

Living Stigma: The Impact of Labeling, Stereotyping, Separation, Status Loss, and Discrimination in the Lives of Individuals with Disabilities and Their Families

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In this study, we examine the direct and vicarious impact of the social processes of felt and enacted stigma and their impact on the lives of individuals with disabilities and their families. Specifically, findings of interactive interviews with eight adults with disabilities and seven mothers of children with disabilities were analyzed for themes related to components of stigma described by Link and Phelan (2001): labeling, stereotyping, separation, status loss, and discrimination within the context of power differential. Findings suggest that while these social processes can have important negative psychosocial consequences for individuals living with disabilities, the severity of the consequences varies among the components. Findings also indicate that these individuals find varied and creative ways to resist and actively counter the negative effects of stigma in their lives. Findings support the complexity of the experience of stigma and the importance of the socio/cultural context to the lived experience of disability.

Introduction

Stigma can be defined as an adverse reaction to the perception of a negatively evaluated difference (Susman 1994). As such, it is not an attribute of the individual who bears the difference but rather resides in interactions between the person with the difference and others who evaluate that difference in negative terms (Goffman 1963). The concept of stigma has traditionally been employed as a unidimensional construct and has been widely criticized as being too broadly conceived (Cahill and Eggleston 1994; Murphy, Scheer, Murphy, and Mack 1988; Susman 1994). Link and Phelan (2001) describe five components of stigma: *labeling*, *stereotyping*, *separation*, *status loss*, and *discrimination* within the context of *power differential*. *Labeling* is the recognition of differences and the assignment of social salience to those differences. In the context of disability, it is the recognition that a certain biological trait differs from the norm in ways that have social significance. *Stereotyping* is the assignment of negative attributes to socially salient differences. Stereotypical differences are differences that matter and are also deemed by others to be undesirable. *Separation* occurs when the reactions of others to these differences lead to a pronounced sense of

“otherness.” When individuals with disabilities perceive that they are labeled, stereotyped, and separated from others, they experience *felt stigma*.

Status loss and discrimination occur when stigma interferes with an individual’s ability to participate fully in the social and economic life of her/his community. When individuals lose status or are discriminated against because of their negatively evaluated differences, they experience *enacted stigma*. Link and Phelan go on to argue that stigma can only be directly enacted upon individuals when there is a *power differential* between those with the trait and those without—when those who have the negatively evaluated difference have less power than those who do not. Thus, the stigmatization of individuals with disabilities is a complex process which involves individual biological differences, the negative evaluation of those differences by others, adverse reactions of others and negative social and emotional outcomes for individuals with disabilities (Cahill and Eggleston 1994; Frame 2001; Jones, Farina, Hastorf, Markus, Miller, and Scott 1984; Link, Cullen, Struening, Shrout, and Dohrenwend 1989; Link and Phelan 2001; Mickelson 2001; Murphy, Scheer, Murphy, and Mack 1988; Perry 1996; Susman 1994; Zola 1993).

Goffman (1963) argues that stigma not only affects the experiences of those in possession of the stigmatizing characteristic (the own), it also tends to spread to close family members and to others with whom the bearer of negative difference associates (the wise). The slim body of recent literature in which the impact of perceived stigma on the well-being of family members of individuals with stigmatized traits (courtesy stigma) is addressed suggests that, like individuals with disabilities themselves, family members who feel stigmatized often experience increased emotional distress and social isolation (Angermyer, Schulze, and Dietrich 2003; Birenbaum 1992; Blum 1991; Gray 1993; Green 2001b, 2004a; Horwitz and Reinhard 1995; MacRae 1999; Mwaria 1990; Seligman and Darling 1997; Sigelman, Howell, Cornell, Cutright, and Dewey 1991; Stockall 2001).

In this study, we examine the impact of felt and enacted stigma in the lives of eight adults with disabilities and impairments, and seven mothers of children with disabilities. Thus, we address both the direct experience of stigma and the indirect or vicarious experience of courtesy stigma.

Methods

Study Participants

The research on which this study is based was conducted by individuals who are members of the own and wise categories of disability experience. Because of this collective experience, we were able to engage with interviewees in shared narrative exchange of disability experience. The lead author (mother of

a child with cerebral palsy) along with a research assistant who is the hearing sister of a deaf woman conducted interviews with seven mothers of children with disabilities as part of a previous project. The children of the mothers interviewed have been diagnosed with a variety of impairments and disabilities including cerebral palsy (3), Down syndrome (1), severe autism (1), non-specific development delay (1), and early childhood stroke (1). Three of the children are girls and four are boys. At the time of the interviews they ranged in age from preschoolers to high-school students. Six of their mothers were still married to the child's father and one was a single mom. The results of these interviews have been used in a number of previous publications (Green 2001a, 2001b, 2002, 2003a, 2003b, 2004a, 2004b). Transcripts of these interviews were reanalyzed for themes related to the purpose of this study.

In addition, the coauthors (one member of the own and three members of the wise category) interviewed eight adults with disabilities as part of a class project in a graduate seminar ("Sociology of Disability in Urban Society"). Interviewees were selected from among the interviewers' contacts in the disability community and represent a diversity of disabilities and other life circumstances. Four of the eight interviewees have obvious physical impairments (one of them also has a hearing impairment). Three have less obvious physical impairments (one of them also has a seizure disorder). One interviewee has a chronic medical condition which, for a time, resulted in both emotional and physical impairments. Three interviewees have had disabilities since birth while five acquired their impairments and disabilities as older children or young adults. The interviewees range in age from young adults to retirees and like the mothers interviewed, represent considerable diversity in terms of socioeconomic status.

Interactive Interviews

Both sets of interviews were interactive in structure. Unlike more traditional qualitative research in which the interaction is primarily one-way, interactive interviewing involves a relationship through which interviewers and interviewees jointly share feelings and experiences (Denzin 1997; Ellis 1998; Ellis, Kiesinger, and Tillman-Healy 1997). This technique is gaining acceptance as a powerful and appropriate tool for in-depth explorations of lived experience that has several advantages over more traditional interviewing techniques when interviewees are members of stigmatized groups. First, researchers who maintain the more traditional objective stance and professional distance while attempting to encourage interviewees to disclose feelings about stigmatizing experiences may find that interviewees are particularly prone to providing socially acceptable responses. There is good reason for this. Individuals with disabilities and their close family members (particularly mothers of children with disabilities) are called upon to tell the "stories of their lives" many times over to health care

and social service professionals. The stories they tell and the way in which they tell them have consequences in terms of both the acquisition of diagnostic labels and services and professional attitudes toward (and sometimes treatment of) the teller and/or her or his family member with the disability. The professional judgments formulated on the basis of the tale and the telling can have profound and far reaching consequences in the tellers' lives. Further, these judgments often become part of the official account of the individual's life through entry in case records and can be extremely difficult to alter or eradicate. As a consequence, over time, individuals with disabilities and their family members become highly skilled in the presentation of self. This is a high-stakes game and they learn to play it well. In a recent narrative account of her experiences in raising a son with learning disabilities, Lissa Weinstein, herself a clinical psychologist, poignantly describes this phenomenon from the dual perspective of professional judge and parental recipient of such judgments. When asked to give her permission for graduate students to observe her son's psychological evaluation through a one-way mirror, she replies:

"Of course" . . . with slightly exaggerated grace, wanting to be seen as the cooperative mother, the one the professionals like. Secretly, I'm cringing . . . it's poetic justice for all those years I sat in case conferences, secretly judging, believing I could have done better than another mother. (Weinstein 2003:15)

As well as discouraging honest disclosure of feelings and experiences, being constantly judged can lead to frustration and even anger toward the community of professionals that is sometimes perceived to be more interested in pathologizing than understanding the experience of disability. The community of people with disabilities has become quite vocal in its criticism of "experts" who profess to know what is in their best interest. The slogan "not a word about us without us" resonates throughout this group as well as others whose life experiences fall under constant professional scrutiny. While there have been some excellent "insider" narratives of the disability experience produced in recent years, the vast majority of studies of the perception and outcomes of stigma have approached the issue primarily from the "objective stance" of "outside expertise" using data collected by individuals who lack disability experience. There is growing concern about the fact that the voices of individuals with disabilities and their families are largely absent in this literature (Fine and Asch 1988; Fleischer and Zames 2001; Kleinman 1988; Link and Phelan 2001; Schneider 1988). Ironically, researchers who wish to give voice to individuals with disabilities are sometimes seen as one more set of "judgmental experts."

This is not to say that skilled researchers cannot break through this barrier while using traditional interviewing techniques. Empathetic researchers who

lack the lived experience of disability certainly can (and do) develop trusting relationships with interviewees over time. The entrenched patterns of “putting your best foot forward” in interviews with professionals and the underlying anger at having to do so, however, are likely to mean that building such trusting relationships will be challenging for both parties. These relationships may need to be built gradually and maintained for some time before meaningful disclosure can occur.

Where both interviewer and interviewee are members of the stigmatized group, open disclosure is facilitated by the presumption of shared experience. Further, because interactive interviewers share some of their own experiences, the balance of power is less one-sided than in traditional interviews where only the interviewee is asked to bare his/her soul for public consumption. Interactive interviews tend to set the interviewee at ease because they involve the give and take of ordinary conversations. Thus, they “reflect the way relationships develop in real life” (Ellis, Kiesinger, and Tillman-Healy 1997:122).

There is, of course, the very real possibility that the “truths” disclosed in such interviews will be co-constructed by the interviewer and interviewee. If so, however, they are representative of the kinds of “truths” that are told within the community of people who experience stigma. Because these are “truths” to which most readers are not privy, they have potential value in increasing our understanding of the ways in which individuals make sense of the lived experience of stigma. They provide a counterpoint to the picture of stigma which has emerged from the accounts given to “objective professionals.” As the majority of our current knowledge about the social experience of stigma comes from the latter, interactive interviewing can provide balance of the kind called for with increasing urgency by the community of people with disabilities (Fleischer and Zames 2001).

Findings

Transcripts of the interactive interview tapes were examined for themes related to the components of stigma proposed by Link and Phelan (2001): *Labeling, Stereotyping, Separation, Status Loss, and Discrimination*. In the following sections, we explore both the experiences and outcomes of these components of stigma in the lives of research participants (interviewees and interviewers). We also examine the rich variety of ways in which study participants resist and actively counter the negative impact of stigma in their daily lives.

Labeling

As noted in the introduction, labeling involves not only the perception that someone is different, but also the assignment of social import to that difference. Unusual eye color, for example, differs from the norm but is not

likely to evoke labeling because the difference does not have social significance. The difference of disability, on the other hand, places people in a social category that does have social significance to others. Murphy, Sheer, Murphy, and Mack (1988) suggest that people with disabilities find themselves in a liminal state; that is, they do not fit into traditional categories. They are neither healthy nor ill in the eyes of others. Thus others are not sure how they should be treated or what to expect from them in public encounters. This can be a source of confusion and social awkwardness that can diminish both the quantity and quality of social interaction. Such social awkwardness is a common theme in the interviews. Carol (a 68-year-old woman who also has lifelong disabilities as a result of physical impairments), for example, says that when she is among others unfamiliar with the disability experience, "no one really knows what to talk about." Similarly, Judy (a young adult wheelchair user who also has a hearing impairment) says that in public encounters with others, there is "a hesitance to look me in the eye or to shake my hand because they don't know how to shake hands with somebody on crutches or in a wheelchair. . . ." Susan (mother of a child with Down syndrome) also reports that people find it difficult to engage in ordinary chit chat about her son and his daily "doings." She says that in order to reduce this social awkwardness she is "constantly educating people . . . by being gentle . . . and frank and saying just the right thing" (Green 2001b:809). In these cases, the difference of disability clearly has social significance to others in that it creates social awkwardness that interferes with ordinary social interaction.

Stereotyping

Just as not all differences are labeled, not all labeled differences result in stereotyping. Extraordinary athletic ability, for example, has social import and may even produce social awkwardness but it is generally not negatively valued. That is, it is not something that others dread acquiring. People with disabilities, on the other hand, are generally perceived to possess traits that others do not want to acquire. Others may consequently feel sadness and pity in the presence of individuals with disabilities and these feelings can further interfere with the shared meanings needed for ordinary social interaction. Seeking to avoid these feelings, others may even avoid individuals who possess the difference they dread. Carol, for example, notes that when she was a young woman, "no one wanted to be associated with people who had problems." Similarly, Judy says that when she encounters others in her community, "[T]hey see the wheelchair before they see me. A lot of people are scared of wheelchairs. It's a sign of physical impairment and a lot of people don't like to think about being physically impaired. . . ." Such avoidance can leave the person with the disability feeling much like Ralph Ellison's *Invisible Man*.

I am an invisible man. . . . I am invisible, understand, simply because people refuse to see me. . . . [I]t is as though I have been surrounded by mirrors of hard, distorting glass. When they approach me they see only my surroundings, themselves, or figments of their imagination—indeed, everything and anything except me. (Ellison 1947:3)

While labeling and stereotyping are common experiences in their lives, interviewees indicate that the reactions of others are certainly not homogeneous. Among other things, perceptions of the permanence and severity of the disability can have an important impact on the way in which others react. Summer (a female martial arts instructor in her mid-forties) has permanent, though no longer visible, orthopedic impairments which, for a time, necessitated the use of crutches or a cane. During the time she used these devices, she noticed that people reacted to her in ways that were vastly different from the ways people react to her aunt who is a wheelchair user.

People around here treated me fine . . . when they would see the crutches or the cane . . . They would be very helpful . . . I was always very touched at how total strangers would come up and say “can I help you?” . . . I have an aunt who is completely disabled. She is in a wheelchair. She has polio and only has the use of one hand . . . I spent some time with her traveling around up in DC . . . What I found to be very eye-opening . . . is how people will refuse to see you . . . if you’re that disabled . . . They’ll see you if you’re only a little bit disabled . . . when you’re trying to get around on your crutches or whatever, but she’s down in a wheelchair . . . People don’t want to see you when you’re that disabled . . . They don’t want to be bothered. They feel uncomfortable . . . They will walk around in circles trying to get away from you.

In other words, people tend to feel that a person with impairment is “still one of us” as long as the impairment is perceived to be minor and/or temporary. This distinction can be especially troubling for individuals whose progressive conditions result in movement from one category of disability to another. John was diagnosed with a slow progressive form of muscular dystrophy when he was eighteen. He has been using a wheelchair for the past five years and he discusses his process of adjustment to this outward symbol of the increasing severity of his disability:

The initial stage of using the chair, or using the cane, becomes an image type of thing in our society. . . . The true freedom came when I accepted that I had to use the chair, and turned it into a tool rather than a hindrance. . . . The person who gets a sports injury, or has some surgery that requires incapacitation for a short period of time, thinks nothing about using a wheelchair or a cane because it is a temporary situation. It’s a necessity, but you know it’s going away, so it’s almost a badge of honor. You know, like “I broke my ankle skiing down Mount Everest.”

It is apparent that both the perceived severity and permanence of the disability can affect the reactions of others when the disability is visible.

Not all disabilities are visible to others, however. Goffman distinguishes between individuals whose stigmatized characteristics are immediately apparent to others (the discredited) and those whose stigmatized characteristics are invisible (the discreditable). For the discreditable, the issue of public perception of severity and permanence is often irrelevant to initial encounters. For such individuals, however, whether, and when, to disclose the presence of the disability can be problematic (Goffman 1963). Both the third author (Elana) and Jane are young women who have recently been diagnosed with seizure disorders. When managed with medication, their disabilities are generally hidden from others. In describing her interactive interview with Jane, Elana notes:

[B]oth Jane and I expressed the fear that our common condition might affect romantic relationships. In becoming involved with another person, especially intimately, the necessity for disclosure increases since the partner is generally present for a long period of time, increasing his/her chances of witnessing the effects of the hidden disability.

In Jane's case, there is good reason for this concern. "[R]ight after I found out about the seizure disorder, I was already dating somebody at the time and he flipped out . . . and we broke up like two weeks later. He broke up with me." The demise of this relationship made her anxious about the effect of her disability on other romantic relationships—including the one in which she is currently involved. She decided to disclose the existence of her hidden disability right away in order to avoid the potential for future heartache:

I was always worried about that when (Frank) and I started dating—I told him pretty quickly because I was really scared that it might drive him away, and I wanted to get it out of the way instead of letting it prolong and then telling him later and having him leave after I'd grown an attachment to him. So I told him pretty much right off the bat. But I was really afraid at first because I had no idea how he'd react.

It is clear that *Labeling and Stereotyping* have affected the lives of the study participants. These individuals have, however, found a variety of ways to resist the negative consequences of these components of stigma. John has been able to handle the awkwardness/sadness responses he encounters by adopting and projecting a positive, confident, and competent self-image, and becoming a disability-rights activist:

People will judge you by how you project yourself. If you project yourself as a loser, . . . you will be a loser. If you project yourself as confident, people will deal with you that way, and that's the way I conduct myself, and I notice that people look me straight in the eye, and they don't see the chair after a while.

Jane has learned to integrate her disabilities into a positive perception of self by actively claiming her orthopedic impairment and her seizure disorder as integral parts of who she is and by disclosing them immediately to others. "I've always said, 'I'm not normal. I like being who I am . . . in fact, I was going tell

you over email you'll recognize me because I have a leg problem' . . . I use it almost like an identifying mark."

Bob, Carol's seventy-one-year-old husband who also has lifelong physical impairments, has developed remarkable patience with the stereotyping reactions of others and has noticed that relationships that start out being awkward can improve with time. Speaking of a former coworker, he says: "He and I didn't get along at first . . . I remember over time he began to have respect for me." In a recent workplace study, Helen Gay (2004) found this to be a common experience. For individuals with disabilities, perceived stigma is negatively correlated with the length of time one works with coworkers who do not have disabilities. People with disabilities may also simply get used to the strange reactions of others. As Judy observes, "Anything that seems weird to you might seem normal to me, after a whole lifetime of dealing with reactions."

Separation

While study participants are highly skilled at managing relatively benign reactions produced by the labeling and stereotyping components of stigma, some reactions of others go far beyond social awkwardness and sadness. Separation occurs when the reactions of others produce a pronounced sense of being devalued, disrespected, or viewed as less than fully human:

We're a young society that reveres youth. We do not revere or respect old age, and we certainly do not revere or respect physical impairment. . . . People have a preconception of [the individual] not being a whole person when they see somebody on crutches or in a wheelchair so you have to kind of overcome that. Show them that you are a person and not an object to be pitied. (Judy)

Interviewees' childhood and adolescent memories of being singled out, shunned, or mistreated because of their disabilities are particularly poignant examples of the separation component of stigma:

You know how kids are, they like everything to be the same, like everybody should be the same. . . . I was the only disabled student in a student body of 1,000 people, so there I stuck out even more like a sore thumb . . . even the ones I knew from church were standoffish. . . . That was painful; nobody ever talked to me unless they had to and I was too shy to initiate conversations with them. So I was completely ignored and that's painful. (Judy)

Similarly, Carol remembers that "[a]t school I was called crippled time and time again. . . . I was shunned. I was shunned because I was a cripple. 'You aren't any good' . . . I had that thrown at me." Sometimes the shunning associated with separation can even take a violent turn. Bob, for example, describes his elementary school experiences as being particularly problematic. "I remember being mistreated by my school mates, . . . I remember one in particular who used to hit me in the face, . . . and I remember him to this day and he'd wad up his fist and strike at me."

Blame can also be a powerful source of social separation. The mothers who participated in the interactive interviews report that they sometimes feel blamed for their children's differences and/or actions related to those differences. Susan, for example, reports that she has been asked by total strangers whether she is sorry she didn't know about her son's Down syndrome before he was born—implying that she should have chosen to abort. This implication causes much anguish and anger (Green 2004a). Other mothers feel blamed for causing their children's disabilities or for outcomes and actions that are out of both their own and their children's control (Green 2003a, 2004a).

Ironically, while disabilities that appear to be mild or are invisible to others may not evoke the kind of social awkwardness and pity associated with the labeling and stereotyping components of stigma, they may lead to heightened vulnerability to blame and separation. Judy, for example, finds that she is more likely to be blamed for actions resulting from her hearing impairment than for those related to her much more obvious physical impairments:

The problem with being hearing impaired is [it's] so insidious . . . it's just not visible, like being in a wheelchair, people don't know you're hard of hearing. And so, when they don't realize it, a lot of problems happen and they can snowball and misunderstanding ensues.

Mothers interviewed report that when their children are very young and their disabilities are not obvious to others, strangers sometimes blame them for the child's apparent laziness or lethargy:

She looked so normal for the longest time. I think that was one of the problems. . . . I'd go to the store . . . and someone would say: "For God's sake aren't you spoiling that child. She's too big to be carrying"—not knowing that you'd love to put her down, but you can't. . . . (Green 2001b:807)

People whose disabilities are invisible may even feel that they are unfairly blamed for "faking" their disabilities in order to gain special privileges or advantages. Jane notes, for example,

When I park in a handicapped parking spot, I see people looking at me when I first get out of the car. "What's the matter with her? She's not in a wheelchair!" They don't realize . . . it may not be completely obvious especially if I'm wearing jeans like I am now. The little brace I wear on my knee is covered up and they can't tell. . . .

Sam, a fifty-one-year-old man who acquired a condition in his mid-forties that resulted in relatively severe disabilities until it was finally diagnosed and treated, suffered a particularly painful form of blame. He feels certain that neither his family and friends nor medical professionals believed in the veracity of his symptoms until his claims to illness finally received a confirming medical label.

[T]ruthfully, the family, by this time they were starting to think it might be psychosomatic, or that I'm just somehow doing this and if we just like cross our arms and resist, he'll snap out of it and get back to work. Tough love! . . . Family, friends, just suddenly like [started]

dumping me. They just didn't understand that this was real disability. . . . There was no proof I was ill. So now I'm in the Goodwill place, I'm getting sicker really fast. It was scaring the dickens out of me. . . . I had to hold the walls just to walk down the hall. . . . The nurse apparently didn't believe this. "You're just doing this to get out of work, another one. You don't have anything that I can see." I still dealt with that kind of resistance to accept that someone could have a disability that had that kind of symptoms. . . .

Thus, individuals with hidden disabilities may suffer the painful indignity of being judged as illegitimate claimants to disability status. Individuals with disabilities may also be their own harshest critics. When individuals who have internalized the popular stigmatizing notions of what it means to have a disability are diagnosed with a disability, these notions become personally relevant to their lives and can result in negative psychosocial outcomes (Link, Cullen, Struening, Shrout, and Dohrenwend 1989; Link and Phelan 2001). Summer's husband, Homer, for example, poignantly describes his reasons for leaving his highly treasured career as a Marine officer after the acquisition of physical impairments which many people would consider minor:

I don't think anyone could tell that I had had both of my hips replaced . . . I walked normally. I looked normal. I weight lifted . . . I was healthy and I had good height/weight proportion but the Marines knew that I couldn't run and that I couldn't do the things that Marines were supposed to be able to do. . . . I don't think they thought less of me, but Marines expect their leaders to be able to lead. . . . Even though I could do it in garrison . . . it was obvious that . . . if we had to go into combat, that I could possibly let them down. . . . That impacts them whether or not they ever say anything (and they never did). . . . I know as a Marine, when you have a leader who cannot do everything he knows he is supposed to be able to do, . . . it affects the unit. . . . I would like to think that I was a Marine 110 percent of my life. . . . So as a Marine officer, knowing that I couldn't do the things I should do to be a leader, to be a Marine, that had a significant impact . . . on my self-esteem. . . . So that's how I came to be retired from the Marines. . . . I wasn't going to remain a Marine officer and possibly get promoted to a higher rank and put in a position where maybe I'd let my Marines down because of my physical disability. . . .

Status Loss and Discrimination

Link and Phelan propose that stigma is enacted upon individuals when labeling, stereotyping, and separation lead to acts of commission or omission on the part of others that impose limits on the social participation of stigmatized individuals. Perhaps the greatest concern among research participants is that the separation imposed by the reactions of others will interfere with the ability to establish stable, loving romantic partnerships.

As the mother of a teenager with severe cerebral palsy, Sara (first author) has spent much time over the years of her daughter's life wondering and worrying about this issue. As a student in a large suburban high school, Amanda's disabilities clearly differentiate her from the vast majority of her classmates. Beyond initial expectations, however, Amanda currently has a boyfriend with

whom she is experiencing the joys, and stresses, of proms and dates. Like Amanda, Michael is a power wheelchair user with mobility and speech impairments as a result of cerebral palsy. Where will this relationship go? What will happen if either of them tires of the relationship? Given public attitudes, could they ever find a replacement for this first love? These concerns are common among the mothers of children with disabilities interviewed. One mother spoke for many when she said that when her son was diagnosed shortly after birth, one of her first agonizing thoughts was: "How will he ever get a date?"

The adults with disabilities who participated in this study indicate that these maternal concerns are not idle. Establishing close personal friendships, including romantic relationships, has been problematic because of the reactions of others to their disabilities. Judy, for example, observes that reactions of others have "made it harder to get romantic." Barnes (1996) suggests that this difficulty, indeed the stigma associated with disability in general, is integrally tied to the values associated with industrial capitalism and "can be traced back to the very foundations of western society. At its core lies the myth of bodily and intellectual perfection or the 'able-bodied' ideal" (p. 57). Individuals with and without disabilities who do not conform to the current trends in beauty and physical perfection may face problems establishing and maintaining romantic relationships. Judy feels that this can be particularly problematic for young women:

Guys don't date women who are physically disabled. That's a painful fact. Because this country . . . , especially young guys, seem to like women who are physically perfect. They like women who are 36-24-36 figures—Barbie dolls . . . Young guys, they're just not mature enough to look past that.

The problem of establishing romantic relationships is, however, not limited to young women with disabilities (Rossiter 2001; Shuttleworth 2001). Bob also indicates that he had difficulty establishing romantic relationships as a young man. He felt hesitant and awkward about trying to instigate such relationships and was particularly distressed by being rebuffed when he "fell in love with a student nurse" whom he had assumed to be capable of seeing past his disabilities. Negative reactions from members of the wise category, who are expected to know better, are also particularly disturbing for mothers of children with disabilities (Green 2001b, 2003a).

Despite the difficulties presented by the reactions of others, however, interviewees have been quite successful in establishing close personal relationships. Only two interviewees were currently without stable partnerships at the time of the interviews. John has been successful in maintaining his pre-disability marriage. Similarly, Summer and her husband, Homer, both of whom acquired orthopedic impairments after their marriage, have remained in this stable relationship. Bob and Carol, and Jane and Frank have found comfort and solace

from the stigmatizing attitudes of others in partnerships in which both people have disabilities. Jane feels that because they both have disabilities, they have been able to develop a symbiotic relationship in which each partner contributes his/her strengths to the partnership—strengths which help to compensate for the other's disabilities. Because of Frank's disability, Jane perceives that he is especially sensitive to her needs and does not see her as "abnormal."

In addition to concern over the potential impact of separation on romantic relationships, interviewees report numerous examples of ways in which the attitudes and actions of others can affect educational and employment opportunities. Interviewees feel that others often do not understand the constraints within which the person with the disability or impairment must operate and fail, or refuse, to make needed accommodations. Failure to make reasonable accommodations can severely reduce opportunities for full participation in the educational, economic, and social life of the community. In some cases, not only have others failed to make reasonable accommodations, they have also acted with overt cruelty:

In the second grade, I was in parochial school . . . and I remember having problems learning. I had some learning difficulties which I attribute to my impaired reaction time to external stimuli. . . . I remember the teacher . . . buffeting me in the face if I didn't learn. If I didn't give her the answers she was expecting. (Bob)

Similarly, Judy describes her experience in a graduate program in which no accommodations were made for her physical and hearing impairments:

The administrators didn't know how to handle me. This was long before ADA [Americans with Disabilities Act]. They made no concessions for my hearing impairment. . . . I'd come home in tears because the students were not particularly understanding. I remember one time my study group called me in almost like a kangaroo court, they said, "We don't know [what] in the hell you're doing here and we don't think you should be here." I remember that was so bad. I've never quite gotten over that. All I remember is the hurt.

Power Differential and Enacted Stigma

Link and Phelan suggest that stigma can only be directly enacted within the context of unbalanced power relationships—specifically, when the person with the stigmatized trait has less power than those who stigmatize him or her. Where both parties hold equal power or where the labeled and stereotyped party's power is greater, the individual with the stereotyped trait may be able to resist overt attempts at discrimination without loss of status. Judy has found this to be the case in a long-standing problematic relationship with a coworker: "If it was up to her, I'd have been gone long ago. Fortunately, she and I are the same level and she's not a manager, so I don't have to worry about that. . . . After thirteen years, I really don't care anymore. I'm still here, that's the best revenge."

The difficulty, of course, is that where the attitudes of others lead to discrimination, chances of attaining positions of power are limited thus encouraging

further discrimination and status loss. The Social Model of Disability, in fact, argues that the direct enactment of stigma on individuals with disabilities is endemic to Western societies because of the structure of industrial capitalism and the corollary construction of dependence and independence. Unbalanced power relationships that disadvantage individuals with disabilities will persist as long as these structures and values go unchallenged (Barnes 1996; Oliver 1996; Priestley 2003).

The interviews suggest, further, that even where power relationships are not unbalanced, discrimination and status loss can be indirectly enacted when the effects of felt stigma lead to negative self-perceptions or depression that in turn discourage social participation. The essence of one's sense of self is developed in reference to the reactions of others (Gergen 1991; Goffman 1963; Jones et al. 1984; Mead 1934; Stockall 2001; Wiley 1994). If the self we see reflected in the eyes of others is devalued, there is little incentive for social interaction. Carol, speaking for herself and Bob, describes the effects of being treated like less than a whole person on their feelings of self worth. "Both of us, we have lost our sense of identity—lost our sense of worth. . . ." Such losses can reduce willingness to interact with others—to being shy or afraid of taking social risks:

I was very shy as a child and felt out of place, felt very self-conscious, and that remained with me throughout my grade school and high-school years—probably right up to college. . . . [Then] I went to work for the . . . public library system. . . . Then as before, while I was in school, I was distracted again about my identity, my self-concept, and overly self-conscious . . . especially in terms of social skills. . . . In my later years, I have come to the conclusion that the lack of these social skills or the lack of interpersonal relationships have led to the difficulties I've had even during my professional life. (Bob)

Mothers of children with disabilities can also be socially debilitated by the emotional consequences of stigma. As one mother put it, "When you're in a difficult situation like that, it's very hard to reach out to somebody. You tend to isolate yourself. You don't want to be social. . . . You don't want to look good. You don't want to have friends over for dinner" (Green 2001b:808).

Such social hesitance can create a spiral of lowered self-image, social isolation, and depression. "Sometimes people expect too much of me, it's really very ego deflating . . . because they're disappointed with me and I hate so much to disappoint them. When I disappoint people, I disappoint myself. I get into a funk" (Judy). The depression associated with felt and enacted stigma can have very serious consequences. At one point in her life, Carol was so devastated by the treatment to which she was subjected by others that she considered suicide. "I'd build up walls so thick that I could not bear to be around people. . . . Things really began to tumble down. . . . I probably would have committed suicide if I had not had the biblical training. I was too chicken." Sam, too, began to question

whether life as the devalued, distrusted, socially isolated person he felt himself to be was worth living:

Here I am, facing being thrown out on the street or get to work and I couldn't do either. This whole situation, everything this whole year, finally became such a burden . . . I was suffering from depression . . . I actually became suicidal. I was ready to say "forget this, my life is obviously over if this is going to keep on." . . . I was very despondent about the way I'd been treated. . . .

While both Carol and Sam found the strength to resist their inclination to consider suicide, other individuals with disabilities and family members who become severely depressed by the belief that they are devalued by the community of others may not be as fortunate. These interviewees suggest that the reactions of others can play a primary role in feelings of depression among individuals with disabilities and their families and that this depression can lead to further social isolation, status loss, and even loss of life.

Discussion

Despite Goffman's early work on the social experience of stigma, both lay and professional conceptions of disability have been dominated by the "individual model" in which the "problem of disability" is seen largely to arise from bodily impairments and resultant emotional stress (Barnes 1996; Fleischer and Zames 2001; Oliver 1996; Priestley 2003). While Goffman called for a language of relationships rather than individual attributes in the study of stigma, traditional social scientific scholarship has often conceived of stigma as an attribute owned by the individual who is stigmatized rather than as an experience imposed on individuals by prevailing socio/cultural conditions (Fine and Asch 1988).

Disability activists and scholars of disability studies (many of whom have personal experience with disability) have, however, made great strides in the past several decades in an alternate construction in which disability is viewed as "something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society" (Union of Physically Impaired Against Segregation/Disability Alliance document quoted in Priestley 2003:13). Proponents of the Social Model of Disability argue that because most research on the disability experience has been conducted by scholars who lack either the direct experience of stigma or vicarious experience of courtesy stigma, much traditional scholarship has been based on faulty assumptions including the belief that the disability experience is all about being a "victim" of biological impairments, that disability is synonymous with dependence and that biological impairments, rather than social experiences, are at the very core of the sense of identity and self-concept of people with disabilities (Fine and Asch 1988). Priestley (2003) suggests that disability can be conceived of as four intersecting circles of

experience: the body, identity, culture, and structure. While traditional scholarship has focused on bodily impairments and their negative impact on individual identity, the Social Model has drawn attention to the disabling impact of structural and cultural factors. A rather polarized discourse has emerged in which critique of the individual model has dominated the scholarship within disability studies while traditional scholarship has continued to construct disability as an individual phenomenon. Priestley proposes that the intersections among the four realms of disability experience are fruitful areas for future research which could highlight the subtleties and complexities of the disability experience. Link and Phelan's model is a promising attempt by traditional stigma scholars to frame the "problem of disability" in a way that highlights the intersections among the four realms of disability described by Priestley.

As noted in the introduction, the concept of stigma, as traditionally employed, has been widely criticized for being too broadly defined to be of much use in explaining the complexities of relationships between people with and without disabilities. By disarticulating various components of stigma, Link and Phelan make a substantial contribution in this regard. In this model, the stigmatization of individuals with disabilities is seen as a complex multidimensional process in which the stigma arising from culturally specific attitudes is attached to individual biological differences within the context of social interactions. Each component from the assignment of social significance to biological differences (labeling) through discrimination and status loss draws attention to the way in which stigma is created within the a socio/cultural context. Findings of this study clearly suggest that the interactional processes of labeling, stereotyping, separation, status loss, and discrimination have relevance to the social experiences of people with disabilities and their families and that these processes can have negative consequences in their lives. Findings also indicate, however, that the seriousness of these consequences varies among the components of stigma. The interviewees seem to easily manage the sometimes irritating but generally rather benign social awkwardness that is associated with labeling and the reactions of sadness and pity that accompany stereotyping. They are also quite successful in creatively resisting and actively countering status loss and discrimination in their social and work lives. Far more problematic and potentially dangerous, however, are the overt, and sometimes violent, acts of hostility and social shunning that result from the pronounced feelings of "otherness" involved in the separation component of stigma. While these acts are relatively rare, and these interviewees have been remarkably successful in coping with them, they have had profound effects in their lives. The indirect enactment of stigma through the pernicious downward spiral of felt separation, reduced self-worth, depression, and social isolation, in fact, seems to have been more difficult to resist and counter than has the direct enactment of stigma through overt acts of discrimination.

While the generalizability of these findings is limited by the size of the sample and the interactive nature of the interviews, they clearly support the complex nature of felt and enacted stigma and their importance in the lived experience of individuals with disabilities and their families. Findings also suggest that the Link and Phelan model can be a useful way in which to frame the experience of disability which calls attention to the complex impact of socio/cultural context on the experience of individuals living with biological differences.

ENDNOTES

The authors wish to thank the seven mothers and eight adults living with the experience of disability for their generous contributions of time, effort, and insight during the interactive interviews. We also wish to thank the editor and the three anonymous reviewers for their invaluable suggestions during the review process. Their assistance is greatly appreciated. This research was funded, in part, by the University of South Florida Institute on Aging Pilot Research Grant Program under Contract #97P00398.

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