THE SOCIAL CONSTRUCTION OF HUMANNESS

Relationships with Severely Disabled People

Robert Bogdan & Steven J. Taylor

While no one can dispute the fact that people with obvious disabilities often have been cast into deviant roles in society, an exclusive focus on rejection has led many sociologists to ignore or explain away instances in which rejection and exclusion do not occur. Symbolic interactionism and labelling theory, though not by nature deterministic, often have been presented in terms of the inevitability of labelling, stereotyping, stigmatization, rejection, and exclusion of people defined as deviant, including those with recognizable disabilities. According to Goffman (1963), people with demonstrable stigma are seen as "not quite human" and "reduced in our minds from a whole and usual person to a tainted, discounted one" (p. 5). Scott (1969) emphasizes how blindness is "a trait that discredits a man by spoiling both his identity and his respectability" (p. 24). The rejection and exclusion of deviant groups are so taken for granted that instances in which nondeviant persons do not stigmatize and reject deviant ones are often described in terms such as "denial" and "cult of the stigmatized" (Davis, 1961; Goffman, 1963).

This chapter is directed toward understanding the perspectives of non-disabled people who do not stigmatize, stereotype, and reject those with obvious disabilities. We look at how nondisabled people who are in caring and accepting relationships with severely disabled people (people with severe and profound mental retardation or multiple disabilities) define those people. Although the disabled people in these relationships sometimes drool, soil themselves, do not talk or walk—traits that most would consider...
highly undesirable—they are accepted by the nondisabled people as valued and loved human beings. They have moral careers that humanize rather than dehumanize (Goffman, 1961; Vail, 1966).

The position taken in this chapter is that the definition of a person is not determined by either the characteristics of the person or the abstract social or cultural meanings attached to the group of which the person is a part, but rather the nature of the relationship between the definer and the defined. In taking this position we call for a less deterministic approach to the study of deviance and suggest that people with what are conventionally thought of as extremely negatively valued characteristics can have moral careers that lead to inclusion. In a more abstract sense, this chapter suggests that the sociology of exclusion is only part of the story and that a sociology of acceptance needs to be added (Bogdan & Taylor, 1987; Taylor & Bogdan, 1989).

In the first section of the chapter, we describe our research methodology and the data on which our analysis is based. In the following section, we discuss accepting relationships between people with severe disabilities and nondisabled people. We then turn to a discussion of the nondisabled people's definitions of their disabled partners, specifically the perspectives that sustain their belief in the humanness of the disabled people. In the conclusion, we briefly present our views on how the relationships and perspectives described in this study should be interpreted.

THE DATA

The theory presented in this chapter is grounded in over 15 years of qualitative research (Taylor & Bogdan, 1984) among people defined as mentally retarded as well as staff, family members, and others who work with or relate to people so defined. Our earliest research was conducted at so-called state schools and hospitals or developmental centers for people labelled as mentally retarded; in other words, “total institutions” (Goffman, 1961). Ironically, in this research, we studied the dehumanizing aspects of institutions and specifically how staff come to define the mentally retarded persons under their care as less than human (Bogdan, Taylor, deGrandpre, & Haynes, 1974; Taylor, 1977/1978, 1987; Taylor & Bogdan, 1980). Similarly, through life histories of ex-residents of institutions, we looked at the life experiences and perspectives of people who had been subjected to the label of mental retardation (Bogdan & Taylor, 1982). This research supported the literature on stigma, stereotyping, and societal rejection of people with obvious differences.

In more recent years, we have studied people with disabilities in a broad range of school (Bogdan, 1983; Taylor, 1982) and community settings (Bogdan & Taylor, 1987; Taylor, Biklen, & Knoll, 1987). For the past 4 years, as part of a team of researchers, we have been conducting site visits to agencies and programs that support people with severe disabilities in the community. To date, we have visited over 20 places located throughout the country and we continue to make visits. Each of these places is selected because it has a reputation among leaders in the field of severe disabilities for providing innovative and exemplary services. We have been especially interested in visiting agencies that support children with severe disabilities in natural, foster, adoptive families, and adults in their own homes or in small community settings. The visits last for 2 to 4 days and involve interviews with agency administrators and staff, family members, and, if possible, the people with disabilities themselves, and observations of homes and community settings. Our design calls for us to focus on at least two people with disabilities at each site. However, at most sites, we end up studying the situations of six to eight individuals. During the visits, we are usually escorted by a “tour guide,” typically an agency administrator or social worker, although this is not always the case. At several sites, we have been provided with the names and addresses of people served by the agency and visited them on our own.

Our methodological approach falls within the tradition of qualitative research (Taylor & Bogdan, 1984). First of all, our interviews are open-ended and designed to encourage people to talk about what is important to them. Second, based on visits, we prepare detailed fieldnotes, recording interviews and observations. To date, we have recorded roughly 1,000 pages of fieldnotes. Finally, our analysis is inductive. For example, the perspectives and definitions described in this chapter emerged as themes in the data.

Over the course of our visits, we have probably learned something about the lives and situations of over 100 people with disabilities or at least about the perspectives of the many nondisabled people who are involved with them. This chapter focuses on the nondisabled people involved with a smaller number of people with disabilities. In the first place, we are concerned here with nondisabled people who are involved with people who have been labelled by professionals as severely disabled, especially people who cannot talk, and whose humanness (for example, the ability to think), as described later in this chapter, is often considered problematic. In the second place, we report on nondisabled people who have formed humanizing definitions and constructions of these severely disabled people. Not all the family members, staff members, and others whom we have met and interviewed hold the perspectives described in this chapter. People who are
involved with people with severe disabilities have a broad range of definitions of those people, from clinical perspectives (Goode, 1984) to dehumanizing perspectives (Taylor, 1977/1978; Vail, 1966) to the humanizing perspectives described here.

The research methodology on which the chapter is based has several obvious limitations. For one, we spent relatively little time with each of the people included in this study. In contrast to other interviewing studies we have conducted, in which we spent from 25 to 50 hours or more interviewing people, the interviews in this study lasted from approximately 1 to 3 hours. This does not afford the opportunity to develop any level of rapport with people, to double check stories, or to probe areas in depth. However, we have spent enough time in institutions, schools, and service settings and interviewing people with disabilities and their families to know when people are merely reiterating formal policy or the official line.

Further, most of our data are generated from interviews and consist of verbal accounts. While we occasionally observed interactions between disabled and nondisabled people, this study is based primarily on what people said to us and not what we observed them do.

Thus, this is a study of how nondisabled people present their disabled partners to outsiders. Depending on one's theoretical perspective, this study can be viewed in terms of either "accounts"—how people "do" humanness in interaction with an outsider—or "social meanings"—how people define others in their lives as revealed by what they say in interviews. Based on our own theoretical framework, symbolic interactionism (Blumer, 1969; Mead, 1934), we are inclined to view this study in the latter way. In other words, how nondisabled people present their disabled partners in interview situations in some way reflects how they view their partners.

**ACCEPTING RELATIONSHIPS**

The nondisabled people described in this chapter have developed accepting relationships with people with severe and multiple disabilities. An accepting relationship is defined here as one between a person with a deviant attribute—for our interests, a severe and obvious disability—and another person that is long-standing and characterized by closeness and affection. In the relationship, the deviant attribute, the disability, does not have a stigmatizing or morally discrediting character. The humanness of the person with the disability is maintained. These relationships are based on a denial of the absence of impugning the other's moral character because of it.

It is when these relationships are compared with staff-to-client relationships in formal organizations designed to deal with deviant populations (Higgins, 1980; Mercer, 1973; Scheff, 1966; Schneider & Conrad, 1983; Scott, 1969) that they become especially interesting sociologically and important in human terms. People with the same characteristics can be defined and interacted with in one way in one situation and in a radically different way in another. As Goode (1983, 1984) points out, identities are socially produced and depend on the context in which people are viewed. The same group of people who are viewed as "not like you and me"—essentially as nonpersons—by institutional attendants (Taylor, 1977/1978, 1987) are viewed as people "like us" by the nondisabled people in this study. Notwithstanding cultural definitions of mental retardation and the treatment of people with mental retardation in institutional settings, nondisabled people can and do form accepting relationships with people with the most severe disabilities and construct positive definitions of their humanness. While we do not claim that accepting relationships of the kind described in this study are common or representative, we do claim that such alliances exist, need to be understood and accounted for, and call into question deterministic notions of labelling, stigma, and rejection.

**DEFINING HUMANNESS**

Twenty-year-old Jean cannot walk or talk. Her clinical records describe her as having cerebral palsy and being profoundly retarded. Her thin, short—4-feet-long, 40-pound—body, atrophied legs, and disproportionately large head make her a very unusual sight. Her behavior is equally strange. She drools, rolls her head, and makes seemingly incomprehensible high-pitched sounds. This is the way an outsider would describe her, the way we as sociologists encountering her for the first time described her.

Some scholars and professionals would argue that Jean and others like her lack the characteristics of a human being (see Frohock, 1986, for a discussion). Jean and the other severely and profoundly retarded people in our study have often been the target of the indictment "vegetable." People like those in our study have been routinely excluded from the mainstream of our society and subjected to the worst kinds of treatment in institutional settings (Blatt, 1970, 1973; Blatt & Kaplan, 1966; Blatt, Ozolins, & McNally, 1979; Taylor, 1987).

To Mike and Penny Brown (these and the other names in the chapter are pseudonyms), Jean's surrogate parents for the past 6 years, she is their
loving and lovable daughter, fully part of the family and fully human. Their sentiments are similar to those expressed by the other nondisabled people in our study when discussing their disabled partners. In the remainder of this chapter, we describe the perspectives of nondisabled people that underlie their relationships with disabled people and sustain their belief in the others' essential humanness. While these nondisabled people seldom use the word "humanness" in describing their partners, we use it because it captures their taken-for-granted view. The nondisabled view the disabled people as full-fledged human beings. This stands in contrast to the dehumanizing perspectives often held by institutional staff and others, in which people with severe disabilities are viewed as nonpersons or subhuman (Bogdan et al., 1974; Taylor, 1987). We look at four dimensions:

1. Attributing thinking to the other
2. Seeing individuality in the other
3. Viewing the other as reciprocating
4. Defining social place for the other

These perspectives enable the nondisabled people to define the disabled as people "like us" despite their significant behavioral and/or physical differences.

Our analysis has parallels to and builds on a small number of interactionist and ethnomethodological studies of how people "do" normalcy or deviance (Becker, 1963; Goode, 1983, 1984, 1986, 1990; Gubrium, 1986; Lynch, 1983; Pollner & McDonald-Wikler, 1985). In contrast to some of these studies, we focus not on interactional practices that produce normalcy or humanness, but on the perspectives (Becker, Geer, Hughes, & Strauss, 1961) associated with defining the other as human. Thus, we are interested in people's mental constructions of the severely disabled person. This is partially a matter of the nature of our data and partially a matter of theoretical framework.

**Attributing Thinking to the Other**

The ability to think—to reason, understand, and remember—is a characteristic that is commonly thought of as defining humanness. Intelligence is what separates people from animals. Many of the disabled people in the relationships we studied are unable to talk and have been diagnosed as severely or profoundly retarded. A few accomplish minimal communication through communication boards—boards with pictures or symbols on them that the person can point to as a method of communicating. In conventional psychological testing, many have extremely low IQs (below 20), so low in some cases that they are considered untestable. Many give few or no obvious signs of experiencing the stimuli presented to them. Most people would say that they lack the ability to think.

At first glance the assumption that people with severe and profound mental retardation and multiple disabilities cannot think makes sense. Upon closer examination the question of whether or not these severely disabled people think is much more complex. The nondisabled people in this study believe and cite evidence that their disabled partners can and do think. Some people state emphatically that they know exactly what the disabled person thinks. Others report that although it is impossible to tell for sure what is going on in the other person's mind, they give the person the benefit of the doubt.

What a person thinks is always subjective and never totally accessible to others (Schutz, 1967, Ch. 3). We know what other people think or experience through their ability to produce symbols, using speech, writing, gestures, or body language, that are meaningful to us. The severely disabled people in this study are extremely limited in their ability to move or make sounds and hence to produce symbols. Yet the inability to produce standard symbols does not prevent their nondisabled partners from attributing thinking to them.

According to the nondisabled people, thinking is different from communicating thought. From their perspective a person can have full thinking capacity, be "intelligent," and reflective but be locked in a body that is incapable of or severely limited in communication.

They hold the view that their severely disabled partners are more intelligent than they appear. Their physiology keeps them from revealing their intelligence more fully. As Gubrium (1986) writes of people with Alzheimer's disease, "Yet, while the victim's outward gestures and expressions may hardly provide a clue to an underlying humanity, the question remains whether the disease has stolen it all or only the capacity to express it, leaving an unmanifested, hidden mind" (p. 40).

For some people, attributing thinking to a person with severe disabilities is a matter of reading into the gestures or movements he or she can make. In a case study of communication between a deaf-blind child with severe mental retardation and her parents, Goode (1990) describes how the mother, in particular, made use of nonlanguage resources and gestures to figure out what the young girl was thinking. Similarly, Gubrium (1986) reports how family members or caregivers of people diagnosed as having Alzheimer's disease "sharpen their perception so that whatever clues there are to the patient's inner intentions can be captured" (p. 45).
In this study, the nondisabled people emphasize the significance of minor sounds and movements in attributing intelligence and understanding to the disabled people. For example, one 3-year-old boy we observed is completely paralyzed. The only movements Mike makes, which are involuntary according to professionals, are slight in-and-out movements with his tongue and slow back-and-forth rolling of his blind eyes. Mike's foster parents have been told by doctors and social workers that the boy is not able to understand or communicate, that he has no intelligence. But the parents see in his movements signs that refute the diagnosis. They describe how when certain people come into his room slight alterations in the speed of the tongue movements can be observed. They also claim that the boy, on occasion, moves his eyes toward the person in the room who is talking, an indication to them that he can hear and recognize people.

These people claim not only that their disabled partners can think, but that they can understand their partners and know what they are thinking. With the limited menu of gestures and sounds that many severely disabled people have, one might think that it would be extremely difficult for a partner to believe that he or she knew what was on the other's mind. For these people, this is not the case. While all the nondisabled people acknowledged sometimes having difficulty in knowing what their partners think, they maintain that they are able to understand them. They say that they can read gestures and decipher signs of the inner state of the other that strangers cannot see. For instance, some claim that they can understand their partners by reading their eyes.

For other people, intuition is the source of understanding people with severe disabilities and what they think. As the parent of a profoundly retarded young woman explained when asked how she knows her daughter understands: "It's just something inside me. ...I really believe that deep in my soul." Goode (1990) reports that parents and others in intimate relationships with people with severe disabilities often "just know" what the person is thinking or feeling.

Finally, some nondisabled people understand their severely disabled partners by putting themselves in their position or "taking the role of the other." That is, they imagine what they would feel in the same situations. One foster mother says that she makes decisions about how to treat her foster daughter by pretending she is the daughter and experiencing her actions. She reports experiencing vicariously the pleasure of being taken care of by looking at what she is doing for her foster child from the child's perspective. While people acknowledge the likelihood that their assessments of the other's inner life often may be flawed, they believe that the process brings them closer to their partners and leads them to a better understanding of what they are experiencing.

The nondisabled people's belief in the ability of their severely retarded friends and loved ones to think often runs counter to professional and clinical assessments (Goode, 1983; Pollner & McDonald-Wikler, 1985). In some cases doctors have told them that their partners are brain dead. The nondisabled people report that they have often been bombardeped with specialists' judgments that, in their eyes, underestimate their partners' capabilities. They argue that specialists are not privy to the long, day-by-day, hour-by-hour observation of the person. Behaviors that they cite as indicating understanding do not occur with such frequency that the professional is likely to see them. Further, unlike the nondisabled partners in the relationships, professionals are not intimately familiar with their clients and therefore are not attuned to the subtleties of their sounds and gestures.

What also bolsters the belief that the professionals are wrong in their assessments of intelligence are numerous examples of past professional judgments that were wrong. Some have watched their disabled companions live through predictions of early death. Others have cared for their disabled partners at home in spite of advice that such living arrangements would not be possible and that the disabled people would be destined to live their lives in an institution.

As a foster parent of a person who was profoundly retarded told us: "They [the physicians] said she'd have to be in an institution. I said to myself, 'That's all I need to hear. We'll see about that.' I knew I could take care of Amy and I have." In one family in which there are one profoundly retarded and two severely retarded adolescents the parents told us that their foster children had been excluded from school because professionals had judged them incapable of attending. Immediately after they were released from an institution and came to live with the family they began attending regular school.

Regarding whether or not people with severe disabilities, including those diagnosed as having severe and profound mental retardation, can understand and think as other people, professional assessments stake no greater claim to truth than the assessments of the nondisabled people reported in this study. Critiquing Pollner and McDonald-Wikler's (1985) account of a family's "delusional" beliefs in the competence of a severely retarded child—what they refer to as the "social construction of unreality"—Goode (1990) points out that clinical and medical bodies of knowledge cannot be used to provide a standard by which to judge the legitimacy of family belief systems. Clinical perspectives are based on different ways of knowing and seeing than the perspectives of people involved in intimate relationships with people and disabilities. Further, clinical diagnoses are often proven wrong based on their own criteria. For example, case histories have come to light of people diagnosed at an early age as having no mental
capacity who later were found to have normal intelligence when provided with communication devices (Crossley & McDonald, 1980; Hay, 1982).

**Seeing Individuality in the Other**

Sitting in the living room of a foster home for a severely retarded young woman who had spent the majority of her life in an institution, the father described her as having very pretty hair and a great sense of humor and as being a very appreciative person. When this young woman arrived home from school she was dressed in a new stylish outfit complete with Reebok running shoes. He told us how Monica loved to get dressed in new clothes and how the color she had on was her favorite. He told us how her hairstyle had changed since she came to live with his family, from an institutional bowl cut to its present high fashion style. Monica had a communication board on her lap. She moved her hand, placing it in the vicinity of the picture of a radio. He said: “Ok, I have to start dinner and then I’ll get the radio. We are having your favorite, chicken.” As an aside he said, “Monica loves to listen to music and she gets very excited when she can smell something that she likes cooking.”

We have discussed how the nondisabled people in our study construct humanness by attributing thinking to their severely disabled companions. But being a person involves something more than thinking. A person is like all other people but also unique; at least in this culture humanness implies individuality. For the people we have been studying an important aspect of constructing humanness is seeing the others as distinct, unique individuals with particular and specific characteristics that set them apart from others. As illustrated in the story of Monica’s foster father, nondisabled people in caring relationships with disabled persons see the others as having distinct personalities, particular likes and dislikes, normal feelings and motives, a distinct background—in short, a clear identity—and manage their appearances to conform to their own views of them.

**Personalities**

The nondisabled people used a variety of words to describe the distinctive qualities of their severely disabled partners. The adjectives silly, fun, shy, live wire, bright, appreciative, nice, likeable, calm, active, kind, gentle, wonderful, amusing, pleasant, and good company fall under the broad category of “personality.” Most of the words are resoundingly positive. Occasionally one might hear phrases like: “He’s a handful,” or “She gave me a lot of trouble yesterday,” indicating a more critical evaluation of the partner. But even here, the tone is accepting and the comments never indicting.

Many nondisabled people have nicknames for their disabled partners. Often the nicknames are given because they capture something unique about the person’s personality. One man who has developed a close relationship with an elderly disabled man who had spent over 50 years of his life in an institution calls the older man “Mr. Rudy.” Mr. Rudy is blind, unable to talk, and walks only by leaning on a wall. The nondisabled man is not able to explain how he came up with the nickname but believes that Mr. Rudy seems to go with the man’s personality. He says that Mr. Rudy has been through a lot in his life, but “he made it and still has it together.” For him, the name Mr. Rudy for the elderly man conveys a sense of dignity.

None of these people use phrases like “profoundly retarded” or “developmentally disabled” to refer to their friend or loved one. Some feel that clinical designations are too impersonal and do not tell much about the character and personality of the labelled person. A few indicate that they believe that clinical labels define a person in terms of deficits rather than positive characteristics, a vantage point they prefer not to see their companions from. The label can strip the person of his or her unique personality. By using a rich repertoire of adjectives and defining the person in specific personal terms, these people maintain the humanness of their severely disabled partners.

**Likes and Dislikes**

Another dimension of individuality involves being discriminating—having tastes and preferences. As illustrated in the remarks Monica’s father made in describing her, the nondisabled people in this study know their partners’ specific likes and dislikes and discuss them willingly. While people with severe disabilities may be extremely limited in their activities and hence have few areas in which they can express preferences, the nondisabled people present them as having definite likes and dislikes regarding the things they do experience (Goode, 1990). Music, food, colors, and individual people are commonly cited as areas where people with severe disabilities have preferences. Monica loves to listen to music, has a favorite color, and prefers to eat chicken. In one home with three disabled young people, nondisabled family members explain that one person prefers classical music, a second likes rock, and a third does not like music. In another case, a woman who has a caring relationship with a 43-year-old severely retarded woman described the woman as enjoying camping, sailing, and canoeing.

By viewing the disabled person as having likes and dislikes, the nondisabled person not only confirms his or her individuality, but often reinforces the bonds between them as well. Comments such as, “She likes to eat
experienced. In recounting these experiences, the nondisabled person often communicated through biographies that are often unique and detailed. Life histories are sometimes told in two parts. The first has to do with the nondisabled people telling stories of the background experiences of the disabled person that explains who he or she is today. In interviews, people describe the suffering and deprivation the disabled person has experienced. For example, the nondisabled partners often point to changes in weight, behavior, skills, personality, and appearance.

Feelings and motives

In everyday interaction, we attribute feelings and motives to other people's words and acts. Rather than defining the actions of the disabled people as symptomatic of an underlying pathological state (Taylor, 1977/1978), the nondisabled people in our study define them in terms of normal motives and feelings. A foster mother tells the following story about her foster child, Mike:

Wednesday night he started to cry continuously. I got real upset and called my husband and told him to come right back. As soon as he got here he talked to Mike like only he can: "Hey, Bubba, what's wrong with you." Mike stopped crying and I held him but then he started up again. My husband told me to give him back and he sat in the rocker and talked with Mike and he stopped again. But the minute he got ready to lay him down he started up again... so he (Mike) has got to know something. How would he know to cry again, that we were going to lay him down?

As the above quotation illustrates, Mike's foster mother, as do the others we have studied, takes outward signs—crying, laughing, sighing—as indicators that the severely disabled person has the same feelings and motives as other people. When crying, laughing, and sighing are observed in conjunction with particular events, the events are said to have provoked them, thus revealing to the interpreters that the person is in touch with his or her surroundings and is expressing human emotion.

Life histories

One aspect of seeing another person as an individual is constructing a biography of the person that explains who he or she is today. In interviews, nondisabled people tell stories of the background experiences of the disabled people. The individuality and the humanness of the disabled people are communicated through biographies that are often unique and detailed. Life histories are sometimes told in two parts. The first has to do with the disabled person's experiences prior to the formation of the relationship. Especially when the person has been institutionalized, the nondisabled person describes the suffering and deprivation the disabled person has experienced. In recounting these experiences, the nondisabled person often puts him- or herself in the disabled person's position and imagines what it would have felt like. In some cases, the people with disabilities are presented as survivors or even heroes for having undergone their experiences. The second part of the life history relates to improvement in the lives of the disabled people, especially when they are living with the nondisabled person telling the story. For example, the nondisabled partners often point to changes in weight, behavior, skills, personality, and appearance.

Managing appearances

The nondisabled people in this study not only see individuality in the disabled people, but actively create it by managing the appearances of the disabled people to downplay their visible differences and to accentuate their individual identities. They present a normal version of the person's self to outsiders and to themselves. By paying attention to clothing style and color and being attentive to other aspects of the person's appearance (cleanliness, hairstyle, nails, make-up for women, beards for men), they help construct an identity consistent with their definitions of the person. In the case of Monica described earlier, for example, her foster parents selected clothes and a hairstyle that made her look attractive. The management of the disabled person’s appearance often conforms to gender stereotypes. Many foster parents of young girls dress them in frilly, feminine dresses, complete with bows in their hair. Thus, the person not only has an identity as an "individual" in an abstract sense, but as a "little girl," "teenage boy," "middle-aged woman," "elderly man," and so on.

To an outsider, many of the disabled people in this study have obvious physical abnormalities, including large heads, frail bodies, bent limbs, and curved spines. However, the nondisabled people seldom mention these characteristics except when a particular condition is causing the disabled person difficulties or when they are recounting an outsider's negative reactions to the person's abnormalities.

The nondisabled people often express pride in the disabled person's appearance. For disabled people who have been institutionalized, many people comment on the significant changes in their looks since leaving an institution. The change is from institutional clothing, unstyled haircuts, dirty skin, and sloppiness to a physical self closer to that of other people. The transformation is symbolic of the disabled person's metamorphosis from dehumanized institutional inmate to family member or friend.

In dramatic contrast to total institutions that strip people of their identities (Goffman, 1961), the nondisabled people in this study see and assist in the accomplishment of individual identities for the people with disabilities with whom they are involved. Personality, likes and dislikes,
feeling and motives, a biography, and appearance are all individualized aspects of a person. By highlighting the severely disabled person's personal attributes and contributing to creating them, the nondisabled people in our study maintain the humanness of their partners.

Viewing the Other as Reciprocating

For somebody to be thought of as a full human participant in a relationship, the person has to be seen as contributing something to the partnership. Exchange theorists (Blau, 1964) have pointed to the tendency for close relationships to be reciprocal, with both parties defining the relationship as one in which they receive as much as they give. According to exchange theorists, people with equal resources (some combination of social worth, talent, material resources, and so on) tend to form enduring relationships. When one person does not have as much to offer, the relationship suffers from disequilibrium and this is experienced as stressful for the parties. Under these conditions the weaker partner is diminished in the other's eyes. Such formulations narrowly define the nature of the commodities exchanged and exclude the type of alliances discussed in this chapter.

From the outside it might appear that the relationships in our study are one-sided (the nondisabled person giving all and receiving nothing) and, using the logic of exchange theory, doomed to stress and disintegration. After all, severely disabled people appear to have so few resources, so little of social value, talent, and material resources to exchange. This is not the way the nondisabled people in our study see their relationships or the people with disabilities. They define the person with a disability as reciprocating or giving something back, however abstract the benefit.

Joe Bain, who, along with his wife and two children, shares his home with three severely disabled young adults, tells why he has the disabled people living with them: "... I am not doing what I'm doing for their benefit. They may benefit from it but I like it. It's fun, I see them as just people I enjoy to be with."

While not all the people in this study are so exuberant, most mention deriving pleasure from their relationships because they like the disabled people and enjoy being with them. For some the disabled person is an important source of companionship. One person says that she does not know what she would do if she did not have her disabled loved one to take care of and to keep her company. A number of people mention how disabled people expand their lives by causing them to meet new people and learn about aspects of their communities they had not been in touch with previously.

Companionship and new social relations are perhaps the most concrete of the benefits people talk about. Some nondisabled people are philosophical about what the person with a disability gives them. A few believe that the relationships with severely disabled people have made them better people. A mother of a 6-year-old boy who is severely retarded and has hydrocephaly says, "He has taught me to accept people for how they are. No matter how limited you are, that everyone has within them a quality that makes them special." Another parent, this time a father whose son is severely retarded and has spina bifida, states, "He made all of our children and ourselves much more caring, much more at ease with all handicapped people."

As discussed in earlier sections, the nondisabled people feel that they know their severely disabled partners intimately. They understand them and know their particular likes and dislikes. Intimately knowing the individual disabled person gives the nondisabled person a feeling of being special. According to one person who has a caring relationship with a profoundly retarded child, "I think we have a very special relationship in that very often we're together alone. I feel like I'm the one person who knows him better than anyone else. I feel like I can tell if he's sick or what he needs better than anybody else."

Another benefit that some nondisabled people report as receiving from their relationships is a sense of accomplishment in contributing to the disabled person's well-being and personal growth. As discussed in the case of personal appearance, the nondisabled people see positive changes occurring in their disabled loved ones or friends. Often the progress would be considered minor by outsiders, something they would not notice or understand, but for the nondisabled person in the relationship it is significant. For example, one person who is in a relationship with a nonverbal, severely retarded child describes how she had told the woman, Susan, to brush her teeth. Commenting that when Susan came out of the bathroom she was holding a toothbrush and toothpaste with the cap stuck, she explains, "That is asking for help; that is communication. No one would have done that 5 years ago; no one would have even gone for the toothbrush and toothpaste!" Regarding a severely disabled woman, another woman says, "She laughs, she didn't do that before. People might think it's minor, but with Jane progress is slow."

Defining Social Place for the Other

Discussions of humanness often point to the social nature of humans as being a defining characteristic. People are social beings. Humans belong to groups and are part of social networks, organizations, and institutions. Within these social groups, individuals are given a particular social place. The concept of role is often used to describe a person's social place. But
social place is not merely a matter of playing a social role. It is also a matter of being defined as being an integral part of the group or social unit. There is a personal dimension to roles. Roles are particularized for each social unit and personalized by each occupant. Through fulfilling particular social roles, social actors are defined as being part of humanity.

The nondisabled people described in this study define their disabled partners as full and important members of their social units and hence create a social place for them. First of all, they incorporate the disabled people in their definitions of their groups or social networks. While some of the relationships discussed in this chapter involve two people, one disabled and one not, most involve the place of people with disabilities within families. In families, in particular, the disabled person is likely to be viewed as a central member. Thus, the person does not simply play the role of a son or daughter, but is seen as "my son" or "my daughter." A foster parent of several children with severe disabilities, who could not have children of his own, says, "This gives us our family." In a foster family, the mother describes how her natural son sees the foster child: "He's the little brother he never had." In many cases, the family would not seem like the same family without the disabled person.

Second, the nondisabled people define a part for the disabled people in the rituals and routines of the social unit. In any group, members develop intertwined patterns of living. For instance, in a family, members coordinate getting up, taking showers, getting breakfast, accompanying each other on important occasions, preparing for holidays, going on vacation, having birthday parties, and so on. The inclusion of a severely disabled person in a family's or primary group's routines and rituals, in its private times and public displays, acknowledges to the members that he or she is one of them. The person fills a particular social place. As a foster parent of two people with severe disabilities explains, "We bring them to all family gatherings. My sister said we could hire a baby-sitter and leave all of the foster children home. We said that where we go, they go... The family accepts them as part of the family." When, because of hospitalization or other reasons, people with disabilities are missing from the social unit, other members talk about how they are missed and how things are not the same without them. The person's absence interferes with normal family routines.

Primary groups belong to larger networks of human relations. When severely disabled people are integrated into primary groups and have their humanness declared there, they have a vehicle to be included in the social web that defines community membership. The mother of a 6-year-old profoundly retarded girl who spent most of her life in an institution said, "We take her to church, the grocery store, and everywhere we go."

CONCLUSION

The humanizing sentiments underlying the relationships described in this chapter are not unique to unions between nondisabled and severely disabled people. They are the same sentiments described in the phenomenological literature as sustaining the perception of the social world as intersubjective (Husserl, 1962; Psathas, 1973; Schutz, 1967). As Jehensen (1973) writes, "As an actor on the social scene, I can recognize my fellow-man not as 'something,' but as 'someone,' a 'someone like me'" (p. 221). So too do the nondisabled people in this study recognize people with severe disabilities as "someone like me"; that is, as having the essential qualities to be defined as a fellow human being. Disability is viewed as secondary to the person's humanness. What makes the perspectives described in this chapter striking is that they are directed toward people who have often been denied their humanity and in some instances defined as nonpersons (Fletcher, 1979).

An understanding of how nondisabled people construct the humanness of severely disabled people can inform ethical debates surrounding the treatment of infants, children, and adults with severe disabilities (Association for Persons with Severe Handicaps, 1984). Whether or not people with severe disabilities will be treated as human beings, or persons, is not a matter of their physical or mental condition. It is a matter of definition. We can show that they are human by proving that we are capable of showing humanity to them. It is easy to dismiss the perspectives described in this chapter. One might argue that the nondisabled people are deceiving or deluding themselves when they attribute human characteristics to people with severe and profound mental retardation and other disabilities. For example, some might consider the belief that people with severe or profound retardation can and do think to be outlandish. Yet it is just as likely that those who dehumanize people with severe disabilities, dispute their human agency, and define them as nonpersons are deceiving themselves. After all, no one can ever prove that anyone else is "someone like me" or that the assumption of common experience is anything but an illusion. What others are depends on our relationships with them and what we choose to make of them.

NOTES

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University). The opinions expressed herein are solely those of the authors, and no official endorsement by the U.S. Department of Education should be inferred.

1. Whether or not people with severe disabilities "really are" human is not a matter of social definition. This is a moral and philosophical question and not a sociological one.

**REFERENCES**


