

FOREWORD

Before It Had a Name: Exploring the Historical Roots of Disability Studies in Education

Steven J. Taylor

Like the area of inquiry on which it is based—Disability Studies—Disability Studies in Education existed before it had a name. That is to say, the key themes underlying Disability Studies in Education can be traced back many years before it was identified as an area of inquiry or associated with professional groups, conferences, and scholarly publications. Of course, in earlier times, some of these themes were not fully developed, and their implications not completely explored. Yet, an understanding of the intellectual forbearers of Disability Studies in Education can help us understand more clearly the foundational ideas underlying this area of scholarship.

Neither Disability Studies nor Disability Studies in Education represents a unitary perspective. Scholarship in these areas includes social constructionist or interpretivist, materialist, postmodernist, poststructuralist, legal, and even structural-functionalist perspectives and draws on disciplines as diverse as sociology, literature, critical theory, economics, law, history, art, philosophy, and others. Despite this diversity, there are key themes or core ideas underlying Disability Studies. I discuss one of these here: the idea that disability is a social phenomenon. In the remaining discussion, I briefly explore the origins of this idea. My review is not intended to be comprehensive; rather, my intention is merely to discuss some of the works that brought us to where we are today.

Central to a Disability Studies perspective is the assumption that disability is a social construction or, if one prefers, creation. In contrast to clinical, medical, or therapeutic perspectives on disability, Disability Studies focuses

on how disability is defined and represented in society. From this perspective, disability is not a characteristic that exists in the person so defined, but a construct that finds its meaning in social and cultural context. Although there are important differences among what are referred to as the social model of disability, the social constructionist view of disability, the minority group model, and other frameworks, they share in common an understanding of disability as a social phenomenon.

The idea that disability is a social phenomenon can be traced back at least to the 1960s sociological theories of “deviance” and “stigma.” The labeling theory of deviance (Becker, 1963; Erikson, 1962) focused attention on how society creates deviants by labeling certain persons as “outsiders.” As Becker (1963) wrote:

...social groups create deviance by making the rules whose infraction constitutes deviance, and by applying those rules to particular people and labeling them as outsiders. From this point of view, deviance is not a quality of the act a person commits, but rather a consequence of the application by others of rules and sanctions to an “offender.” The deviant is one to whom that label has been applied; deviant behavior is behavior that people so label. (p. 9)

Labeling theory was soon applied to people defined as disabled or handicapped in society. Scheff (1966) examined the labeling processes associated with being diagnosed as mentally ill. Scott’s (1969) *The Making of Blind Men* challenged the notion that the personality and other characteristics associated with blind people are inherent in being blind. Rather, Scott argued, blind people are socialized into playing a social role:

The major thesis of this book has been that blindness is a learned social role. People whose vision fails will learn in two contexts the attitudes and behavior patterns that the blind are supposed to have, in their personal relationships with those with normal vision and in the organizations that exist to serve and to help blind people. (p. 117)

Mercer (1965, 1973) applied labeling theory to people defined as mentally retarded. Her influential 1973 book *Labeling the Mentally Retarded* started with a statement of her basic thesis:

The questions “Who are the persons in a community who are really mentally retarded? What is the right prevalence rate?” are nonsense questions, questions that are not capable of being answered. Persons have no names and belong to no class

until we put them in one. Whom we call mentally retarded, and where to draw the line between the mentally retarded and the normal, depends upon our interest and the purpose of our classifications. (p. 1)

Long before Disability Studies scholars distinguished between the medical model of disability and the social or minority group model of disability, Mercer made the distinction between a clinical perspective and social system perspective on mental retardation. From the clinical perspective, mental retardation was a pathological condition existing within the individual that could be objectively diagnosed by trained professionals using standardized instruments. From a social system perspective, mental retardation was a social role played by individuals in specific social systems in which they participated: "From a social system perspective, the term mental retardate does not describe individual pathology but rather refers to the label applied to a person because he occupies the position of mental retardate in some social system" (Mercer, 1973, pp. 27–28).

Closely related to labeling theory was Goffman's (1961) dramaturgical analysis of stigma in his influential book with that title. According to Goffman, a stigma was a condition that discredited a person's social identity. He distinguished among three major types of stigma, those associated with physical differences, those associated with presumed blemishes in individual character, and those associated with race, nation, or religion. Goffman's analysis focused on how people managed actual or potentially stigmatizing conditions in their relations with others.

Labeling theory and Goffman's *Stigma* had an immediate and profound influence on the helping professions in disability and especially in the fields of mental health and mental retardation. These theories resonated with the critique of institutional psychiatry as a vehicle for social control by psychiatrists Szasz (1961, 1970a, 1970b) and Laing (1967). Goffman's (1963) *Asylums*, a devastating analysis of the effects of mental hospitals and other "total institutions," also supported critics of involuntary commitment and treatment.¹

In the latter part of the 1960s, leaders in the field of mental retardation began to translate sociological concepts into a philosophy of caring for people with mental retardation. In 1969, the President's Committee on Mental Retardation (PCMR) published an influential book, *Changing Patterns in Residential Services for the Mentally Retarded* (Kugel and Wolfensberger, 1969).

Established by President John F. Kennedy as the President's Panel on Mental Retardation in 1962, PCMR intended *Changing Patterns* to serve as a resource in formulating recommendations on residential care to the President and the nation (Kugel, 1969). The book included invited contributions from American and international leaders, including two chapters by Burton Blatt (1969a, 1969b) based on his 1966 photographic expose of institutions.

Changing Patterns contained two chapters by Bengt Nirje, then Executive Director of the Swedish Association for Retarded Children. In the first chapter, "A Scandinavian Visitor Looks at US Institutions," Nirje (1969a) described his observations during visits to institutions and confirmed Blatt's reports. Nirje's (1969b) second chapter, "The Normalization Principle and Its Human Management Implications," was more important.

The concept of normalization was developed in Scandinavia and incorporated into a 1959 Danish law governing services for people with mental retardation (Bank-Mikkelsen, 1969). Until Nirje's *Changing Patterns* chapter, it had not been systematically defined and explained (Wolfensberger, 1972). Nirje (1969b) provided the following definition: "the normalization principle means making available to the mentally retarded patterns and conditions of everyday life which are as close as possible to the norms and patterns of the mainstream of society" (p. 181).

In the introduction to *Changing Patterns*, Kugel (1969) wrote regarding the normalization principle:

This construct has never been fully presented in the American mental retardation literature, but it is of such power and universality as to provide a potential basis for legal and service structures anywhere. Indeed, the editors of this book view the normalization principle as perhaps the most important concept that has emerged in this compendium (p. 10).

Various contributors to *Changing Patterns* approached mental retardation from the perspective of the sociology of deviance. Dybwad (1969), the past executive director of the Association for Retarded Children (now The Arc of the United States), described normalization as a sociological concept: "The normalization principle draws together a number of other lines of thought on social role, role perception, deviancy, and stigma that had their origin in sociology and social psychology" (p. 386). Wolfensberger's (1969) history of the origin and nature of institutions started with a review of the "role

perceptions” of people with mental retardation (for example, as sick) and explained:

Social scientists in the recent past have elaborated a concept of great importance to the understanding of the behavior and management of retarded persons. The concept is that of deviance. A person can be defined as deviant if he is perceived as being significantly different from others in some overt aspect, and if this difference is negatively valued. An overt and negatively valued characteristic is called a “stigma.” (p. 65)

Dunn (1969) used language to describe institutions that could have come from labeling theorists in sociology in his chapter in *Changing Patterns*: “Frequently, they have been operated on the medical model which views mental retardation as a disease, and has an emphasis on labeling and determining etiology; and once one has viewed mental retardation as a disease and affixed a label to an individual, one has a built-in, self-fulfilling prophecy” (p. 214).

Three years after *Changing Patterns*, Wolfensberger (1972) published another influential and widely read book, *The Principle of Normalization in Human Services*. In this book, Wolfensberger (1972) elaborated on the dimensions of normalization and offered a reformulated definition: “Utilization of means which are as culturally normative as possible, in order to establish and/or maintain personal behaviors and characteristics which are as culturally normative as possible” (p. 28). In later work, Wolfensberger (1983, 1998) promoted “social role valorization” as a refined version of the normalization principle.

Sociological theories of labeling and stigma led not only to a questioning of institutions but of special education as well. Dunn, a contributor to *Changing Patterns*, published a 1968 article, “Special education for the mildly retarded—Is much of it justifiable?” in which he questioned the legitimacy of special education. Dunn’s article is still cited by critics of inclusion (Kavale and Forness, 2000) as the beginning of “ideological” attacks on segregation in the schools.

In 1969, PCMR and the U.S. Bureau of Education for the Handicapped sponsored a conference that resulted in a report titled *The Six-Hour Retarded Child*. The report was consistent with Mercer’s studies that showed that many children placed in special education, especially those from minority groups, were only “retarded” during school hours and functioned perfectly well at home and in their communities. The report began with the following

quote: "We now have what may be called a 6-hour retarded child—retarded from 9 to 3, five days a week, solely on the basis of an IQ score, without regard to his adaptive behavior, which may be exceptionally adaptive to the situation and community in which he lives." Thus, the report did not merely endorse the development of more precise diagnostic techniques, but recognized that the determination of mental retardation depended on social context and environment.

By the 1970s, critiques of labeling in special education became widespread. In 1975, Hobbs published a major two volume edited series titled *Issues in the Classification of Children* that examined the labeling of children by schools and other social institutions. The inside jackets of the volumes described their purpose:

What happens when children are classified *delinquent, retarded, hyperkinetic, mentally ill, or emotionally disturbed*? What treatment are they likely to receive? What will their experiences be in schools, the courts, or hospitals? What effect does classification have on their families? Are labels for children applied and used fairly? How do they affect children's behavior, their opinions of themselves, and their future? To find the answers, ten federal agencies joined to sponsor the Project on Classification of Exceptional Children. This milestone book, the report of the project's task forces, examines current classification procedures—often harmful, biased, or inadequate—and provides the foundation for new public policy, effective legislation, and improved professional practice.

Although many of the chapters in these volumes merely offered revised and more precise classification systems, Rains et al. (1975), Rhodes and Sagor (1975), and others directly challenged labeling itself and school and societal structures that placed certain children in the role of outsiders.

Many of the earliest critiques of labeling in special education focused on people with mild mental retardation and other disabilities. Increasingly in the 1970s, the critiques shifted to the constructs of mental retardation, disability, and handicaps themselves. In an article based on the abbreviated life history of a man labeled mentally retarded, Bogdan and Taylor (1976) wrote, "mental retardation is a social construction or a concept which exists in the minds of the 'judges' rather than in the minds of the 'judged'...A mentally retarded person is one who has been labeled as such according to rather arbitrarily created and applied criteria" (p. 47). Bogdan and Biklen (1977) coined the term "handicapism" to describe the widespread prejudice and discrimination against people with disabilities based on their labels:

Our purpose is to introduce the concept of *handicapism* as a paradigm through which to understand the social experience of those who have previously been known as mentally ill, mentally retarded, deaf, crippled, alcoholic, addict, elderly, deformed, deviant, abnormal, disabled, and handicapped. Handicapism has many parallels to racism and sexism. We define it as a set of assumptions and practices that promote the differential and unequal treatment of people because of apparent or assumed physical, mental, or behavioral differences. (p. 14)

As Gabel (2005) notes, the term ableism is more commonly used today to refer to the sentiments and practices described by Bogdan and Biklen.

Today, labeling theory, Goffman's theory of stigma, and normalization seem overly simplistic, one-sided, and inadequate. Labeling and stigmatization are not inevitable (Bogdan and Taylor, 1989). Disability is not merely a label forced on people so defined; it can also be an identity and source of pride (Linton, 1998; Longmore, 2003). People with disabilities are not passive agents who willingly accept societal beliefs, attitudes, and stereotypes; they also can resist or even ignore the sentiments of the broader culture (Gabel, 2005; Taylor, 2000). Normalization tended to dismiss self-determination and to promote conformity or assimilation².

Yet labeling theory and the theory of stigma shifted the focus away from the presumed deficits of people with disabilities to the social and cultural contexts in which disability is constructed. The critiques of labeling, stigmatization, and the medicalization of deviance and the medical model (Conrad and Schneider, 1992) provided a solid foundation for what has come to be known as the interdisciplinary area of inquiry of Disability Studies. It is not a coincidence that the Society for Disability Studies was originally founded by Irving Zola and other sociologists as the Section of Chronic Illness, Impairment, and Disability of the Western Social Science Association in 1982.

An understanding of disability as a social phenomenon has important implications for educational policy and practice. Enter Disability Studies in Education. What distinguishes Disability Studies in Education from Disability Studies generally is a practical concern with schooling practices. In contrast to a traditional special education perspective and consistent with a Disability Studies perspective, Disability Studies in Education examines disability in social and cultural context. Constructions of disability are questioned and special education assumptions and practices are challenged.

To regard disability as a social construction or creation is not to deny human variation. Human beings differ in many ways. Variations according to ability do not need to be valued negatively or wrapped in stereotypes and

stigma. Disability is not viewed as a condition to be cured but rather as a difference to be accepted and accommodated. It is a social phenomenon through and through.

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Notes

¹Foucault's *Madness and Civilization* would later become influential, but this was not translated into English until 1979. In Disability Studies, Foucault was not widely cited until the 1990s.

²Normalization does not necessarily mean that people with disabilities should be made "normal." Wolfensberger's (1972) formulation placed equal emphasis on changing society and service systems, on the one hand, and changing individuals, on the other. It is true that Wolfensberger's notion is incompatible with the concepts of disability culture and disabled identity (Linton, 1998). The Scandinavian version of normalization (Nirje, 1969) had subtle, but important differences from Wolfensberger's version. For Nirje and others, normalization meant that human services should stop treating people with disabilities in abnormal ways.

Vital Questions Facing Disability Studies in Education

EDITED BY

Scot Danforth and Susan L. Gabel



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