human. Along a similar path, those people with IDD who were not living in large and isolated state schools, received more education than in the past and in the community they had more contact with “normals.” In some states, such as California, some long-term residents of state schools were deemed capable of taking care of themselves and were returned to the communities where they were born.

Preliminary Conceptions

Goffman taught us that social reality was made through interaction. An individual's identity was a product of the information he or she gave off when in contact with others and therefore it established the right to be present in an encounter. Early on in *Stigma*, Goffman lays out the rules related to social identity: “Society establishes the means of categorizing persons and the complement of attributes felt to be ordinary and natural for members of each of these categories.

Social settings establish the categories of persons likely to be encountered there (Goffman, 1963, p. 2). But what happens when individuals are regarded as not fitting in?

“The term stigma, then, will be used to refer to an attribute that is deeply discrediting, but it should be seen that a language of relationships, not attributes, is really needed. An attribute that stigmatizes one type of possessor can confirm the usualness of another, and therefore is neither creditable nor discreditable as a thing in itself” (p. 3).

An individual who does not measure up in a particular situation, and now is regarded as "the other," has to come up with a strategy to deal with this differentness in face-to-face interaction:

“The term stigma and its synonyms conceal a double perspective: does the stigmatized individual assume his differentness is known about already or is evident on the spot, or does he assume it is neither known about by those present nor immediately perceivable by them. In the first case one deals with the plight of the discredited, in the second with that of the discreditable” (p. 4).

From the perspective of the person who is doing the stigmatizing, i.e., the "normal," there are concerns about how to characterize this social inferior. Sometimes there is an existing set of expressions available to facilitate the categorization of someone as a social inferior:

“By definition, of course, we believe the person with a stigma is not quite human. . . . We construct a stigma theory, an ideology to explain his inferiority and account for the danger he represents, sometimes rationalizing an animosity based on other differences, such as social class. We use specific stigma terms such as cripple, bastard, moron in our daily discourse as a source of metaphor and imagery, typically without giving thought to the original meaning” (p. 5).

Once Goffman establishes the structural parameters of his interests in writing *Stigma*, he reveals his focus: "The issue of 'mixed contacts'—the moments when stigmatized and normal are in the same 'social situation,' that is, in one another's immediate physical presence, whether in a conversation-like encounter or in the mere co-presence of an unfocused gathering" (p. 12).

There may be tension or at least awkwardness in these encounters. Every transgression of these norms in the form of a discrediting discrepancy between an actor's expected and actual identity calls into question the validity of these rules because those who cannot sustain competency may still seek to do so. The everyday grounds for judging others and oneself are made problematic because actors are uncertain about the kinds of claims that may be made by both the discrepant and the conventional individuals.

These “primal scenes” of social life are often filled with embarrassment, awkwardness, and confusion. Generated by gaps between the way things are anticipated and the way they turn out, such encounters between discrepant and conventional individuals need to be made routine in order to end uncertainty on many levels. The discrepant person needs to be defined in a permanent way to end the discrepancy to organized social life. Once society's designated agents redefine the discrepant person as being outside the conventional social order, the everyday grounds for the judgment of social identities are confirmed, thereby restoring belief of all members of society in the cultural formula they have learned to follow. Moreover, the removal of uncertainty allows the stigmatized person to continue his or her membership in the social order, albeit assigned to a radically different master status.

The Stigma of Disability in Everyday Life

If we start with individuals possessing the social skills of any member of society, despite the acquisition of a disability, that may limit performing the tasks of daily life, calls into question one's right to be treated as an equal. Acquiring a disability, or becoming a "significant other" of someone with a disability, involves a new social identity. Adaptation to this new fact about oneself is complicated by its social consequences or stigmatizing impact--what amounts to having a spoiled identity. A fully competent social actor, has to learn how to deal with a diminished social status and play an unwanted role. The acquisition of a disability equals the acquisition of a stigma—the individual is seen by others, and is often seen by him- or herself, as being tarnished or spoiled.

Confirming the impact of stigma beyond disability itself is evident in the personal experience of social anthropologist Robert Murphy, who acquired a severe disability in midlife. He viewed the linkage between physical difference and social stigma this way:

“Disablement is at one and the same time a condition of the body and an aspect of societal identity—a process set in motion by somatic causes but given definition and meaning by society. It is permanently a social state. . . .The onset of quadriplegia, I discovered, had placed me in a new social dimension” (Murphy, 1987, p.195).

Stigma acquisition is also a form of downward social mobility as Murphy explains. People who cannot fully do basic things for themselves and who are perceived as not able to do for others cannot take part in a fundamental ritual of social life in any society—the principles of reciprocity, as identified by the French anthropologist, Claude Levi-Strauss (1969), almost 50 years ago.

The more conformist the culture, the more people with disabilities are shunned, their families are embarrassed by their presence, and little effort is made to accommodate people with

physical limitations. In contemporary Japan—one of the most modern and developed societies technologically—individuals with disabilities "are often discouraged from working, from marrying, from going to movie theaters or restaurants." (Kristof, 1996) In comparison, countries like Sweden, Denmark, and even the United States, appear willing to promote the civil rights of people with handicapping conditions, even when full acceptance by others may not take place.

Acquiring a disability, or becoming a "significant other" of someone with a disability, involves a new social identity. Taking off from Goffman, I note that the problem of stigma is a problem of everyday existence for the bearer. He dealt with the following questions: (1) What does it mean to play a stigmatized role in society? and (2) Why do people who are considered imperfect continue to act competently.

People with disabilities, despite their differentness, can take the role of the other. Being a fully competent member of society includes recognizing the meaning of membership and competency. This reflexiveness or being able to take the role of the other, involves knowing what a member must possess and who is allowed to participate in particular social situations. Alternatively, knowledge of what it means not to be a member is part of the general role of the member. These rules or constitutive norms of social life are acquired relatively early in life.

Encounters between discrepant and conventional individuals are made routine in order to end uncertainty on many levels; the discrepant person needs to be defined in a permanent way to end the disruptions to organized social life. Society is protected when designated agents redefine the discrepant person as being outside the conventional social order; beliefs of all members of society in the cultural formulas they have learned to follow are restored. Harold Garfinkel (1956), a contemporary of Goffman, regarded these rituals as "degradation ceremonies."

Moreover, the removal of uncertainty through these rituals allows the stigmatized person to continue his or her membership in the social order, albeit assigned to a radically different master status. Once an individual acquires a disvalued identity, later encounters in his or her life as a stigmatized person acquire a predictable quality (Schutz, 1962).

Novelist and literary critic Leonard Kriegel regards the presence of disability much in the same way as Alfred Schutz, but also as a barrier to being validated as a person. In his powerful autobiographical account, Kriegel presents the other as failing to recognize the self present in the person with a disability. Note that he avoids the use of softer language when referring to his situation:

"What the cripple must face is being pigeonholed by the smug. Once his behavior is assumed from the fact that he is a cripple, it doesn't matter whether he is viewed a holy or damned. Either assumption is made at the expense of his individuality, his ability to

say "I." He is expected to behave in such-and-such a way; he is expected to react in the following manner to the following stimulus. And since that which expects such behavior is that which provides the stimulus, his behavior is all too often Pavlovian. He reacts as he is expected to react because he does not really accept the idea that he can react in any other way. Once he accepts, however unconsciously, the image of self that his society presents him, then the guidelines for his behavior are clear and consistent" (Kriegel, 1969, p.424).

When we examine childhood-onset disability, as was the case in Leonard Kriegel's life, the focus has largely been from the perspective of how families cope with stress. When a child becomes disabled, or is recognized as such at a young age, families invoke common-sense understandings related to the causes of the disability, hold different expectations concerning the child's survival, and make judgments as to what success, or lack of it, this child will have in school, work and family life. Not unexpectedly, the family now is engaged in a multi-member career as a group with a disabled member (Groce & Zola, 1993).

A family's culture supports the interpretations and problem-solving efforts brought about by the presence of a child with a disability; it is also the force behind the coping strategies they adopt. The family's unique character is derived from deeply held beliefs and values, what Hamilton I. McCubbin and his co-authors (1993) called a family schema. With this cultural foundation, often based on ethnic values, the family develops a set of guidance mechanisms (paradigms) that steer their behaviors and functioning.

Courtesy Stigma and Parents of Children with Intellectual and Developmental Disabilities

While the concept of stigma in the field of disability usually applies to individuals with disabilities, it is also used to gain greater understanding of those who are underdogs because of their relationships to fully stigmatized individuals.

In my early work, I followed the social relationships of mothers of young children with IDD and found that they too were seen as having a spoiled identity, or what Goffman called a courtesy stigma. First published in *The Journal of Health and Social Behavior* in 1970, my article "On Managing a Courtesy Stigma," was republished twice and often cited during the following four decades. The idea of a courtesy stigma has been applied to other family members, such as siblings and to group home workers and neighbors of individuals with intellectual and developmental disabilities (Birenbaum, 1970). More recently, the concept has also been applied to parents of adolescents who are heavy drug users.

Goffman's Influence on Anthropology

Around the same time, using the concept of stigma, Robert B. Edgerton, an anthropologist, initiated a community-based study of several "mildly retarded" adults who were released from state schools. His monograph, *The Cloak of Competence*, was considered a pioneering effort at urban field work. Using a very loosely structured interview schedule and participant observation, Edgerton became part of the lives of his subjects. He brilliantly focused on "the perception and management of incompetence—stupidity if you will—among the mildly retarded" (Edgerton, p. 6). Edgerton learned about their lives in the institutions or state schools they had come from, and also about their current concerns. This study, "Beyond its possible merits as a description of the lives of such folk, . . . is also intended to be a study of a stigma, a stigma which galvanizes the most basic feelings of these retarded persons into a single-minded effort to 'pass' and to 'deny' "(p. 205).

The Cloak of Competence uses succinct quotes from these former patients in order to get at the sense of stigma they were facing:

Woman: "When I got out of this place it was horrible. I knew everybody was looking at me and it was true what they thought I was.

Man: "I don't believe that anyone from the hospital has it easy outside. There are problems from being in that place. I mean with people you meet. They take me as if I am not a smart person" (p. 206).

The struggle to command respect involves avoiding being seen as a person with a disability. In the efforts of the former patients in the present study to evade the stigma that they feel and fear, we see an eloquent testament to man's determination to maintain his self-esteem in the face of overwhelming cultural rejection and deprecation (p. 219).

Direct Applications of Stigma Theory to Practice in the Intellectual and Developmental Disability Field

Stigma theory moved beyond academia and helped shape human service policy and practices in several countries in Western Europe in the 1960s. While Wolf Wolfensberger, a German-born policy maker in the Swedish social services system, held an advanced degree in psychology, his approach to human services was basically sociological. In *The Principle of Normalization in Human Services*, he defined human management as the "entry of individuals or agencies acting in societal-sanctioned capacities, into the functioning spheres of individuals, families, or larger social systems in order to maintain or change conditions with the intent of

benefiting such individuals, their family or other social systems, or society in general” (1972, p. 2).

The idea of normalization is directly related to Goffman’s concept of stigma and mixed with famous American sociologist Robert K. Merton’s self-fulfilling prophecy (a concept now used regularly on cable channel news broadcasts). Normalization implies that a person would be enabled to project an image that does not mark him as deviant in the sight of others. The rationale for this is twofold. First, as stated, how a person is perceived affects the way he is treated, and a person seen as deviant is very apt to elicit pity, rejection, persecution, and other behaviors which tend to diminish a person’s dignity, adjustment, growth, etc. Secondly, the way a person is treated by others will affect his self-image, as well as the way in which he will respond. It is well known that a person perceived to be deviant is expected to act with deviance, and such expectations are often so powerful as to elicit the expected behavior, thus becoming self-fulfilling prophecies (Wolfensberger, 1972, p. 229). Normalization, according to Wolfensberger, “Can be viewed as being most consistent with a sociotherapeutic approach in that it uses concepts and constructs rooted primarily in sociology, and does so at a time at which the field appears to be ready to orient itself increasingly toward sociotherapeutic concepts” (p. 103). Inspired by international conferences of adults with IDD in Sweden in 1968 and 1970, Wolfensberger and his colleagues moved toward the concept of self-determination. The focus on leisure time activities generated a preference for participation in small groups, whether in public or in smaller settings. The idea of self-determination was born through discussions regarding programs and programming (p. 184). The strong opinions held by the people with intellectual disabilities on their right to take part in decisions regarding their own leisure time activities reflect their dissatisfaction with situations they have so often experienced when things have been arranged for them and not with them, thus increasing their feeling of dependency and depriving them of a part of the pleasure of motivation (p. 185).

Further Use of Sociological Theory and Methodology to Improve Services for People with Disabilities

By the late 1960s, the social environment and cultural disadvantages experienced by people with developmental disabilities was becoming a major concern to government policy makers since the environment in which this population lived was changing. Adults with intellectual and developmental disabilities were now viewed as much a product of their environment (large and isolated institutions) and the stigmatization experienced by being separated from mainstream society.

Resettlement was not deemed enough of a public policy solution to promoting inclusion. Residential care in group homes often consisted of being in the community but not of it. It also

became apparent in this decade of emerging civil rights that individuals, whether coming from their homes or resettled back in the communities where they were born from the traditional state school, often needed to be taught the skills required for community living. Understanding how social organization impacted the development of the self when there are differences in intellectual capacity became something that sociologists could untangle, often with the help of other academic disciplines.

Based on a conference sponsored by the National Institute for Child Health and Human Development and the Rose F. Kennedy Center for Research in Mental Retardation and Human Development at Albert Einstein College of Medicine, *The Mentally Retarded and Society* contains 22 major articles by leading specialists in intellectual disabilities and human development, psychology, psychiatry, sociology, mental health, developmental disabilities, pediatrics, maternal and child health, education, public health, education, law, anthropology and epidemiology (Begab and Richardson, 1975). (One of the attendees was Erving Goffman, who acted as a gadfly and did not contribute a paper.)

Following in the footsteps of Edgerton, the conference featured the policy study of the consequences for adults with intellectual disabilities who move from a large, traditional, isolated mental retardation institution to smaller residential care units in the community. Noting the importance of the civil rights movement, organized citizen groups, professional societies and human rights-minded attorneys, editor Michael Begab suggests that these agents of change have “embarked on aggressive campaigns of public education and class action suits to secure for the retarded the basic rights presumably guaranteed by our Constitution. In the process, old concepts such as community integration of the retarded and normalization have been rejuvenated” (1975, p. xi).

The Fields of Vocational and Physical Rehabilitation as Subjects for Sociological Study

The road to inclusion for all people with disabilities, including those with IDD, often involves partnerships between federal agencies and social scientists. In response to what was deemed the "dramatic and frightening growth of dependency" on the part of people with disabilities on public assistance, the Commissioner of the U.S. Vocational Rehabilitation Administration, Mary E. Switzer, challenged the discipline of Sociology to come up with "something special" that could help alleviate the mounting burden on public funding. Writing in 1965 in the introduction to *Sociology and Rehabilitation*, Commissioner Switzer noted that people with disabilities were seen as deviants and therefore stigmatized by the larger society (p. viii). These "deviants," according to Switzer, were made up of both those with physical and nonphysical disabilities, including "the mentally ill and the mentally retarded." Consequently,

they were treated as unworthy of being included in the larger society and incapable of making a contribution to it.

Clearly, Erving Goffman's conceptualization regarding spoiled identities hovered over the proceedings where academics were seeking to guide policy formation in the field of rehabilitation. At the conference sponsored by the Vocational Rehabilitation Administration, most of the papers presented began with the acknowledgement that the stigmatization of people with disabilities has a long tradition in western societies and rooted in their cultures. Social stigma, according to Jerome Myers (p.37), one of the presenters at this conference, was rooted in the classification system of people with different disabilities and their acceptance in social situations. Social distance has often led to the creation of subcultures and communities among those who are similarly situated.

While not specifically addressing the problems of integrating people with IDD into the workforce, the distinguished sociologists at the conference presented and critiqued six foundation papers that linked sociological theory and research to the conditions under which rehabilitation was successful. These papers, which were published by the American Sociological Association in 1965 in *Sociology and Rehabilitation*, a volume edited by Marvin B. Sussman, looked at how disability could be defined in terms of the social stigma attached to it as well as “the degree of social isolation of the disabled person, the amount of role impairment, or the theory of causation of disability” (Jerome K. Meyers, p. 37).

Meyers also notes that one of the consequences of disability “is the promotion of a higher degree of interaction among the disabled than would otherwise occur. In a sense, the disabled frequently develop subcultures or communities of their own. This tendency for disabled persons to seek social satisfaction with each other has produced a complex system of social organization” (p. 41).

Continuing in the Goffmanian tradition, Eliot Freidson, in his essay in *Sociology and Rehabilitation*, introduces the conceptualization of disability as social deviance in his discussion of rehabilitation, and systematically identifies what activities the rehabilitation field conducts. First, they specify what personal attributes shall be called “handicaps.” Second, they seek to identify who conforms to their specifications. Third, they attempt to gain access to those whom they call “handicapped.” And fourth, they try to get those to whom they gain access to change their behavior as to conform more closely to what the institutions believe are their potentialities (p. 71).

The Corporate World of Rehabilitation

While the concepts of total institutions and stigma were powerful applications of sociology to the world of the other, more sociological approaches to disability and rehabilitation emerged, largely due to the emergence of the recognition of the need for intervention on a scaled-up level. The sheer growth of the field of rehabilitation has produced interests that go beyond face-to-face interaction. Few subjects in the area of disability studies are more controversial than whether rehabilitation empowers individuals to make improvements or, on the other hand, subjects them to a new kind of stigma. At issue today is how to help individuals with disabilities make the transition from sheltered workshops and occupational day programs into either competitive or supportive employment.

Many vested interests in the rehabilitation field depend on keeping clients in programs that restrict their opportunity for independence and inclusion. Advocates for people with disabilities often point to how vocational rehabilitation facilities discourage their trainees from seeking more challenging employment. Fueled in the United States by the infusion of funding from federal and state agencies and some insurance programs, rehabilitation has become a complex process, one that begins with limitations in an individual's functional activities.

This enormous world of rehabilitation starts, once again, with an individual's differentness. The differences in a person's life as a result of a disability impact on the way roles are performed and how one acts in social situations. As sociologist Gary Albrecht (1992) observes, "Persons with disabilities discover that their social activities and by analogy their social identities are redefined by the attributions assigned to the disability with which they have been labeled. These labels and stereotypes often inaccurately reflect the behavioral capacity and identity experienced by persons with disabilities. As a consequence, persons with disabilities may try to take the definitional process into their own hands" (p. 18). Starting from a Marxist or materialist perspective, and examining who controls the means of production in rehabilitation, Albrecht identifies the commodification of the field. These rehabilitation "goods and services are commodities that are marketed, sold and purchased. In such a market, consumers, providers, investors, and regulators profit and/or lose in the transactions" (p. 27).

How can these forces be resisted or reshaped? Albrecht speaks to empowerment as coming from people with disabilities and /or those with a deep humanitarian devotion to the cause. The two necessary elements of leadership empowerment are self-awareness and the acquisition of resources to act on their own behalf (p. 311). Self-advocacy can be a solution for creating greater equity when people with different disabilities are able to form alliances. Paradoxically, the recognition of stigma promotes solidarity and calls for a remedy to the social inferiority experienced by people with disabilities.

The most powerful response to these structural conditions is likely to be exerted through a national coalition formed by different disability interest groups. Such a coalition can be organized to achieve strong lobbying but preserve the identity of the member organizations (p. 314).

Inclusion: Continued Research on Community Living by People with IDD

With the closing of large and isolated state schools in many countries, policy makers and planners have expressed concern about how to promote integration of individuals with IDD in ordinary neighborhoods. Resettlement continues to take place in the Netherlands as recently as the last decade. What factors in social contact promote integration at the neighborhood level?

To answer this question, a study of a neighborhood with group homes in the Netherlands started with 53 potential informants, and eventually learned about neighboring experiences from 39 people with IDD, ranging from superficial neighboring to the formalization of relationships with some non-IDD neighbors. As the authors state:

“There seemed a preference for social contacts to be with other people with ID, family and volunteers, rather than people from outside the context of the organization” (Van Alphen, et. al., 2009, p. 753).

Accordingly, staff of the organization that ran the group home were active in setting guidelines for how residents should behave when in the presence of neighbors. Residents were grateful for this help. As noted in other articles by the same team of researchers:

“There may . . . be a certain insecurity to approach others because past experiences have taught some people to be wary, or if they do not feel competent enough, and think that their disability may frustrate interactions” (p. 755).

The Dutch team of sociologists then spoke with 30 neighbors near these group homes to get their impressions of the people with IDD who lived in several resident facilities. These “normals” expressed concern about the often-noted lack of appropriate distance, reciprocity and accountability among their neighbors with IDD. Inclusion can be difficult to attain when neighbors are involved:

“Integration of people with IDD into everyday neighboring relationships raises complex challenges for care organizations that need to find a balance between supporting the needs of people with IDD they care for, adequate support and mediation for other neighbors when necessary, and all the while avoid becoming overly involved in neighboring as a formal partner” (Van Alphen, et. al., 210, p. 347).

The authors identified as a theme the need to try to strike a balance between ordinary neighboring and being mindful of the special needs and challenges presented by their neighbors with IDD, including understanding that their neighbors may be pressed to become more involved than intended. Fear of becoming a benefactor—as addressed by Edgerton in *The Cloak of Competency*—was an unspoken concern.

Finally, the article outlines some theoretical and practical implications for inclusion, such as how staff are required to take into account the insecurity of residents when meeting unfamiliar others, the need to pass on an understanding of local customs, and how to teach what are the possible roles people with IDD can play as good neighbors, with the aim of establishing mutually acceptable forms of neighboring.

Conclusion

Without empirical evidence, but with years of observational experience, I find it likely that generations of students who went into the field of services for people with disabilities were moved by reading Goffman, or perhaps some of his disciples, as undergraduates or graduate students in sociology, social-psychology, or social work. These opportunities for learning a nuanced approach to disability helped to create more quality service providers than in the past. The numbers of young people who went into this field expanded with the proliferation of community care.

The idea of capacity-building, a concept often found as part of the mission of organizations funded to improve the quality of care in the disability field, along with systems change and advocacy, especially self-advocacy, rests largely on being able to take the role of the other even when the experiences of the other are very remote from a person with training. The enduring impact of sociology on the study of disability, policy formation, and planning remains evident in the twenty-first century.

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