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How do sociological and anthropological research promote the inclusion, independence and empowerment of people with intellectual and developmental disabilities?

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EVOLUTION OF SERVICES FOR THE DEVELOPMENTALLY DISABLED
by Herbert J. Cohen, M.D.

The development of institutions for individuals with intellectual disabilities was predominantly a phenomenon of the western world.

The institutions that developed prior to the 19th century tended to be punitive. Then new training schools were founded in several places in Europe and the U.S.

In the early 20th century, congregate care facilities grew into overcrowded, isolated facilities where individuals were usually warehoused and provided little or no treatment. Unfortunately, the eugenics movement influenced public beliefs that undesirables should be isolated from the rest of society.

After World War II several important developments led to changes.

- A civil rights movement initially focused on the rights of ethnic or racial minority groups subsequently broadened in scope to include advocacy for the rights of other groups, including those with disabilities.
- Families of individuals with intellectual disabilities formed organizations to advocate for better care and educational programs for their affected family members.

In some states, change from institutional models of care began to emerge and official standards of care were promulgated.

Of great significance were changes in the philosophy of care and subsequent legislative efforts in the U.S. to bring about change. The concept of normalization was formally promoted by Bank-Mikkelsen in Denmark, Nirje in Sweden and Wolfensberger in the U.S.

A key event occurred when President John F. Kennedy announced that he had a mentally retarded sister and then appointed a President's Panel on Mental Retardation which made recommendations that led to legislation to effect changes in the care of the mentally retarded.

Since the late 1960s, attempts to implement the concept of normalization have led to deinstitutionalization efforts and the development of community-based residential alternatives. Federal funds enabled the development of smaller ICF-MRs in the community that required certain standards of care.

In 1969, there were over 190,000 individuals with DDs in U.S. institutions. Due to lawsuits against institutions and more flexible use of federal funds, by 2005, the total number in these large facilities had dropped to 40,532.

By 2009, there were over 300,000 individuals with DDs living in smaller U.S. community facilities, and most communities now had small residences.

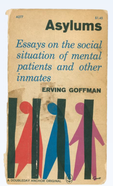
By 2013, the vast majority of people with intellectual disabilities who had lived in institutions were now in community settings. They and millions of others who had always lived in the community are now receiving appropriate care, treatment and education, with much progress toward normalization and self-determination.

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 concentration camps and prisoner-of-war camps were studied closely by sociologists and anthropologists to determine the impact on the self of these experiences. Moreover, criticism of mental hospitals in the United States by psychiatrists and psychologists led to participant observation studies of these facilities. Erving Goffman was one of those scholars who adopted a role of an employee in a mental hospital in Washington, D.C. to study how behavior was influenced by organizational constraints and opportunities.

Goffman, in turn, 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 a half century after it was published.

Erving Goffman, *Asylums: Essays on the social situation of mental patients and other inmates*, 1961.



"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." (p. 4)

Arnold Birenbaum and Samuel Seiffer, *Resettling Mentally Retarded Adults in a Managed Community*, 1976.

"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 understimulation 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." (p. 6)

TALES OF GOFFMAN
Sociology and Anthropology Recognize the Importance of "the Other." The origins of the concept of stigma.

With ethnic and racial minorities migrating to northern cities during and after World War II to take jobs in an expanding economy, social scientists began to see opportunities for research on what happens when minority group members come into the presence of dominant, or ordinary people. Diaries and memoirs published by people with physical disabilities documented the indignities they were subjected to by "normals" who treated them as nonhuman. Along a similar path, people with intellectual and developmental disabilities, not always placed in large and isolated state schools, received more education than in the past and remained in the community. In some states, e.g., 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. Former residents learned that inclusion in the community sometimes required managing information about the time they had spent in institutions.

Erving Goffman, *Stigma: Notes on the Management of Spoiled Identity*, 1963.

Preliminary Conceptions

"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." (p. 2)

"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)

"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)

"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, sometime 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)

"This book. . . . is specifically concerned with 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)

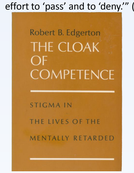
Robert B. Edgerton, *The Cloak of Competence: Stigma in the Lives of the Mentally Retarded*, 1967.

"The concern of this research is with the perception and management of incompetence—stupidity if you will—among the mildly retarded." (p. 6)

"Since this research was dedicated to learning about the problems of mental retardates in the community by observing and participating in the lives in their own words, the interview schedule, though focused upon certain information areas, was very loosely structured." (p. 16)

"Conjointly with these friendly and informal interviews, as much participant-observation as possible in the lives of former patients was undertaken." (p. 17)

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)



- (A 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."
- (A 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. That take me as if I am not a smart person." (p. 206)

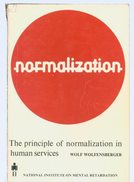
"In the efforts of the former patients in the present study to evade the stigma that they feel and fear, we see an eloquent testament to man's determination to maintain his self-esteem in the face of overwhelming cultural rejection and deprecation." (p. 219)

Courtesy Stigma and Parents of Children with IDD

Goffman was a powerful thinker who inspired many who studied the sociology of the underdog. A parallel track was established by the then-young sociologist Arnold Birenbaum in his work on stigma management among mothers of children with intellectual and developmental disabilities. First published in the *Journal of Health and Social Behavior*, "On Managing a Courtesy Stigma (1970)," was often cited during the following four decades. This article followed up on Goffman's observation that those who are related to people with disabilities or other stigma-generating attributes, are often stigmatized as well. The idea of a courtesy stigma can be applied to workers in group homes and even to neighbors of individuals with intellectual and developmental disabilities.

THE HOUR OF THE WOLFENSBERGER
***The Principle of Normalization in Human Services*, by Wolf Wolfensberger, with additional texts by Bengt Nirje, Simon Olsansky, Robert Perske, and Philip Roos, 1972.**

Sometimes, sociology received converts. While Wolfensberger held an advanced degree in psychology, his approach to human services was basically sociological. In *Normalization,* he defined human management as the "entry of individuals or agencies acting in societally 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." (p. 2)



"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 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 deviantly, and such expectations are often so powerful as to elicit the expected behavior, thus becoming self-fulfilling prophecies." (p. 229)

Normalization "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)

Propelled by an international conference of adults with intellectual and developmental disabilities, 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 retarded 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).

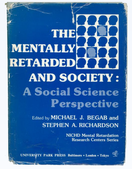
***The Mentally Retarded and Society: A Social Science Perspective*, edited by Michael J. Begab and Stephen A. Richardson, 1975.**

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, this volume contains 22 major articles by leading specialists in mental retardation and human development, psychology, psychiatry, sociology, mental health, developmental disabilities, pediatrics, public health, maternal and child health, education, law, anthropology and epidemiology.

The conference featured the policy study of the consequences for mentally retarded adults who move from a large, traditional, isolated 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, 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." (p. xi)

Two studies (Kushlick and Birenbaum) of the resettlement of adults with intellectual and developmental disabilities in group homes called for using sociological research to identify which qualities of individuals or adaptive skills would predict successful transition to community living. Prospective studies are recommended so that individuals who leave large and isolated state schools can be followed and the process and problems of transition can be identified.

On the organizational level, Herbert J. Cohen, the director of a regional mental retardation center in the Bronx identified problems encountered in developing a network of services for individuals with developmental disabilities in an urban community, including greater complexity of fiscal procedures and controls, bureaucratic resistance to change, lack of clarity on how to integrate consumers in decision-making processes, overlapping jurisdictions, differences in professional and lay attitudes, and the pervasive issue of community priorities.

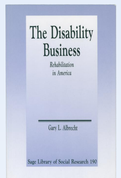


As there is greater reliance on community-based programs and consequent inclusion in the community, the work of Richardson and Gottlieb becomes more and more relevant to understanding how people who are not intellectually and developmentally disabled react to the presence of individuals with IDD in the community. Stephen Richardson carefully reviewed the administrative classifications of young children, school-aged children, the post-school career and older adults as well as the identification of mental retardation outside of the administrative classification process. Gottlieb deals with the old dichotomy between attitudes and behavior.

Gottlieb's literature review--from a social psychological perspective--suggests that there may be a large gap between "normals" attitude toward IDD and their actual behavior. He recommends that future research place greater emphasis on the study of behavior toward IDDs. In turn, there is a need to research the extent to which people with IDD internalize the behavior of others. Finally, it is vital to find out whether close proximity to people with IDD promotes greater acceptance. Gottlieb advocated more research on whether integrated classrooms promote inclusion.

THE CORPORATE WORLD OF REHABILITATION
***The Disability Business: Rehabilitation in America*, by Gary L. Albrecht, 1992.**

Few subjects in the area of disability studies are more controversial than whether rehabilitation empowers individuals to make improvements or rather subjects them to a new kind of stigma. At issue today is how to help individuals with disabilities transition from sheltered workshops and occupational day programs into competitive or supported employment.



Many vested interests in the rehabilitation field depend on maintaining clients in programs that restrict their opportunity for independence and inclusion.

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 starts with limitations in an individual's functional activities.

This enormous world of rehabilitation starts 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 Albrecht 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 perspective, 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 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. 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)

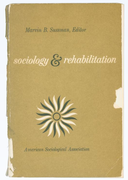
SOCIOLOGY PROMOTES INCLUSION
***Sociology & Rehabilition,*
edited by Marvin B. Sussman, 1965.

While not specifically addressing the problems of integrating people with IDD into the workforce, almost 50 years ago the American Sociological Association, in cooperation with the Vocational Rehabilitation Administration, held a conference where distinguished sociologists presented and critiqued six papers that linked sociological theory and research to the conditions under which rehabilitation was successful. These papers were published by the American Sociological Association.

These papers 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) According to Meyers, "rehabilitation is an intervening variable occurring between the advent of the disability and its subsequent consequents." (p. 42)

Eliot Freidson continues the conceptualization of disability as social deviance. In his discussion of rehabilitation, he 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.
- 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)

WHO ARE THE PEOPLE IN YOUR NEIGHBORHOOD?
"The significance of neighbors: views and experiences of people with intellectual disability on neighboring." Van Alphen, L. M., Dijker, A. J., van den Borne, H. H. H. and Curfs, L. M. G., *Journal of Intellectual Disability Research*, 2009.

With the closure of large and isolated state schools in many countries, concern has been expressed by policy makers and planners as to how to promote integration of individuals with IDD in ordinary neighborhoods. What factors in social contact promote integration at the neighborhood level? To answer this question, the above-cited authors in the Netherlands started with 53 potential informants and eventually learned about neighboring experiences from 39 people with IDD. There were several types of neighboring experiences, ranging from superficial neighboring to the formalization of relationships with a select number of 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." (p. 753)

Accordingly, staff of the care organization that ran the group home were active in setting guidelines for residents of the group home regarding how to behave when in the presence of neighbors. Residents were grateful for this help. As noted in some other studies done in the recent past,

"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)

FROM THE OTHER SIDE
"People with Intellectual Disability as Neighbors: Toward Understanding the Mundane Aspects of Social Integration." Van Alphen, Laura M., Dijker, Anton J. M., Van Den Borne, Bart H. W., Curfs, Leopold M.G. *Journal of Community and Applied Social Psychology*, 2010.

Following conversations with informants with IDD, a Dutch team of sociologists spoke with 30 of their neighbors to get their impressions of the residents of several group homes. Concern was expressed by these "normals" 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." (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 that those with IDD present, including understanding that they may be pressed to become more involved than intended. Fear of becoming a benefactor—as addressed in *The Cloak of Competence*—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.