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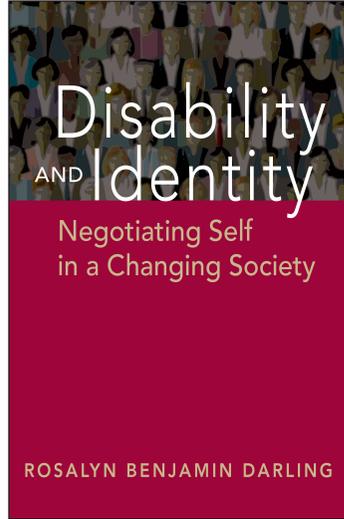
Disability and Identity:
Negotiating Self in a
Changing Society

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1

Introduction

People with disabilities constitute a significant portion of the population. According to the US Bureau of the Census, in 2010 18.7 percent of the noninstitutionalized US population had a disability, and the numbers increase with age (Brault 2012). Although so many people are affected, until fairly recently, most of the literature on this population viewed disability as a form of deviance from the ability and appearance norms of Western society. During the past several decades, newer views have reconceptualized disability as a normal form of human variation, much like race or gender. However, much conceptual variability continues to exist. How have the self-conceptions of this population been affected by the views of others in society over time? I address this question by exploring the interactions between people with disabilities and the societies in which they live.

Certainly not all disabilities are the same, and societal reactions vary greatly from one disability to another. Some disabilities are readily apparent, whereas others remain hidden unless those who have them choose to reveal them to others. Some disabilities are congenital, but others develop later in life, and disability tends to increase dramatically with aging. Clearly, a person with an impairment such as asthma or diabetes may experience some limitations in life activities but probably will not encounter the stigma and social exclusion experienced by an individual with cerebral palsy who uses a wheelchair and a speech synthesizer. Most sociological research on disability has focused on individuals with impairments that have significant social consequences, and who are likely to have incorporated

their disability into their self-definitions or identities. In this book, I am concerned with those individuals who have the kinds of disabilities that tend to be associated with differential treatment in a variety of social situations.

Sociologist Erving Goffman's *Stigma* (Goffman 1963), perhaps the most influential study of the interaction between societal views and the self-concepts of people with disabilities, is subtitled, *Notes on the Management of Spoiled Identity*. Goffman was writing at a time when prevailing views of disability were overwhelmingly negative. Consequently, he believed that individuals with disabilities needed to learn techniques to minimize their differences in order to be accepted in society. More recently, the concept of spoiled identity has been increasingly questioned and challenged. However, few empirical studies have directly measured the identities of the population of people with disabilities in society today. This book is my attempt to increase knowledge about this understudied area and suggest directions for further research.

The concept of disability identity has been receiving increased attention in recent literature, much of which has come from scholars in the humanities and has been based largely on the personal experiences of disabled individuals. Although this literature certainly broadens our knowledge of the disability experience and provides important insights into the self-views of members of this population, it does not tell us whether these views are representative of the population as a whole. Studies undertaken from a social science perspective are needed to address the diversity of disability identity in modern society. In this book I take such a perspective, relying especially on sociological theories, concepts, and empirical studies to explore the evolution of the concept of disability identity from Goffman's time to the present. This inquiry seems especially appropriate on the fiftieth anniversary of Goffman's seminal publication.

Overview of the Book

Much of the early literature on the self-conceptions of people with disabilities suggested that prevailing self-views were negative. This literature was commonly based on a psychoanalytic perspective that suggested that bodily aberrations would have negative consequences for psychological well-being. In Chapter 2 I show that some of the

empirical work that attempted to verify this suggestion was methodologically flawed, yet these views persisted for many years.

Early sociological perspectives of the self-conceptions of people with disabilities also suggested that these individuals would view themselves negatively. These sociological ideas derived from the premise that self-conceptions develop in response to interactions in a society that holds negative views of disability. This position was most clearly presented in the work of Erving Goffman, and his concept of stigma dominated sociological studies of disability for many years. He argued that an individual seen as having attributes of disability would be “reduced in our minds from a whole and usual person to a tainted, discounted one” (Goffman 1963, 3). In Chapter 2 I review the literature on stigma as part of an overview of attitudes toward disability in society.

Much of the sociological literature linking stigma with low self-esteem has roots in the symbolic interactionist perspective in general and “looking-glass self” theory in particular. The concept of the looking-glass self originated in the work of Charles Horton Cooley (1964). This concept suggests that our self-definitions derive from the definitions that we encounter when interacting with others. The theory posits that positive definitions will be reflected in favorable self-views, whereas negative definitions will have the opposite effect. Consequently, stigmatization would be expected to result in negative self-definitions.

However, as I show in later chapters, not all individuals with disabilities view themselves negatively. The existence of positive self-definitions in a stigmatizing society does not necessarily invalidate the looking-glass self argument, though. Symbolic interaction theory also includes the concepts of reference groups and significant others. These concepts suggest that the larger society’s views may be filtered through interactions in smaller groups. We are likely to pay particular attention to the definitions we receive from the people who are most important to us. G. Becker (1980), for example, found that membership in a close-knit deaf community protected the older people she studied from the negative definitions of deafness in the larger society. In Chapter 3 I review concepts from symbolic interaction theory that are useful in understanding the relationship between societal views and the self-concepts of individuals with disabilities.

For some individuals, their disability is the most salient component of their self-concept. For others, having a disability plays only a minor role in the way they view themselves. In some cases, other de-

valued statuses overshadow disabilities in self-definitions. For example, P. Devlieger and G. Albrecht (2000) found that, in a sample of poor African Americans, race and class were more important than disability in determining self-identity. Studies of women with disabilities (see, e.g., Thomas 1999a) have suggested that “double oppression” may magnify the salience of disability identity. In Chapter 4 I explore how the relationships between disability and other devalued group identities shape the development of self-concept.

Since the 1970s and 1980s, many people with disabilities have become empowered as the disability rights movement (DRM) has grown. A number of sociologists (e.g., Anspach 1979; Britt and Heise 2000) have suggested a link between identity politics and a more positive construction of the disabled self. In fact, more recent writings by disability activists and disability studies scholars have introduced the concept of disability pride (see, e.g., Swain and French 2000). In Chapter 5 I look more closely at this concept. The idea of disability pride has been associated with a shift in the literature from a medical model that views disability as a pathological condition to a social model (Oliver 1996; Swain and Cameron 1999) that views disability as a normal form of human diversity. The social model sees disability as a social construction rather than as an inherent biological condition. Various writers have noted parallels between positive constructions like disability pride and similar constructions, such as gay pride and black pride, among other minority groups.

Much of the writing on disability pride has been theoretical or polemical. The writers have assumed that positive self-identities among individuals with disabilities have been increasing along with the increasing popularity of the social model. However, not everyone has been exposed to the social model, and even those who have been exposed to the model may not espouse it. A number of years ago, I suggested a typology of orientations toward disability (Darling 2003) that included other disability identities in addition to pride. I explore the diversity of identities among individuals with disabilities in society today in Chapter 6.

Since the 1990s, the existence of a variety of disability identities has been tested empirically. C. J. Gill (1997) and H. D. Hahn and T. L. Belt (2004) have attempted to measure the existence of disability pride among activists. More recently, my colleague and I (2010a) developed and tested an instrument to measure the diversity of orientations to disability suggested by the typology described above. The results confirm the existence of a variety of disability identities in US

society today. In Chapter 7 I look more closely at these studies and discuss the empirical evidence for the existence of various disability identities.

Perhaps the most important variable in determining whether individuals view their disabilities positively is the point in the lifespan at which the disability is acquired. My colleague Alex Heckert and I (2010b) found that individuals with lifelong disabilities were much more likely to have an identity of disability pride, whereas those who acquired their disabilities later in life had more negative views. I explore the relationship between identity and age, along with the related variable of age at disability acquisition, in Chapter 8. I also focus on disability orientation at two points in the life course: childhood/adolescence and old age.

Views of disability appear to be changing slowly in modern society. Older, stigma-based views seem to be giving way to newer, more positive views. However, negative views continue to exist and to influence the self-esteem of people with disabilities. Newer technologies allow for the prenatal diagnosis of many impairments, commonly resulting in pregnancy termination among those who view disability negatively. If many disabilities become rarer in the future, will the identities of those living with disability be affected? In Chapter 9 I address this question in addition to speculating about trends relating to disability identity development in the future.

In the next section I review the theoretical paradigms that will be used in this book, namely symbolic interactionism and its derivative, identity theory. I define key concepts from these paradigms, including self and identity, and introduce the concept of disability orientation, which is broader than those of self and identity and encompasses the related variables of model and role. Finally, I briefly discuss the meanings of impairment and disability, and explain their use in this book.

Conceptual Framework and Definitions of Key Concepts

Self, Identity, and Orientation

In the chapters that follow, I apply a sociological framework to explain the relationship between society and self-concept in individuals with disabilities. Specifically, the perspective that will be used will

be symbolic interactionism, the sociologically-based social psychology that originated in the work of G. H. Mead (1934), H. Blumer (1962), and others. Its basic premise is that individual attributes such as thought and self-concept derive from the individual's interactions in society. These interactions occur through language, or through shared meanings that enable a person to understand and respond to ideas expressed by others.

The mechanism through which interaction occurs is "taking the role of the other" (Mead 1934) or "role-taking," the process of understanding and internalizing the messages one receives in the course of interaction. Shared language makes role-taking possible. The symbolic interactionist view of the self begins with the premise that individuals receive definitions of themselves in the course of interacting with others. Through the mechanism of role-taking, they understand and internalize these definitions, incorporating them into their beliefs about themselves. For example, a student who receives positive feedback in the form of good grades and praise from teachers is likely to think of himself or herself as a good student. Over the years, many studies have explored the nature of the process of internalization and have shown that not all definitions have equal weight in determining a person's self-concept; however, the general association between the appraisals of others and self-appraisals has been supported (Lundgren 2004).

This book is about the self-concepts of people with disabilities. I use the terms *self*, *self-concept*, *self-view*, and *self-definition* interchangeably to refer to how people think about themselves. M. H. Kuhn and T. S. McPartland (1954) have noted that self-definitions include both "consensual," or fixed, attributes, such as gender and race, and "subconsensual" attributes that involve judgments about the self ("I am a good student"). Judgments about the self collectively constitute what has been called self-esteem or self-efficacy. Self-esteem thus describes the evaluative part of the self-concept and includes both positive and negative evaluations.

A concept that is closely related to that of self is identity. This term has become popular among writers and researchers interested in modern social movements, such as the feminist and gay rights movements, to describe identification with movement principles. In sociology, identity theory is largely associated with the work of S. Stryker and P. J. Burke: "Identity theory began by attempting to specify and make researchable the concepts of 'society' and 'self' in Mead's frame" (Stryker and Burke 2000, 285). For Stryker, identity is the empirically testable form of the self-concept.

Last year I attended a talk by historian Dan Diner, who argued that, in the case of ethnic identity, identity awareness arises from freedom of choice. When people are oppressed, they may take their identity for granted and not view it as a source of pride. This argument suggests that identity has a political component. Similarly, K. A. Cerulo (1997) claims that, in sociology, the concept of identity has come to coincide with the concept of collective identity. Thus identity is being used in a more specific sense than self to refer to the individual counterpart of group agency and political action. She argues further that identity reflects a conscious sense of the group as an agent and therefore becomes linked with an activist stance. M. Bernstein (2005) describes identity politics as a process through which identities are deployed strategically to bring about social change.

In this book, I use the term *identity* a little more broadly than those who argue for a political definition. *Disability pride* represents an ideal-typical identity that has come to be associated with disability rights activists; its polar opposite is *disability shame*, a view based on stigma. I would argue that individuals who are ashamed of their disabilities also have an identity, albeit an apolitical one. Shame, like pride, is learned in the course of interactions in groups and is a social construction. Thus, *disability identity* is used in this book to refer to that part of the self-concept that emerges from the disability-related self definitions that exist within an individual.

Two complementary versions of a theory of identity have developed: identity theory and social identity theory. M. A. Hogg and colleagues (1995, 255) explain that identity theory “is a microsociological theory that sets out to explain individuals’ role-related behaviors,” whereas social identity theory “is a social psychological theory that sets out to explain group processes and intergroup relations.” As the authors note, identity theory’s roots are in sociology, and social identity theory grew out of the discipline of psychology. J. E. Stets and P. J. Burke (2000) have argued that, although their terminologies differ, the theories have substantial similarities and can be linked. Because this book is primarily a work of sociology, I will use the terminology of identity theory to discuss the identities of individuals with disabilities.

G. J. McCall and J. L. Simmons (1978) describe the process of identification through which individuals categorize themselves as occupants of a role. Through interaction with other people, individuals learn about the social positions or statuses recognized in society and locate themselves within various categories, such as gender, race, or

socioeconomic status: they learn that certain behaviors, or roles, tend to be associated with these statuses. Identities form through a process of identification with a variety of roles. Because they play multiple roles, individuals with disabilities have other identities in addition to their identity as a disabled person. In this book I focus on identity as a disabled person, or disability identity.

Because all individuals occupy a number of statuses and have the ability to play multiple roles, they must decide which role to play. In order to determine how to act in any given situation, the individual must first define the situation (Thomas 1928). Doing so requires the ability to take the role of the other, as described earlier, in order to choose the most appropriate role to play. Identity theorists refer to this process as role-choice behavior (Stryker and Burke 2000).

Stryker and Burke (2000) explain that the term *identity* refers to each of the group-based selves that a person occupies as a result of his or her social relationships, and *identities* are defined as internalized role expectations. These identities, in turn, are organized in a hierarchy of salience. Behavioral choices depend on which identities are most salient. For example, a woman may see herself as both a mother and a business owner, but if her identity as a mother is more salient, she may choose to stay at home with her child rather than go to the office on a day when the child is ill. Salience tends to be situational, varying with the role opportunities that present themselves at any point in time.

Stryker and Burke (2000, 286) also discuss the concept of commitment, which “refers to the degree to which persons’ relationships to others in their networks depend on possessing a particular identity and role.” In other words, interactions in some social groups are more valued (and often more frequent) than interactions in others. Commitment to the role relationships in these groups produces more highly salient identities. A related concept, significant others (Sullivan 1947), refers to those people whose opinions are most important to an individual. Interactions with significant others result in definitions that are more likely to be incorporated into a person’s self-concept. T. Shibutani (1961) uses the term *reference groups* to describe those groups that are most important in shaping their members’ perspectives.

The nature of a social structure may be important in determining commitment. Stryker and Burke (2000) note that the density of ties within a social network may be significant. Other characteristics of a network also play a role. For example, J. W. Kinch (1968) and others

have discussed the role of frequency, intensity, duration, and recency of interactions in determining effects on self-concept.

Stryker and Burke (2000) argue that, through their behavior, individuals seek to maintain their existing identities or identity standards. They call this process self-verification. However, when individuals find themselves in new situations, new relationships may become significant to them. A. Strauss (1962) uses the phrase *turning points* to describe the times in people's lives when they encounter new groups, leading to relationships that change their identities. For example, when a student enters college, he or she is likely to meet other students and professors with ideas that are different from those encountered earlier in life. The student's own ideas and identity may change if these new relationships become significant.

Self-concept and identity exist within a person's mind. They are internal and only become apparent when a person plays a role. Behavior, or role playing, is the external manifestation of identity and the means by which others become aware of a person's identities and self-concept. Goffman (1958) contrasts "backstage" behavior, which is more or less automatic, with "front-stage" behavior that is intended to convey to others an actor's desired self. At job interviews, for example, people usually present themselves as capable of doing the job, whether or not they really believe in that capability. The others in the situation, in turn, make judgments about people based on their presented selves. Although role playing may or may not reflect a person's true identity, it is the basis on which people are typically judged.

The concept of identity, then, represents only one aspect of an individual's location in society. A broader concept that is useful in understanding the social location of individuals with disabilities is disability orientation, which has three related components: identity, model, and role. In the following paragraphs I briefly explain each one.

Identity has been described above as the empirically verifiable aspect of the self-concept that arises through social interaction. In the case of individuals with disabilities, two major disability-related identities have received attention in the literature: shame and pride. Shame presumably develops in response to interaction in a stigmatizing society. As noted earlier, disability pride has been identified in disability rights activists who reject society's devaluation of their disabilities. I have suggested elsewhere (Darling 2003) that both pride and shame are ideal types and that actual individuals may have elements of both in their identities.

Model refers to a paradigm or perspective related to a social condition such as disability. Those who subscribe to a medical model see disability as a form of illness and view people with disabilities as needing rehabilitation or cure. This model has been associated with the sick role (Parsons 1951), an undesirable state that requires the patient to cooperate with medical treatment in order to return to full participation in society. The sick role focuses on individual action rather than on social change. In this view, individuals with disabilities are commonly viewed as people to be pitied. The polar opposite of the medical model has been called the social model of disability (Oliver 1996). In this view, the locus of disability can be found in a society that fails to accommodate the diverse needs of individuals with disabilities. Those who subscribe to a social model see a need for social change in the form of physical changes to the environment, such as curb cuts and ramps, as well as changes in attitudes away from stigma and toward acceptance. Again, the medical and social models are ideal types that only approximate the views of actual individuals. As later chapters will show, most people adhere to some tenets of both models.

The third component of disability orientation is *role*, which encompasses the cluster of disability-related behaviors in which people with disabilities engage. Some may play the classic sick role and continue to search for cures for their impairments, whereas others may choose to forgo rehabilitative services. As I have explained elsewhere (Darling 2003), role choices are closely related to opportunities, which, in turn, are associated with one's location in society in terms of socioeconomic status (SES) and other statuses. Those who have been exposed only to the medical model may play the sick role because they are not aware of other behavioral options. Another role that has received considerable attention in the literature is disability rights activism. Activists join groups, participate in demonstrations, lobby their congressional representatives, or engage in other activities intended to increase opportunities for people with disabilities. The literature suggests that activists tend to espouse the social model of disability and to have disability pride; however, as I show later in this book, identity, model, and role are not always associated in expected ways. For example, some people with pride in their identities as individuals with disabilities reject activism and play a more passive role with respect to disability rights. The concept of disability orientation enables the exploration of other factors that may or may not be associated with disability identity.

Opportunity Structures

As noted earlier, identity, self, and disability orientation are believed to result from an individual's interactions in society in general and in smaller reference groups in particular. Microsociologists focus on these interactions and the selves and identities they engender. However, social structure plays an important role in determining where and whether interaction occurs. For example, individuals living in poverty with limited access to computers may not be aware of much of the culture of disability rights activism that can be found online. Thus, although role choice may involve a conscious decisionmaking process for those with access to multiple role options, it may not exist at all for others.

In this book, I use the concept of opportunity structure (Cloward and Ohlin 1960) to describe an individual's place in society with respect to opportunities for exposure to various identities and roles. Because of differences in SES, race and ethnicity, gender, age, area of residence, and other stratifying factors, not everyone is exposed equally to society's definitions and ideologies. Consequently, exposure to stigma or to the social model varies by opportunity structure. If symbolic interaction theory is correct, this diversity in exposure will result in a diversity of disability identities.

Disability and Impairment

Various terms have been used to describe conditions that deviate from social norms relating to appearance and functioning, most notably, *impairment*, *handicap*, and *disability*. The *International Classification of Functioning, Disability and Health*, 2nd ed., no longer includes the term *handicap* because of its pejorative connotations for some people (World Health Organization 1999). The document defines *impairments* as problems in body function or structure. Many would include mental function in this category as well. However, not all impairments limit or restrict participation in life activities; that is, they are not necessarily disabilities.

While recognizing the diversity of definitions that exist, in this book I adopt the terminology of the *International Classification of Functioning, Disability and Health* and most writers in the field of disability studies and use the term *impairment* to refer to an anatomical or physiological trait or condition. I use the term *disability* as it is defined in the Americans with Disabilities Act (ADA): "A physical

or mental impairment that substantially limits one or more of the major life activities of such individual; a record of such an impairment; being regarded as having such an impairment” (Jones 2006, 4). Of particular importance in a sociological analysis such as the one in this book is the inclusion of the third element of the definition, “being regarded as having such an impairment.” Although the biopsychological consequences of an impairment may be significant for the person who has it and may contribute to the salience of the impairment in the person’s mind, identity theory posits that only the definitions of other people are relevant in determining disability identity. In the perspective adopted here, disability is a social status, not a biological condition, and identification (or lack of identification) with the status is assumed to occur through social interaction.