

Viewing Persons with Disabilities as a Culture

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Jonathan is an articulate, intelligent, 35-year-old man who has used a wheelchair since becoming a paraplegic when he was 20.¹ He recalls taking an able bodied woman out to dinner at a nice restaurant. When the waitress came to take their order, she patronizingly asked his date, "And what would *he* like to eat for dinner?" At the end of the meal the waitress presented Jonathan's date with the check and thanked her for her patronage. Although it may be hard to believe the insensitivity of the waitress, this incident is not an isolated experience for persons with disabilities.

Jeff, an ablebodied student, was working with a group that included Helen, who uses a wheelchair. He recalls an incident that really embarrassed him. "I wasn't thinking and I said to the group, 'Let's run over to the student union and get some coffee.' I was mortified when I looked over at Helen and remembered that she can't walk. I felt like a real jerk." Helen later described the incident with Jeff, recalling,

At yesterday's meeting, Jeff said, "Let's run over to the union" and then he looked over at me and I thought he would die. It didn't bother me and I don't know why Jeff was so embarrassed. I didn't quite know what to say. Later in the group meeting I made it a point to say, "I've got to be running along now." I hope that Jeff noticed and felt OK about what he did.

Like Jonathan's experience, this situation between Helen and Jeff is also a common experience.

There has been a growing interest in the important area of health communication among communication scholars, with a core of researchers studying communication between ablebodied persons and those with disabilities. Persons with disabilities are becoming an increasingly large and active minority in U.S. culture, with the numbers growing yearly. In some states, disabled persons constitute the largest minority group, composing as much as seven percent of the population (Wheratt, 1988). There are two reasons for the increase in the number of persons with disabilities. First, as the population ages and lives longer, more people will develop disabilities. Second, advances in medical technologies now allow persons with disabilities to survive life-threatening illnesses and injuries.

In the past, persons with disabilities were kept out of public view, but today they are mainstreaming into all facets of society. Significant legislation, like the Americans with Disabilities Act, seek to guarantee equal rights to persons with disabilities. All of us have or will have contact with persons with disabilities of some kind and many of us will find family, friends, coworkers, or even ourselves part of the disabled culture.

From *Intercultural Communication: A Reader*, 7th ed., eds. Larry A. Samovar and Richard E. Porter (Belmont, CA: Wadsworth, Inc., 1994), 148-154. Reprinted by permission of the author.

Marie, a college student who became quadriplegic after diving into a swimming pool, says “I knew there were disabled people around, but I never thought this would happen to me. I never even knew a disabled person before I became one. If before this happened I saw a person in a wheelchair, I would have been uncomfortable and not known what to say.” As persons with disabilities continue to move into the mainstream, the need for both able-bodied and disabled persons to know how to communicate with members of the other culture will continue to grow.

The purpose of this article is to discuss communication between able-bodied persons and persons with disabilities as *cultural communication* (Carbaugh, 1990). Several researchers have described the communication of disabled and able-bodied persons as cultural communication (Braithwaite, 1990; Emry & Wiseman, 1987; Padden & Humphries, 1988). That is, we must recognize that persons with disabilities develop certain unique communication characteristics that are not shared by the majority of able-bodied individuals in U.S. society. In fact, individuals who were disabled after birth must assimilate from being a member of the able-bodied majority to being a member of a minority culture (Braithwaite, 1990).

This essay presents research findings from a series of interviews with persons who have visible physical disabilities. First, we introduce the communication problems that can arise between persons in the able-bodied culture and those in the disabled culture. Second, we discuss some problems with the way research into communication between able-bodied and disabled persons has been conducted. Third, we present results from the interviews. These results show persons with disabilities engaged in a process whereby they critique the prevailing stereotypes of the disabled held by the able-bodied and engage in a process that we call *redefinition*. Finally, we discuss the importance of these findings for both scholars and students of intercultural communication.

Communication Between Able-bodied and Disabled Persons

Persons with disabilities seek to overcome the barriers associated with physical disability because disability affects all areas of an individual’s life: behavioral, economic, and social. When we attempt to understand the effects of disability, we must differentiate between disability and handicap. Many aspects of disability put limitations on an individual because one or more of the key life functions, such as self-care, mobility, communication, socialization, and employment, is interrupted. Disabilities are often compensated for or overcome through assisting devices, such as wheelchairs or canes, or through training. Disabilities become handicaps when the disability interacts with the physical or social environment to impede a person in some aspect of his or her life (Crewe & Athelstan, 1985). For example, a disabled individual who is paraplegic can function in the environment with wheelchairs and curb cuts, but he or she is handicapped when buildings and/or public transportation are not accessible to wheelchairs. When the society is willing and/or able to help, disabled persons have the ability to achieve increasingly independent lives (Cogswell, 1977; DeLoach & Greer, 1981).

Many physical barriers associated with disabilities can be detected and corrected, but the social barriers resulting from disabilities are much more insidious. Nowhere are the barriers more apparent than in the communication between able-bodied persons and

persons with disabilities. When ablebodied and disabled persons interact, the general, stereotypical communication problem that is present in all new relationships is heightened, and both persons behave in even more constrained and less spontaneous ways, acting overly self-conscious, self-controlled, and rigid because they feel uncomfortable and uncertain (Belgrave & Mills, 1981; Weinberg, 1978). While the ablebodied person may communicate verbal acceptance to the person with the disability, his or her nonverbal behavior may communicate rejection and avoidance (Thompson, 1982). For example, the ablebodied person may speak with the disabled person but stand at a greater distance than usual, avoid eye contact, and cut the conversation short. Disability becomes a handicap, then, for persons with disabilities when they interact with ablebodied persons and experience discomfort when communicating; this feeling blocks the normal development of a relationship between them.

Most ablebodied persons readily recognize that what we have just described is representative of their own communication experiences with disabled persons. Ablebodied persons often find themselves in the situation of not knowing what is expected of them or how to act; they have been taught both to “help the handicapped” and to “treat all persons equally.” For example, should we help a person with a disability open a door or should we help them up if they fall? Many ablebodied persons have offered help only to be rebuffed by the person with the disability. Ablebodied persons greatly fear saying the wrong thing, such as “See you later!” to a blind person or “Why don’t you run by the store on your way home?” to a paraplegic. It is easier to avoid situations where we might have to talk with a disabled person rather than face discomfort and uncertainty.

Persons with disabilities find these situations equally uncomfortable and are well aware of the discomfort of the ablebodied person. They are able to describe both the verbal and nonverbal signals of discomfort and avoidance that ablebodied persons portray (Braithwaite, 1985, 1992). Persons with disabilities report that when they meet ablebodied persons, they want to get the discomfort “out of the way,” and they want the ablebodied person to see them as a “person like anyone else,” rather than focus solely on the disability (Braithwaite, 1985, 1991).

Problems with the Present Research

When we review the research in the area of communication between ablebodied and disabled persons, three problems come to the forefront. First, very little is known about the communication behavior of disabled persons. A few researchers have studied disabled persons’ communication, but most of them study ablebodied persons’ reactions to disabled persons (most of these researchers are themselves ablebodied). Second, most researchers talk *about* persons with disabilities, not *with* them. Disabled persons are rarely represented in the studies; when they are, the disabled person is most often “played,” for example, by an ablebodied in a wheelchair. Third, and most significantly, the research is usually conducted from the perspective of the ablebodied person; that is, what can persons with disabilities *do* to make ablebodied persons feel more comfortable. It does not take into consideration the effects on the person with the disability. Therefore, we have what may be called an *ethnocentric bias* in the research, which focuses on

ablebodied/disabled communication from the perspective of the ablebodied majority, ignoring the perspective of the disabled minority.

We shall discuss the results of an ongoing study that obtains the perspectives of disabled persons concerning their communication with ablebodied persons. To date, fifty-seven in-depth interviews have been conducted with physically disabled adults about their communication with ablebodied persons in the early stages of relationships. Here we are concerned with understanding human behavior from the disabled person's own frame of reference. This concern is particularly important in the area of communication between ablebodied and disabled persons and, as we have said, previous research has been conducted from the perspective of ablebodied persons; disabled persons have not participated in these studies. Doing research by talking directly to the person with the disability helps to bring out information important to the individual, rather than simply getting the disabled person's reaction to what is on the researcher's mind. This research represents a unique departure from what other researchers have been doing because the focus is on the perspective of the disabled minority.

Process of Redefinition

When discussing their communication with ablebodied persons, disabled persons' responses often deal with what we call *redefinition*. That is, in their communication with ablebodied persons and among themselves, disabled persons engage in a process whereby they critique the prevailing stereotypes held by the ablebodied and create new definitions: (1) of the disabled as members of a "new" culture; (2) of self by the disabled; (3) of disability for the disabled; and (4) of disability for the dominant culture.

Redefinition of the Disabled as Members of a "New" Culture

Persons with disabilities report seeing themselves as a minority or a culture. For some of the subjects, this definition crosses disability lines; that is, their definition of *disabled* includes all persons who have disabilities. For others, the definition is not as broad and includes only other persons with the same type of disability. Most persons with disabilities, however, do define themselves as part of a culture. Says one person:

It's (being disabled) like West Side Story. Tony and Maria; white and Puerto Rican. They were afraid of each other; ignorant of each others' cultures. People are people.

According to another man:

First of all, I belong to a subculture because of the way I have to deal with things being in the medical system, welfare. There is the subculture...I keep one foot in the ablebodied culture and one foot in my own culture. One of the reasons I do that is so that I don't go nuts.

Membership in the disabled culture has several similarities to membership in other cultures. Many of the persons interviewed likened their own experiences to those of other cultures, particularly to African Americans and women. When comparing the disabled to both African Americans and women, we find several similarities. The oppression is biologically based, at least for those who have been disabled since birth; one is a member of the culture by being born with cerebral palsy or spina bifida, for example. As such, the condition is unalterable; the disability will be part of them throughout their lifetime.

For those persons who are not born with a disability, membership in the culture can be a process that emerges over time. For some, the process is a slow one, as in the case of a person with a degenerative disease that may develop over many years and gradually become more and more severe. If a person has a sudden-onset disability, such as breaking one's neck in an accident and waking up a quadriplegic, the movement from a member of the dominant culture — "normal person" — to the minority culture — disabled person — may happen in a matter of seconds. This sudden transition to membership in the disabled culture presents many challenges of readjustment in all facets of an individual's life, especially in communication relationships with others.

Redefinition of Self by the Disabled

How one redefines oneself, then, from normal or able-bodied to disabled, is a process of redefinition of self. While African Americans struggle for identity in a white society and women struggle for identity in a male-dominated society, the disabled struggle for identity in an able-bodied world. One recurring theme from the participants in this study is "I am a person like anyone else" (if disabled since birth) or "I'm basically the same person I always was" (if a sudden-onset disability). The person who is born with a disability learns the process of becoming identified as "fully human" while still living as a person with a disability. The individual who is disabled later in life, Goffman (1963) contends, goes through a process of redefinition of self. For example, the subjects born with disabilities make such statements as "I am not different from anyone else as far as I am concerned" or "disability does not mean an incomplete character." Persons whose disabilities happened later say "You're the same person you were. You just don't do the same things you did before." One man put it this way:

If anyone refers to me as an amputee, that is guaranteed to get me madder than hell! I don't deny the leg amputation, but I am me. I am a whole person. One.

During the redefinition process, individuals come to terms with both positive and negative ramifications of disability. Some subjects report that "disability is like slavery to me." In contrast, one woman reports:

I find myself telling people that this has been the worst thing that has happened to me. It has also been one of the best things. It forced me to examine what I felt about myself...confidence is grounded in me, not in other people. As a woman, not as independent on clothes, measurements, but what's inside me.

One man expresses his newfound relationship to other people when he says, "I'm more interdependent than I was. I'm much more aware of that now." This process of redefinition is evident in what those interviewed have to say.

Redefinition of Disability for the Disabled

A third category of redefinition occurs as persons with disabilities redefine both disability and its associated characteristics. For example, in redefining disability itself, one man said, "People will say, 'Thank God I'm not handicapped.' And I'll say, 'Let's see, how tall are you? Tell me how you get something off that shelf up there!'" This perspective is centered on the view of the disability as a characteristic of the person rather than the person himself; it recognizes disability as situational rather than inherent or grounded in the person. In this view, everyone is disabled to some extent; by race, gender, height, or physical abilities, for example.

Redefinition of disability can be seen in the use of language. Says one subject who objected to the label *handicapped person*: "Persons with a handicapping condition. You emphasize that person's identity and then you do something about the condition." This statement ties into viewing one's self as a person first. Research reveals movement from the term *handicapped* to *disability* or *disabled*, although a wide variety of terms are used by these subjects to talk about the self. Another change in language has been the avoidance of phrases such as "polio victim" or "arthritis sufferer." Again the emphasis is on the person, not the disability. "I am a person whose arms and legs do not function very well," says one subject who had polio as a child.

There have also been changes in the terms that refer to able-bodied persons. Says one man:

You talk about the able-bodied. I will talk about the nonhandicapped...It's a different kind of mode. In Michigan they've got it in the law; "temporarily able-bodied."

It is common for the persons interviewed to refer to the majority in terms of the minority; "nondisabled" or "nonhandicapped," rather than "able-bodied" or "normal." More than the change in terminology, the phrase "temporarily able-bodied" or TABS serves to remind able-bodied persons that no one is immune from disability. The persons interviewed also used TABS as a humorous reference term for the able-bodied as well. "Everyone is a TAB." This view jokingly intimates, "I just got mine earlier than you...just you wait!"

In addition to redefining disability, the disabled also redefine "assisting devices:

Now, there were two girls about eight playing and I was in my shorts. And I'll play games with them and say "which is my good leg?" And that gets them to thinking. Well, this one (pats artificial leg) is not nearly as old as the other one!

Says another subject:

Do you know what a cane is? It's a portable railing! The essence of a wheelchair is a seat and wheels. Now, I don't know that a tricycle is not doing the exact same thing.

Again, in these examples, the problem is not the disability or the assisting device, such as a cane, but how one views the disability or the assisting device. These assisting devices take on a different meaning for the persons using them. Subjects expressed frustration with persons who played with their wheelchairs; "This chair is not a toy, it is part of me. When you touch my chair, you are touching me." One woman, a business executive, expanded on this by saying, "I don't know why people who push my chair feel compelled to make car sounds as they do it."

Redefinition of Disability for the Dominant Culture

Along with the redefinitions that concern culture, self, and disability comes an effort to try to change society's view of the disabled and disability (Braithwaite, 1990). Persons with disabilities are attempting to change the view of themselves as helpless, as victims, or merely sick. One man says:

People do not consider you, they consider the chair first. I was in a store with my purchases on my lap and money on my lap. The clerk looked at my companion and said, "Cash or charge?"

This incident with the clerk is a story that has been voiced by every person interviewed in some form or another, just as it happened to Jonathan at the restaurant with his date. One woman has multiple sclerosis and uses a wheelchair told of her husband accompanying her while she was shopping for lingerie. When they were in front of the lingerie counter, she asked for what she wanted, and the clerk repeatedly talked only to her husband saying, "And what size does she want?" The woman told her the size and the clerk looked at the husband and said, "and what color?" Persons with disabilities recognize that able-bodied persons often see them as disabled first and persons second (if at all), and they express a need to change this view. Says a man who has muscular dystrophy:

I do not believe in those goddamned telethons...they're horrible, absolutely horrible. They get into the self-pity, you know, and disabled folk do not need that. Hit people in terms of their attitudes and then try to deal with and process their feelings. And the telethons just go for the heart and leave it there.

Most of the subjects indicate they see themselves as educators or ambassadors for all persons with disabilities. All indicate they will answer questions put to them about their disabilities, as long as they determine the other "really wants to know, to learn." One man suggests a solution:

What I am concerned with is anything that can do away with the “us” versus “them” distinction. Well, you and I are anatomically different, but we’re two human beings! And at the point we can sit down and communicate eyeball to eyeball...the quicker you do that, the better!

Individually and collectively, persons with disabilities do identify themselves as part of a culture. They are involved in a process of redefinition of disability, both for themselves and for the able-bodied.

Conclusions

This research justifies the usefulness of viewing disability from an intercultural perspective. Persons with disabilities do see themselves as members of a culture and viewing communication between able-bodied and disabled persons from this perspective sheds new light on the communication problems that exist. Emry and Wiseman (1987) argue that intercultural training should be the focus in our perceptions of self and others: They call for unfreezing old attitudes about disability and refreezing new ones. Clearly, from these findings, that is exactly what persons with disabilities are doing, both for themselves and for others.

Of the fifty-seven persons with disabilities interviewed, only a small percentage had any sort of education or training concerning communication, during or after rehabilitation, that would prepare them for changes in their communication relationships due to their disabilities. Such education seems especially critical for those who experience sudden onset disabilities because their self-concepts and all of their relationships undergo sudden, radical changes. Intercultural communication scholars have the relevant background and experience for this kind of research and training, and they can help make this transition from majority to minority an easier one (Emry & Wiseman, 1987; Smith, 1989).

As for able-bodied persons who communicate with disabled persons, this intercultural perspective leads to the following suggestions:

Don't assume that persons with disabilities cannot speak for themselves or do things for themselves.

Do assume they can do something unless they communicate otherwise.

Don't force your help on persons with disabilities.

Do let them tell you if they want something, what they want, and when they want it. If a person with a disability refuses your help, don't go ahead and help anyway.

Don't avoid communication with persons who have disabilities simply because you are uncomfortable or unsure.

Do remember that they have experienced others' discomfort before and understand how you might be feeling.

Do treat persons with disabilities as *persons first*, recognizing that you are not dealing with a disable person but with a *person* who has a disability.

Note

1. The names of all the participants in these studies have been changed to protect their privacy.

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