

## “Just sit down so we can talk:” Perceived stigma and community recreation pursuits of people with disabilities

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### **Abstract:**

Research shows that leisure can provide mental and physical benefits to individuals with disabilities. Unfortunately, many individuals with disabilities are denied these benefits through attitudinal as well as architectural barriers. Research by West (1984) suggested that the perception as well as the practice of negative attitudes can prevent individuals from pursuing satisfying leisure activities in the community. The purpose of this study, therefore, was to follow up on West's (1984) work and explore the perceptions of stigma and subsequent responses to those perceptions in adults with disabilities in community recreation experiences. In-depth interviews were conducted with 15 respondents with physical and/or psychological disabilities. Qualitative data analysis uncovered themes that suggested three different responses to negative attitudinal experiences in community recreation pursuits: (a) becoming helpless, (b) resisting the stigma, or (c) yielding and embracing their situation. Implications and recommendations for both practitioners and researchers are presented.

**KEY WORDS:** Perceived Stigma, Labeling, Community Recreation, Disability, Helplessness, Resistance, Yielding

### **Article:**

#### ***Introduction***

Leisure and recreation have been shown to contribute to the mental and physical wellness of individuals with and without disabilities (e.g., Coleman & Iso-Ahola, 1993; Coyle, Kinney, Riley, & Shank, 1991; Roberts, Lamb, Dench, & Brodie, 1989; Schreyer, 1984). The Americans with Disabilities Act, a civil rights act for people with disabilities, has provided legal opportunities for people with disabilities previously denied the chance to participate in recreation activities in the community. Attitudes toward people with disabilities, however, remain a significant barrier for these individuals with regard to pursuing a satisfying leisure life (e.g., Bedini, 1991; Dattilo, 1994; Kennedy, Austin, & Smith, 1987; Schlei, Ray, & Green, 1997). Regardless of the opportunities and architectural accessibility a community can provide, attitudes toward those members with disabilities can affect their decisions about leisure participation and satisfaction.

Although the negative attitudes of others can have a strong impact on the recreation behaviors of people with disabilities, negative attitudes alone are technically not the true vehicle of this oppression. Rather, it is the perception, as well as the practice of negative attitudes, that can affect individuals' decisions to pursue and engage in leisure activities in the community. For example, in a study of people with physical and mental disabilities, West (1984) found that the respondents' perceptions of community stigma often negatively affected their pursuits of recreation and leisure experiences. Perceptions of being stigmatized or labeled as disabled (and all that accompanies that label) played a major role in the pursuit of recreation opportunities in the community by people with disabilities. Although West's research was conducted prior to the enactment of the Americans with Disabilities Act, few studies then and now have explored the effects of perceived stigma on the behaviors of people with disabilities; and none in regard to leisure pursuits specifically.

The purpose of this study, therefore, was to pursue further the concepts presented by West (1984) and identify the perceptions of stigma in adults with disabilities in their pursuit of recreation experiences in the community. In addition, this study sought to examine the relationship of existing perceptions of stigma with coping and behavioral responses of individuals with disabilities regarding their pursuit of recreation in the community.

### **Stigma and Labeling**

Attitudes can be one of the most powerful barriers to their pursuit of leisure that individuals with a disabilities can experience (e.g., Bedini, 1991; Schleien, Ray, & Green, 1997). Historically, people with disabilities have been subjected to negative attitudes from "able-bodied" members of their communities. Society has tended to stigmatize people who are different as ones who should be avoided or rejected. Goffman (1963) described the term stigma as ". . . an attribute that is deeply discrediting" (p. 3). This stigma can breed animosity, pity, or fear from the "non-stigmatized" members of a community. For example, in some instances, people with disabilities have been patronized as animals or children; in others, they have been treated as dangerous or a menace to society (e.g., Bedini, 1991; Goffman, 1963; Linveh, 1980). Fine and Asch (1988) posited several [stigmatizing] assumptions that society makes about people with disabilities. For example, they stated that it is assumed that ". . . the disabled person is a 'victim' " (p. 10) or that "having a disability is synonymous with needing help and social support" (p. 12). Together these assumptions described society's perception of an individual with a disability as helpless, and society having to make downward social comparisons to preserve their own self-esteem. This concurs with Wolfensberger (1972) who noted that people in society have disenfranchised people with disabilities because the latter are perceived as lesser beings or as a threat to the well-being of the former. Additionally, stigmatized individuals may not fully accept themselves as equals, which in turn can create "self-derogation" (Goffman, 1963, p. 7) for these individuals. Baumeister and Scher (1988) stated that, "negative affect, such as anxiety, fear, anger, and embarrassment, appears to be an important cause of self-destructive behavior" (p. 18).

Labeling theorists (e.g., Scheff, 1966) have suggested that people who are negatively labeled will be treated based on their labels rather than their behaviors. For example, Socall and Holtgraves (1992), in a study of individuals without disabilities' reactions to people with mental illness, found that ". . . the label has an effect on rejection independent of that accounted for by illness severity" (p. 441).

Additionally, Gardner (1991) described how more powerful groups have traditionally tried to restrict different or "stigmatized" groups from being in public. The dominant group either denies access or makes it uncomfortable for the stigmatized individuals to be present in public. Gardner stated:

Measures insuring reduced presence are also mandated by folk beliefs, as when stigmatized people believe that they should not go where they are not wanted or that they should stick to areas or facilities where they know they will be welcome or meet others like themselves. (p. 254)

The labeling theory also suggests that labeled individuals who accept their label as deviant or different function less well than those who reject it. Warner, Taylor, Powers, and Hyman (1989) tested the labeling theory with individuals with mental illness. They found partial support for the proposition that participants in their study who accepted the label of mentally ill as a description of themselves showed lower self-esteem than those who rejected the labeling.

What these studies suggest, then, is that it is not the actual disability as much as society's (individuals with disabilities as well as others) perceptions of the disability that pose the greatest barriers to pursuits for individuals with disabilities. As Susman (1994) noted, it is the "perceptions of disability, not an immutable reality, which explains the experiences of disabled individuals" (p. 21).

### **Reacting to Perceived Stigma**

Beyond how an individual with a disability perceives her or himself, or how others perceive her or him, it is important to explore how that individual chooses to react to these perceptions. Researchers seem to agree that

stigmatized individuals choose a variety of methods to deal with the negative experience of stigma. Perhaps one of the most common reactions is avoiding public places or only venturing out when accompanied because of their perceptions of not being tolerated by the mainstream public (Gardner, 1991; Link, Mirotznik, & Cullen, 1991; West, 1984). Similarly, secrecy, or not disclosing a hidden disability is a common reaction (Link, Mirotznik, & Cullen, 1991; Schneider & Conrad, 1980).

Gardner (1991) discussed how communication between strangers is dependent on appearance. For individuals with disabilities, those with "hidden" disabilities stand a better chance of acceptance and less risk, emotionally and physically, from the mainstream public. For those who have visible disabilities, they might experience being stared at. Gardner went on to suggest that as a result of the negative attitudes, stigmatized individuals reduce their presence in unwanted places. She termed these individuals as "agoraphobic" to describe the fears of public places experienced by the "stigmatized" groups. She suggested that the public environment can pose just as large a barrier to the pursuits of a person with a disability as any physical inaccessibility. She concluded by acknowledging that individuals from stigmatized groups often make decisions based on how they were treated in public places.

West (1984) presented an alternative method of how people with disabilities react to perceived negative attitudes. He noted that almost half of the respondents in a study on attitudes did not avoid public places because of negative attitudes they perceived. Instead, these individuals used what West called "adaptive strategies" which entailed techniques such as studied inattention (or ignoring), passive-aggression, confrontation, and crusading. Using these strategies, according to West, allowed the respondents to negotiate public park settings "armed" with techniques to handle the perceived negative attitudes of others.

### **Conceptual Framework**

Several conceptual frameworks underlined this study. First, symbolic interactionism (Blumer, 1969) allowed the researcher to understand the meanings the respondents identified for their interactions in a dynamic society. Symbolic interactionism suggests that individuals find their own meaning in these interactions which then support their action. Using a symbolic interactionist perspective for the current study allowed the researcher to understand the context within which the individuals with disabilities perceived stigma and how these perceptions affected their leisure. Additionally, the theoretical frameworks of stigma (Goffman, 1963) and labeling (Scheff, 1966) provided guidance in exploring the issues of assumed identity in the community setting.

### **Methodology**

#### ***Procedures***

This study was conducted from an interpretive paradigm. Respondents were people with disabilities who had participated in a quantitative study earlier on the same topic and had volunteered to participate in a qualitative study as well. If they were interested in being interviewed about perceived stigma, willing participants of the quantitative study completed and returned an information card included in their original survey packet. From the 104 respondents of the original quantitative survey, 55 respondents returned cards indicating willingness to be interviewed. Although the information card did not request as much demographic information as did the quantitative questionnaire, it was assumed that these volunteers represented similar characteristics to the larger sample of subjects. Subjects in overall sample were solicited from 11 agencies that served people with disabilities who lived independently in the community. All of the 104 participants were at least 18 years old and had a minimum of a high school education. Racially, they represented the geographic region in which the study was conducted with approximately 20% of the sample being people of color. These individuals represented both traumatic and congenital disabilities that included both psychological and physical conditions. Additionally, both sexes were represented equally.

Since the researcher did not have access to all of the original demographic data for the subsample of 55 volunteers, a modified theoretical sampling was employed. As Henderson (1991) noted, theoretical sampling is a procedure that directs the researcher to cases that have the potential to contribute new insights to the study's theoretical development. This procedure was modified in that after the first few interview respondents were

chosen randomly from the 55 volunteers, subsequent subjects were selected based on the limited demographic information that was requested in the information card. Additionally, theoretical sampling suggests that data are collected until saturation of data occurs (Henderson, 1991). In other words, interviews should cease when no new information or contribution to the conceptual development emerges from the data. For this study, saturation of data occurred after 15 volunteers were interviewed.

Face to face, semi-structured, in-depth interviews were conducted to allow the respondents to discuss their perceptions of stigma and how these perceptions affected their leisure experiences. An interview guide was developed based on themes that emerged from the previous quantitative study on the same topic. The quantitative study consisted of mailed questionnaires to people with disabilities in the community asking specific questions about their perceptions of stigma in community recreation experiences. Factor analysis determined that the primary themes related to perceived stigma of people with disabilities included feelings of being demeaned, helplessness, intimidation, and empowerment in community recreation. Questions for the in-depth interviews were based on these four factors as well as on relevant written comments that some of the respondents put on their questionnaires. Additional questions included a description of the respondents, the nature of their recreation pursuits, their current perceptions of others' attitudes and behaviors toward them in recreation environments, and how the respondents reacted to the stigma they perceived.

### *Data Collection and Analysis*

The interviews were tape-recorded and transcribed. Constant comparison (Glaser & Strauss, 1967) and analytic induction (Bruyn, 1966) techniques were used for analysis to determine patterns and themes from the data. Initially, the researcher read, re-read, and coded all the transcripts and interviewer notes to determine overall themes and patterns within the data. Once prominent themes were established, the transcripts were re-analyzed to explore each theme specifically and in more detail.

Issues of reliability and trustworthiness (Lincoln & Guba, 1985) were addressed in several ways. First, a modified theoretical sampling from the subjects who were selected from the return cards addressed issues of representativeness of the sample in terms of age, sex, race, education, and disability type. Second, interviews were conducted until saturation of the data (no new information) was attained. Third, interviewer's notes were analyzed to enhance the understanding of the themes generated from the transcripts. Finally, credibility was addressed by using the data discovery/data interpretation loop (Henderson, 1991) repeatedly to uncover and confirm themes within the data.

### **Respondents**

The respondents consisted of 15 individuals with disabilities comprised of 7 men and 8 women between the ages of 20 and 71 years. Fourteen respondents were European-American and one was African-American. Six of the respondents were married at the time of the interview while two were widowed, one was divorced, and six reported that they were never married. Eight of the respondents had children with ages that ranged from 8 to 37 years. Their education ranged from technical school to a doctoral degree (which was in progress) with all of the respondents having at least a high school degree. Five of the respondents were employed at the time of the interview and the remaining 10 identified themselves as student, retired, or unemployed. Three of the respondents had congenital disabilities and the remaining 12 had experienced adventitious disabilities with a duration of 5 to 51 years. Three respondents reported having more than one disability each. The remaining 12 respondents reported only one primary disability. Disability types among all of the respondents included "mutism" [respondent's term], arthritis, fibromyalgia, spondylosis, chronic pain, multiple sclerosis, epilepsy, chronic depression, borderline personality disorder, osteogenesis, communicative hydrocephalus, cerebral palsy, spinal cord injury, traumatic brain injury, and post-polio syndrome.

## Results

### *Perceptions of Disability*

The respondents shared a common overall perspective about their disabilities and the role of leisure in their lives. As a group, the respondents' current leisure activities were similar to activities pursued by people without disabilities (i.e., swimming, reading, traveling, hiking, sports, theater, and gardening).

Many of the respondents with traumatic disabilities expressed that their leisure had changed drastically for the worse since their disability because of both internal and external factors such as poor accessibility, attitudinal barriers, effects of medications, and loss of function. Other respondents, however, found the disabilities beneficial for not only their activities of daily living, but also for their recreation and leisure experiences. For example, one woman with fibromyalgia and arthritis noted that sometimes she saw her disability as a good thing in that it slowed her down. She noted:

... I started doing some birding, um, I enjoy looking for wildflowers in the spring. I think it has actually slowed me down some. I'm just, I'm pretty much a Type A person. Just wide open all the time, and I think that this [disability] has helped me to slow down.

Additionally, several respondents discussed how their disability was helpful to them socially. A woman (41 years old) with depression noted that her disability made it easier to meet people. Previously, she had been a loner and now her disability was something she had in common with others in a support group which recreated on a regular basis. In another situation, a 66 year old woman with epilepsy described how in one incident she blacked out in front of oncoming traffic. She explained how she met the drivers who almost hit her and have been friends with them ever since. She stated, ". . . They'd [the drivers] ... some excellent friends, they ... have kept in touch now for um, quite some time, ever since this happened and ... I really appreciated ... meeting them, because they were ... lovely people and are lovely people."

Most existing literature suggests that people with disabilities see their disability as a loss and a barrier to leisure that requires negotiation. As noted above, however, some of these respondents perceived their disabilities as a facilitator to their leisure. This suggests that their own perceived stigmas about disabilities may be important in how they approach life and leisure and recreation pursuits.

### *Approaches to Coping with Perceived Stigma*

As a group, the respondents clearly held the perceptions that people with disabilities were stigmatized by others in the community. Their perceptions of how and why this stigma existed, however, varied greatly. In addition to emotional and cognitive reactions to perceived stigma, the respondents manifested various behaviors based on personal experiences of barriers and stigma in their previous community recreation pursuits. How they chose to react to these experiences raised new perspectives on the impact of perceived stigma as well as the perception of their power or ability to address it. The results demonstrated three "types" or categories of responses that emerged from the data representing "approaches" to coping or reacting to the perceived stigmas identified. When presented with frustrations due to lack of access, or negative attitudinal experiences in community recreation pursuits, these respondents: (a) became helpless, (b) resisted the stigma, or (c) yielded and embraced their situation.

**Becoming helpless.** The perceptions of the first group were consistent with the research results on perceived stigma by West (1984). Some respondents demonstrated "learned helplessness" (Seligman, 1975) taking a passive, victim-like role and not pursuing recreation due to feelings of anxiety or lack of entitlement. Many of the respondents anticipated prejudice (real or unreal) from their community and as a result assumed the responsibility for interactions (or no interactions) in the community. Often these behaviors manifested in hiding the disability, and often themselves, from the community. For example, some of the respondents felt obligated to protect family and friends, as well as strangers, from the "effects" of their disability. They would hide their disability when pursuing recreation in public or hide themselves by not going out. A 34 year old man with scars on his face grew a beard before visiting his parents to "protect them" from remembering his disability.

Similarly, a 44 year old woman with epilepsy stated that she avoided some recreation pursuits because of the unpredictability of her seizures. She stated that she felt she always had to explain her situation. She also stated that she worried about what other people thought of her. She did not want others to think ". . . the worst of her." A different woman with epilepsy (67 years old) shared that she does not go out to public settings often so to protect the other participants from embarrassment if she had a seizure. She stated, "I will stay home rather than ... attempt to go out in ... certain places where, I, my seizures could cause me to be in danger. [pause] And I would not like to cause other people to be embarrassed."

Similarly, a 45 year old woman with borderline personality disorder and depression explained how she did not pursue much recreation because of the negative experiences she had on the recreation outings when hospitalized earlier in her life. She described that because of having to travel in a group and wear name tags on hospital recreation outings in the past, she felt "extremely stigmatized" in public even today. She noted that when she has a negative experience today, she tends to ". . . go hide and don't do it [recreation activity] no more." Another 41 year old woman with depression shared how little she went out now that she had a disability. She was afraid that she would have a panic attack and "look stupid." She stated that she feels people look and laugh at her because she cannot do some things. Similarly, a 34 year old man with communicating hydrocephalus stated that when he has a bad experience in community recreation environments, he will not go back. He shared how, although he likes to bowl, he will not go now because, "They make fun of you and so, yeah, that's one of the main reasons we [wife and he] don't do it [bowling] now." He did share that he felt safe at movies because, "Nobody says anything to you when you go to the movies."

Although some research has demonstrated that the negative attitudes of people without disabilities often affect the community pursuits of people with disabilities, this "influence" of people without disabilities was perceived by this sample of respondents in various ways. As noted in the examples cited, the respondents "understood" the poor attitudes and ignorance from individuals without disabilities as lack of information or interest rather than maliciousness for these situations. Unfortunately, many of these respondents accepted the intention of the ignorance, often suggesting their own "second-class status." For example, a 40 year old woman with multiple sclerosis summarized the lack of awareness of accessibility needs by stating that:

... because people are not used to looking for it. I think a lot of it is not a deliberate attempt; it's just not been in your realm of experience, so you're not used to looking for it and you don't really understand what would be the correct way to do it.

Similarly, the 67 year old woman with epilepsy suggested that, "People cannot, they simply cannot help being prejudice against... a person whose mind isn't all there ... It's just one of those things that is ... human nature." The 45 year old woman with borderline personality disorder and depression took some responsibility for the behaviors of others by noting that in public recreation situations she would feel self-conscious and walk with her head down because she didn't want others to see her but that her body language just reinforced, in her mind, the opinion of others. She stated:

... and I know that when I'm really conscious of it [body language], it's sort of self-fulfilling, `cause I'll do things that, like, you know, like if I'm, my head is low or something like that ... You don't want to see `em [public] but that, that to other people, that is an indication.

This mindset of justifying the inappropriate reactions and behaviors of others merely reinforces the notion of helplessness of those with disabilities.

**Coping by resistance.** The second group responded to their perceptions of stigma in community recreation by resisting what they thought people without disabilities were assuming about them. While the respondents who accepted and potentially internalized the public stigma of having a disability noted that it was best to just ". . . ignore people's ignorance," many of these respondents thought that the "ignorant" people needed to be made accountable. For example, a 50 year old woman with fibromyalgia and arthritis stated, ". . . so I have taken it on

as my personal mission when I see people parked in handicapped [sic] spaces who have no stickers to ask in a very polite way, um, do you have a sticker, are you legally parked?" She went on to say that ". . . people need, need to know that what they say, what they do and their actions, they're accountable for." Similarly, a 49 year old man with spinal cord injury described how he had little sympathy for individuals who violated access laws. He said, "I report people; it's their stupidity for not doing things right." Another 40 year old woman with multiple sclerosis shared that she had to argue with the builders of a new swimming pool about access. She described:

... I ended up arguing with them about the placement of the handicapped parking ... they just didn't seem to understand that it made more sense to put it nearer to the entrance than the other side of the parking lot. While members of this group readily pursued their activities and "challenged" inappropriate actions of the public in recreation environments, they seemed to expend a lot of extra energy in doing so. Some of these respondents thought in terms of employing a "hard work ethic" to achieve a status considered equal to able-bodied individuals. They noted, however, that they had to "prove their worth." Many of these respondents talked about having to put out more effort, or making sure they looked as "normal" as possible in public to be considered equal by people without disabilities. For example, a 70 year old man with spondylosis and chronic pain stated, ". when I use crutches, use them briskly. I refuse to act like a cripple. And people don't even notice that I've got them ... which I like." He stated that he would crutch "quickly" to prove he was not "handicapped."

Similarly, a woman with fibromyalgia felt the need to explain to others each time why she was using an accessible parking space at the mall because she appeared non-disabled but in reality needed the opportunity. A 20 year old woman who cannot speak noted, "If I don't do a good job [playing soccer], people assume it is the disability." She continued that she ". . . must do more to be equal because of the disability."

While this level of resistance seemed to serve its purpose in making the respondents more "equal" to individuals without disabilities, this group could be considered victims of society as well. By their sense of need to challenge the existing barriers and work harder to prove themselves as "able," they were forced to respond to their perceptions of being oppressed by others. In particular, these individuals shared that they expended great amounts of energy anticipating and preparing for possible negative reactions from others in the community. In many cases, this response compromised their leisure experiences as well.

**Embracing the disability and yielding.** The last group seemed to present a new dimension to negotiating their disabilities and the effects of perceived stigma, especially in terms of pursuing community recreation and leisure experiences. Rather than giving in to (becoming helpless) or resisting (fighting) the stigma they perceived, this group "yielded" to the perceived effects of having a disability without giving in. Synonyms for the word "yield" include consent, be pliant, and acknowledge (Roget's Thesaurus, 1946). Indeed, then, these respondents acknowledged the strength of their abilities as well as conceded or consented to the limitations of their disabilities. In essence, they "embraced" their identity as a person with a disability calculating when to apply some control and when to let go.

For example, a 32 year old man with multiple sclerosis talked about the importance of facing the reality of having a disability. He spoke in reference to embracing his disability and asked rhetorically how should he consider himself in relation to others because of it. He said, "Who am I hiding? Who is anybody else?" He spoke of a balance between giving in to and resisting the disability, stating, ". . . this [disability] is only as bad as I want to make it."

A 49 year old man with a spinal cord injury described similar feelings about being disabled, noting how it does no good to deny your limitations. He stated, "Ah, I mean, it's there, so, . . . got to accept it; you go ahead on with it .... I mean, it doesn't bother me. It's there, so no need to, no reason, no reason to deny it ." He went on to explain why he does not feel different than "able-bodied" people. He noted, "Everybody's got some ... disability, whether it's having to wear glasses or whatever it is; basically everybody on earth has some disability. Some better, some worse." A 44 year old man with a traumatic brain injury shared his philosophy of having a

disability and how it affected his life. He stated, "Life is hard. I don't understand it, but not supposed to. . . . I live till I die."

Several of these respondents shared philosophies of life that they applied in recreation settings specifically. A 57 year old man with osteogenesis described how, although many of his recreation experiences could be considered demeaning, ". . . demeaningness is in the eye of the beholder." He referred to having to sit in the back of a theater or a restaurant because of inaccessibility. He said the impact of that depends on the person with the disability's self-image. He stated, "And if you have a good self-image, then there is very little that can demean you, but if you have a poor self image, if you have an inferiority complex, almost everything demeans you." He also said that individuals who have had a disability for a long time probably have ". . . internalized the mistaken attitudes" of their own. Using the example of being given an assigned "accessible" table in a restaurant, he explained that there are two ways to look at a situation. He stated:

One person can look at that and he can say, 'well, this is terrible I can have only one place that I can sit in this whole restaurant and I can't go up there and sit with those other people.' Or, he can say, 'ahh, I have my special table at this restaurant. Well, you know, some of the fanciest people in the world have special tables at special restaurants. . . .'

Similarly, several of the respondents suggested that their own attitude and behavior were the key to successful coping and yielding to stigma in today's society. The respondents were likely to suggest it was they who needed to make some changes in how they perceived their own identity and approach recreation environments in the community.

Another 32 year old male with multiple sclerosis suggested that attitude awareness begins with the individuals with the disabilities first. He stated that his attitude is what will help him through his disability. He stated: I want to be 100, just to see what's going on. And if I'm a sour puss, nobody would want to be around me. And it's my intent, since I'm going to be here, to make the best of a bad situation, to enjoy myself as best I can. And I think I'm doing that.

Key elements to this perspective of yielding were not only giving up control but also "relearning" methods of daily living that were interdependent in nature. For example, a 44 year old woman with epilepsy noted that to pursue her leisure interests, she learned how to ask for help. Another man with osteogenesis stated that he had to learn to "refocus" on ". . . things that, that I wanted to think about or that were good to think about. [I] think that's just an important skill for anybody."

This group of respondents felt secure with their disabilities and several respondents took the initiative to educate the "ignorant" individuals in the community settings rather than blame them. A 71 year old woman with postpolio syndrome stated that she believes people with disabilities should go to church. She stated that it is not only a good social environment, but she feels that she ". . . changed a lot of attitudes by being at church, dressed nice, etc. . . ."

Perhaps a 57 year old man with osteogenesis had the simplest perspective on the responsibility to "allay" the "bad feelings" of strangers. He noted that:

A stranger sees you coming and all those feelings come up inside of him [sic] in less or greater extent. And it's up to the disabled person to ally all that, you know. I'm not real touchy; I'm not sick; I'm not unhappy; ... I don't care if you're walking. Just sit down so we can talk.

This group appeared to have the confidence to pursue their leisure while not overextending themselves to deal with perceived stigma. They typically did not alter their lives significantly to address perceived stigma, showed little to no resentment for their disability, and still actively pursued their leisure.

## Discussion

The purpose of this study was to identify the perceptions of stigma in adults with disabilities and how these perceptions related to their pursuit of recreation experiences in the community. Prior to identifying three types of approaches to coping with perceptions of stigma regarding recreation pursuits, the respondents described how having a disability could facilitate their leisure as well as compromise it. It seemed particularly significant that several of the respondents saw their disabilities as an enabling element to their leisure pursuits. Much has been written about how recreation professionals can minimize the effects of disabilities and make recreation environments more accessible and satisfying for individuals with disabilities. This perspective of one's disability facilitating rather than compromising one's leisure, however, raises the issue of how we, as leisure service providers, make decisions regarding accessibility and least restrictive environments. This result also reinforces using individually "customized" recreation programs rather than the common "recreation in a can" activities, whereby individuals with disabilities are clumped into group programs without individualized assessment.

Regarding coping with perceptions of stigma from individuals without disabilities, the respondents presented expected reactions as well as an approach that appears to be less common. The first two approaches to coping with perceived stigma in community recreation (i.e., being helpless or being resistant) can be supported, at least partially, by the literature (e.g., Gardner, 1991; West, 1984).

Additionally, Godbey (1985) proposed a model of non-participation in leisure services that has particular relevance to the first group of respondents (those who were helpless). This model was presented as a flow chart wherein individuals eventually fall into one of three categories dealing with knowledge of existing leisure services. For those who are aware of leisure services, four possible directions exist. The path of participants that is relevant to this study is the group that chooses not to participate because of previous experiences in leisure pursuits. The model explains that for these individuals, previous experiences could have been negative with (a) leisure resources, (b) social factors, or (c) the activity itself. This model reinforces what the first group of individuals with disabilities in this study noted about how they chose to react to perceived stigma. For this group of respondents who found themselves feeling helpless, the social elements within the recreation context were, in many cases, a significant factor in their nonparticipation in leisure activities.

The second group, who actively resisted the stigma they perceived, was more successful in pursuing and enjoying leisure experiences in the community; however, they expended excessive amounts of energy to "prove themselves." Wright (1983) described a concept called, "idolizing normal standards versus normalization" (p. 121). She defined this as "the normal standards of behavior are rigidly defined [by the individuals with disabilities] and held forth as the single criterion for the desirable or even allowable" (p. 122). She continued to explain that these individuals, "will continue to battle feelings of inferiority . . ." (p. 122). Often the respondents in this study who fell in the second group expressed a sense of imposed responsibility for their disabilities. This extra obligation seemed to force these respondents to explain, prepare for, or even perform more intensely to make interactions in the community more acceptable, leveling on them an emotional toll. Several respondents identified resentment for having to try harder to be considered equal.

For both of these groups, their approaches posed a potential consequence to the leisure pursuit or satisfaction of the respondents who adopted it. Crocker and Major (1989) noted that stigmatized individuals who believe that prejudice is "widespread and enduring," are likely to experience "universal helplessness" (p. 622). In a review and analysis of selfdestructive behaviors, Baumeister and Scher (1988) noted that these tendencies have "clear, definitely, or probably negative effects on the self or the self's projects" (p. 3). They described the "Trade-offs Model of Self-Destructiveness" which illustrates an individual's attempt to reach normal goals but use of counterproductive strategies. According to the authors, this model involves "choosing some response option that has certain benefits but also some self-harmful costs" (p. 4). It always must involve two competing goals and the pursuit of one will decrease the possibility of achieving the other. The individual is aware of the harm or risk and accepts them in an effort to reach some other goal. In reference to the respondents whose behaviors fell in the first group, those who became helpless often chose to stay at home and deny themselves recreation and

leisure opportunities for fear of negative reactions from the public. Thus, this group faced two incompatible goals-that of recreation or emotional safety-and actively chose to give up recreation activities to achieve an anticipated freedom from ridicule. This "trade-off model of behavior is similar to what West (1984) found in that participants in his study stopped going to the park after perceiving negative experiences there. The second group who chose to resist the stigma they perceived, experienced consequences as well. Although they were able to pursue their select leisure activities, the trade-off for them was the amount of energy and vigilance required in that effort.

The last group, those who yielded to their disability and related perceptions of stigma, seemed to offer a new and more optimistic approach to accepting their disability and feeling entitled to pursuing recreation. This group was unique in two ways: (a) they saw themselves as equal to others in society, with or without disabilities; and (b) they accepted the ignorance of others as something that needed enlightenment, rather than conquest. This third group was similar in some respects to a subgroup of respondents in a study by Weinberg (1988) who explored the attitudes that people had toward their own disabilities. She found that her respondents formed a continuum with those who were bitter about the disability on one end, those who adapted in the middle, and the third group who "embraced" their disability on the far end of the continuum. According to Weinberg, these individuals recognized that "without their disability they would be different from what they are, and they have no desire to be different" (p. 151). Goffman (1963) discussed identity norms as determining what is deviant in a society. While, in the perceptions of the respondents, some of the norms might be changing, the third group (yielding) also demonstrated alternative forms of coping with disabling conditions which struck a balance between fighting and giving up to stigma. Many of the respondents in this category attributed the potential for power or ability to themselves rather than to the outside community. Perhaps, the description by a 67 year old woman with epilepsy best summarized the essence of the third group of respondents. In response to a question asking how to make community recreation more satisfying for people with disabilities, she supported the notion of one's own attitude adjustment. She suggested, "I would make everyone capable of doing . . . good. . . recreational . . . experiences for their own memory banks to . . . make themselves feel good about it, and to feel that, . . . they were a welcome addition to the public scene."

### **Limitations**

Several limitations existed for this study. The major barrier to this interpretive study resulted from limitations experienced in the initial quantitative sampling from the stigma questionnaire. The sampling pool for the quantitative study was chosen through groups and organizations in the community that addressed issues of people with disabilities. Respondents in this study were solicited through liaisons because of confidentiality requirements by cooperating organizations. As a result, the return rate for the questionnaire study was low (26%). This low return rate could have had negative effects of the type and number of respondents who accepted the invitation to participate in the qualitative interview study. Additionally, those who did volunteer were self-selected. Nevertheless, it seems that a diverse and representative sample was approached, if not attained.

### **Conclusions and Implications**

Several implications and recommendations for practice as well as for future research exist from this study. It is clear that people with disabilities approach their sense of "right" to leisure in different ways. As a marginalized group in society, more research should be done to understand the sense of entitlement to leisure among different strata of individuals with disabilities and how that relates to their perceptions of stigma. Also, do demographic factors such as age or race modify the sense of entitlement that these individuals experience? Researchers should also consider longitudinal studies on coping methods and leisure lifestyles for people with disabilities. A focus on coping mechanisms as applied to recreation environments specifically can generate rich data on this topic.

Recommendations for practitioners suggest several approaches. Typically, research about attitudes toward people with disabilities suggests that professionals in community leisure service provision should explore attitudinal as well as architectural access for altering exclusive identities. This study is no different. The

perception of welcoming environments by people without disabilities toward people with disabilities is equally as important as functional accessibility. Leisure service programmers should be alert to the sentiment in their communities and initiate learning opportunities where needed.

Similarly, recreation programmers themselves should occasionally conduct self-evaluations to guarantee that they are providing inclusive and fully accessible programs. While programs today seldom "stigmatize" participants to the extreme that the respondent with borderline personality disorder and depression noted (wearing nametags on outings), leisure service providers must make sure their language, signage, titles, advertisements, as well as staff are appropriate and respectful of all participants.

Not all responsibility for attitude change should fall on those without disabilities, however. The data suggest that education and training for self-awareness and entitlement toward leisure would be helpful and should begin early for people with disabilities. For individuals who have experienced a traumatic disability, therapeutic recreation specialists in hospitals can be instrumental by including information in their community re-integration programs about the experiences of stigma and how it might affect the clients' community recreation choices. Programs such as these could prepare individuals with specific coping approaches that could help them embrace their disability and integrate into their community leisure programs more easily.

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