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Abstract

A qualitative paper which looks at friendships between non disabled people and people who have disabilities. It is especially concerned with examining non disabled people who are in relationships with those labelled 'severely disabled', those who cannot talk and those whose humanness is often considered problematic. "An accepting relationship is one that is long standing and characterised by closeness and affection". The paper highlights the reasoning that who we are depends on our relationships with others as well as what we choose to make of ourselves. **Keyword: Friendship**

Relationships with Severely Disabled People: The Social Construction of Humanness*

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This paper presents the perspective of nondisabled 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 others define them. Although the disabled people in these relationships sometimes drool, soil themselves, and 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. We look at four dimensions of the nondisabled people's perspective that helps maintain the humanness of the other in their minds: (1) attributing thinking to the other, (2) seeing individuality in the other, (3) viewing the other as reciprocating, and (4) defining social place for the other. The paper illustrates a less deterministic approach to the study of deviance, suggests that people with what are conventionally thought of as extremely negatively valued characteristics can have moral careers that lead to inclusion rather than exclusion, and argues that the study of acceptance needs to be added to the more common focus on rejection.

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 (1963:5), 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." Scott (1969:24) emphasizes how blindness is "a trait that discredits a man by spoiling both his identity and his respectability." The rejection and exclusion of deviant groups are so taken for granted that when labeled deviants are not stigmatized and rejected, such reaction is often described as "denial" and the "cult of the stigmatized" (Davis 1961; Goffman 1963).

This paper presents and seeks to understand the perspectives of nondisabled 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 others (people with severe and profound mental retardation or multiple disabilities) define them. 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.

We argue in this paper that the definition of a person is to be found in the relationship between the definer and the defined, not determined either by personal characteristics or the abstract meanings attached to the group of which the person is a part. This position illustrates a less deterministic approach to the study of deviance and suggests that people with what are conventionally thought of as extremely negatively valued characteristics can have moral careers that lead to inclusion rather than exclusion (Goffman 1961; Vail 1966) and that a sociology of acceptance needs to be added to the more common focus on rejection (Bogdan and Taylor 1987; Taylor and Bogdan 1989).

In what follows, we describe our research methods and data, discuss accepting relationships between those with severe disabilities and nondisabled people, and examine the latter's definitions of their disabled partners[1] and how they sustain their beliefs in the humanness of the disabled people. At the end of the paper, we suggest how the relationships and perspectives described in this study might be interpreted.

Data and Methods

For over 15 years we have conducted qualitative studies among people defined as mentally retarded and their family members, various medical and rehabilitative staff members, and others who work with or relate to people so defined (Taylor and Bogdan 1984). Our earliest research was conducted at "state schools" and "hospitals" or developmental centers for people labeled mentally retarded, in other words, total institutions (Goffman 1961). Ironically, in that research we studied the dehumanizing aspects of institutions, specifically, how staff defined the mentally retarded persons under their care as less than human (Bogdan et al. 1974; Taylor 1977, 1987; Taylor and Bogdan 1980). We also constructed life histories of ex-residents of institutions to look at the experiences and perspectives of people who had been labeled "mental retarded" (Bogdan and Taylor 1982). This research supported many of the arguments and conclusions in the literature on the stigma, stereotyping, and societal rejection of people with obvious differences.

More recently, we have studied people with disabilities in a broad range of school (Bogdan 1983; Taylor 1982) and community settings (Bogdan and Taylor 1987; Taylor, Biklen, and Knoll 1987). As part of a team of researchers for the past four years, 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 sites throughout the country, and we continue to make visits. Each site is selected because it has a reputation 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, and adoptive families and adults in their own homes or in small community settings. The visits have lasted from two to four days and involve observations of homes and community settings and interviews with agency administrators and staff, family members, and, if possible, the people with disabilities themselves. Our research design calls for us to focus on at least two people with disabilities at each site. However, we have studied the situations of six to eight individuals at most sites. During the visits, we often are escorted by a "tour guide," typically an agency

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1. Throughout this paper, we use the term "partners" (as well as "person" or "people") to refer to the severely disabled people with whom nondisabled people have formed relationships. This is our term, rather than a folk or member's term, and we use it to underscore the fact that these disabled people are members of caring and accepting relationships. The nondisabled people refer to the disabled people in friendship ("friend"), kinship ("son," "daughter"), or pseudo-kinship ("foster son," "foster daughter") terms. In the remainder of this paper, we describe the perspectives of nondisabled people that underlie their relationships with disabled people and sustain their belief in the other's 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.

administrator or social worker. At several sites we have gotten the names and addresses of people served by the agency and subsequently visited them without these "guides."

Our methods are qualitative (Taylor and Bogdan 1984). Interviews are open-ended to encourage people to talk about what is important to them; we have thus far made roughly 1,000 pages of detailed fieldnotes, transcribed interviews, and observations. Our analysis is inductive. The perspectives and definitions described in this paper emerged as themes in the data.

Over the course of our visits, we have learned about aspects of the lives and situations of over 100 people with disabilities, mainly through the perspectives of the various nondisabled people who are involved with them. This paper focuses on a subset of these relationships. We are especially concerned here to examine the nondisabled who are in relationships with those labeled "severely disabled," those who cannot talk and whose humanness is often considered problematic. We report on nondisabled people who have formed humanizing definitions or constructions of these severely disabled people. Not all of the family members, staff members, and others whom we have met and interviewed hold the perspectives described in this paper. Those involved with people who have severe disabilities use a broad range of characterizations and labels to define them, from clinical perspectives (Goode 1984) to dehumanizing perspectives (Taylor 1977; Vail 1966) to the humanizing perspectives described here.

Our research methods do, of course, have their limitations. For instance, we spent relatively little time (from one to three hours) interviewing each of the people included in this study. This length of time does not afford the opportunity to develop a deep rapport with people or to probe many topics that emerge. However, we have spent enough time in institutions, schools, and service settings, and in interviewing people with disabilities and their families to help us recognize responses in which people simply tell us what they think we want to hear. 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 paper is primarily based on what people said to us and not what we observed them do.

This then is a study of how nondisabled people have presented their disabled partners to outsiders, in particular, to us. Depending upon theoretical perspective, one can view the object of this study 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. Our preference for a symbolic interactionism (Blumer 1969; Mead 1934) leads us toward the latter view.

Accepting Relationships

The nondisabled described in this paper have developed accepting relationships with those who have severe and multiple disabilities. An accepting relationship is one that is long-standing and characterized by closeness and affection. In our case, those involved are people with severe and obvious disabilities and ostensibly nondisabled others. In such relationships, the deviant attribute, the disability, does not bring stigma or discredit. The humanness of the person with a disability is maintained. The difference is not denied, but neither does it bring disgrace.

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 and Conrad 1983; Scott 1969) that they become especially interesting sociologically and important in human terms. People who have similar characteristics can be defined and interacted with quite differently from one situation to another. As Goode (1983, 1984) points out, identities are socially produced and depend upon the context in which people are viewed. The same group of people who were viewed as "not like you and me"—essentially as

nonpersons—by institutional staff (Taylor 1977, 1987) were seen by the nondisabled in this study as "people, like us." Notwithstanding cultural definitions of mental retardation and the treatment in institutional settings of those so labeled, nondisabled people can and do form accepting relationships with those who have the most severe disabilities, and they construct positive definitions of them as human beings. While we do not claim that accepting relationships of the kind described in this study are common or that our data are statistically representative, we do claim that such alliances exist and need to be understood as one way to complicate overly deterministic conceptualizations of labeling, 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—four feet long, forty 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. But this is the way an outsider would describe her, the way we described her as sociologists encountering her for the first time. .

Some scholars and professionals would argue that Jean and others like her lack the characteristics of a human being (see Frohock 1986). Jean and the other severely and profoundly retarded people in our study have often been called "vegetables." People like those in the relationships we studied 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 and Kaplan 1966; Blatt, Ozolins, and McNally 1979; Taylor 1987).

To Mike and Penny Brown (these and the other names in the paper are pseudonyms), Jean's surrogate parents for the past six 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 paper, we describe the perspectives of nondisabled people that underlie their relationships with disabled people and sustain their belief in the other's 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.[2] 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 non-persons or sub-human (Bogdan et al. 1974; Taylor 1977, 1987). We look at four dimensions: (1) attributing thinking to the other, (2) seeing individuality in the other, (3) viewing the other as reciprocating, and (4) defining social place for the other. These perspectives enable the nondisabled people to define the disabled people as "like us" despite their 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 (Goode 1983, 1984, 1986, forthcoming; Gubrium 1986; Lynch 1983; Pollner and 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 et al. 1961) associated with defining the other as

2. 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 sub-human (Bogdan et al. 1974; Taylor 1977, 1987). We are interested in perspectives and social definitions in this paper. The term "humanness" captures the underlying perspective on severely disabled people held by the nondisabled people described in this study. 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.

human. Thus, we are interested in how these nondisabled intimates construct their severely disabled others.

Attributing Thinking to the Other

The ability to think—to reason, understand, and remember—has sometimes been presented as defining humanness (Fletcher 1979). Intelligence is what separates people from animals. Many of the disabled people in the relationships we studied have been diagnosed as severely or profoundly retarded and were unable to talk. A few accomplished minimal communication through communication boards—boards with pictures or symbols on them that the person can point to as a method of communicating. In the conventions of 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.

The assumption that people with severe and profound mental retardation and multiple disabilities cannot think initially seems plausible. Upon closer examination, whether or not these severely disabled people think is a much more complex question. The nondisabled people in this study believe and cited evidence that their disabled partners can and do think. Some people stated emphatically that they know exactly what the disabled person thinks. Others reported that, although it is impossible to tell for sure what is going on in the other person's mind, they grant them the benefit of the doubt.

What a person thinks is always subjective and never totally accessible to others (Schutz 1967). We know what other people think or experience by observing the symbols of speech, writing, gestures, or body language that are meaningful to us. The severely disabled people in this study were extremely limited in their abilities to move or make sounds and, hence, to produce symbols. Yet this inability did 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 its capacity for communication. They hold the view that their severely disabled partners are more intelligent than they appear and that their physiology keeps them from revealing their intelligence more fully. As Gubrium (1986:40) 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."

Attributing thinking to a person, with or without severe disabilities is a matter of reading meaning into the gestures or movements the person makes. That people with severe disabilities may have a limited repertoire of gestures or movements does not prevent the nondisabled people described in this study from recognizing meaning in the gestures and movements they make. In a case study of communication between a deaf-blind child with severe mental retardation and her parents, Goode (forthcoming) describes how the mother, in particular, made use of nonlanguage resources and gestures to figure out what the young girl was thinking. Similarly, Gubrium (1986:45) reports how family members or caregivers around 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."

In our study, nondisabled people similarly emphasize the significance of minor sounds and movements in attributing intelligence and understanding to the disabled partner. One three-year-old boy we observed is completely paralyzed. The only movements Mike makes, ones professionals consider involuntary, are slight in and out movements with his tongue and slow back and forth rolling of his blind eyes. The boy'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 this diagnosis. They describe how they can observe, when certain people come into his room, slight alterations in the speed of the tongue movements. They also claim that Mike, on occasion, moves his eyes toward the person in the room who is talking, an indication to them that he can hear and recognize others.

Many of the nondisabled people not only claimed that their disabled partners can think, but that they can understand the partners and know what they are thinking. With the limited range of gestures and sounds that many severely disabled people have, one might think such understanding would be extremely difficult. But these nondisabled people said this is not the case for them. While they all acknowledged that sometimes it was difficult to know what their partners thought, they maintained that most of the time they are able to understand them. They said they can read gestures and decipher signs of the inner state of the other that strangers cannot see. For instance, some claimed that they can understand their partners by reading their eyes.

Other nondisabled people said 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 (forthcoming) reports that parents and others in intimate relationships with those having severe disabilities often "just know" what the other 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 particular situations. One foster mother said that she makes decisions about how to treat her foster daughter by pretending she is the daughter and experiencing her actions. She reported experiencing, vicariously, the pleasure of being taken care of by looking at what she is doing for her foster child from her perspective. While people acknowledged the likelihood that their assessments of the other's inner life often may be flawed, they believed that the process brings them closer to their partners and leads them to a better understanding of what they are experiencing.

The nondisabled's belief in the capacity of their severely retarded friends and loved ones ability to think often runs counter to professional and clinical assessments (Goode 1983; Pollner and McDonald-Wikler 1985). In some cases, doctors have told them that their partners are brain dead. The nondisabled people reported that they have often been bombarded 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 these 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 nondisabled people's belief that the professionals are wrong in their assessments of intelligence are numerous examples of past professional judgments that are 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 person was destined to live his or her life 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 with one profoundly retarded and two severely retarded adolescents, the parents told us that their foster children have 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.

Whether or not people with such severe disabilities can understand and think as other people, professional assessments stand no greater claim to truth than the assessments of the nondisabled people reported in this study. While professional assessments may carry more authority or political weight in determining the life circumstances of people with disabilities, we do not consider them more accurate in an absolute sense or any less a reflection of social definitions and perspectives. Goode (forthcoming) critiques 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"—and argues 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 those who have 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 are found to have normal intelligence when provided with communication devices (Crossley and 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. The father told us how the girl, 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 coming to live with his family from an institutional bowl cut to its present high fashion form. 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."

A second way the nondisabled people in our study constructed their severely disabled companions as persons was to see them as individuals. The people we have been studying use perspectives toward their disabled others that define them as distinct, unique individuals with particular and specific characteristics that set them apart from others. Monica's foster father, for instance, saw her as having a distinct personality, particular likes and dislikes, normal feelings and motives, a distinct background—in short a clear identity. He and others we interviewed managed the disabled person's appearances to conform to such definitions.

Personality. The nondisabled people used a large variety of words to describe these distinctive qualities. Adjectives such as silly, fun, shy, live-wire, bright, appreciative, nice, likable, 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 but not precluding the attribution of a distinctive personal quality.

Many nondisabled people in our study have nicknames for their disabled partners. Often the nicknames are given to capture something unique about the individual'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 only walks by leaning on a wall. The nondisabled man said he couldn't

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 nickname conveys a sense of dignity.

None of these people use technical 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 person's character and personality. They said they believe that clinical labels define the person in terms of deficits rather than positive characteristics, a vantage point they prefer not to take. Such labels 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 partner.

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 partner's specific likes and dislikes and discuss them willingly. While people with severe disabilities may be severely limited in their activities and hence have few areas in which they can express preferences, the nondisabled people present them as having definite preferences about the things they do experience (Goode forthcoming). Music, food, colors, and certain other people are commonly cited as areas in which 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, two young men and a young woman, nondisabled family members explained 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 partner not only confirms the other's individuality, but often reinforces the bonds between them as well. Comments such as "She likes to eat everything we do!" and "He loves the banana bread I make" indicate that the nondisabled people see themselves sharing things in common with these disabled others.

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), the nondisabled people in our study define them in terms of normal motives and feelings. A foster mother told 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 he only 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 did 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 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 in familiar, shared-in-common ways.

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 told stories of the background experiences of the disabled person. 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 described the associated suffering and deprivation. In recounting these experiences, the nondisabled person often put himself or herself in the disabled person's position and imagined what such experiences would have been like. In some cases, the people with disabilities are presented as survivors or even heroes for having undergone such 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 pointed to changes in weight, behavior, skills, personality, and appearance.

Managing Appearances. The nondisabled people in this study not only see individuality in the disabled partner, but actively create it by managing the other's physical appearance to downplay visible differences and accentuate individual identities. They sought to present the person to outsiders and to themselves as normal. By paying attention to clothing style and color and being attentive to other aspects of the person's appearance (hair style, nails, make-up, cleanliness, beards for men), they helped construct an identity consistent with their definitions of the person. In the case of Monica, described earlier, her foster parents selected clothes and a hair style 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 is given not only an identity as an "individual," but also 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 recounting the negative reactions to the person's abnormalities by an outsider.

Nondisabled people often expressed pride in the disabled person's appearance. For disabled people who have been institutionalized, many of their partners commented on the significant changes in their looks since leaving an institution. The change had been from institutional clothing, unstyled haircuts, dirty skin, and sloppiness to a physical self more nearly like 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, feelings and motives, a biography, and appearance are all individualized aspects of a person. By highlighting the severely disabled person's personal attributes, the nondisabled people in our study accept and include their partners rather than rejecting and excluding them from the mundane rounds of normal, everyday life.

Viewing the Other as Reciprocating

In order for somebody to be thought of as a fully competent participant in a relationship, they have 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 receiving as much as they give. According to exchange theorists, people with equal resources (some combination of, for instance, social worth, talent, material

resources) tend to form enduring relationships. When one person does not have much to offer, the relationship suffers from disequilibrium, which is experienced as stressful. 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 paper.

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 saw their relationships or their disabled others. They defined the person with a disability as reciprocating or giving back something important.

Joe Bain, who, along with his wife and two children, shares his home with three severely disabled young men and a young woman, told why he lives with disabled people: "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 of the people in this study are so exuberant, most mentioned 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 said 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 mentioned how disabled people expanded 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 discussed. Some nondisabled people were philosophical about what the person with a disability gives them. A few said they believe that the relationships with severely disabled others have made them better people. A mother of a six-year-old boy who is severely retarded and has hydrocephaly said, "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, stated, "He made all of our children and ourselves much more caring, much more at ease with all handicapped people."

Clearly the nondisabled we spoke to felt that they know their severely disabled partners intimately. They said 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 reported from their relationships is a sense of accomplishment in contributing to the disabled other's well-being and personal growth. As with personal appearance, the nondisabled people saw positive changes occurring in their disabled loved one or friend. Although the progress might be considered minor by outsiders, something they would not notice or understand, for the nondisabled person in the relationship it is significant. For example, one person who is in a relationship with a nonverbal severely retarded woman described how she had told the woman, Susan, to brush her teeth. Commenting on how, when Susan came out of the bathroom she was holding a toothbrush and tooth paste with the cap stuck, she explained, "That is asking for help; that is communication. She never would have done that five years ago; she wouldn't have even gone for the toothbrush and toothpaste!" Regarding a severely disabled woman, another woman said,

"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

People belong to groups and are part of social networks, organizations, and institutions. Within these social groups, individuals are given and assume particular social places. 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 role. It is also a matter of being defined as an integral part of the group or social unit. Roles are particularized for each social unit and personalized by each occupant; there is a personal dimension to roles. Through playing particular social roles, social actors are defined as being part of the human community, "one of us."

The nondisabled in this study defined their disabled partners as full and important members of their social units; hence, they 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 paper involve two people, one disabled and one not, most involve people who have disabilities within families. In families, in particular, the disabled person is likely to be viewed as a central member. The person is not simply son or daughter, but "my son" or "my daughter." A foster parent of several children with severe disabilities, who could not have children of his own, said, "This gives us our family." In another foster family, the mother described how her natural son sees the foster child: "He's the little brother he never had." In short, the family would not be the same family without the disabled person.

Second, the nondisabled people defined 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, members of a family coordinate getting up, taking showers, getting breakfast, accompanying each other on important occasions, preparing for holidays, going on vacation, having birthday parties, and many other joint activities. 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 and to others that he or she is one of them. As a foster parent of two people with severe disabilities explained, "We bring them to all family gatherings. My sister said we could hire a babysitter 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, they have a vehicle to be included in the social web that defines community membership. The mother of a profoundly retarded six-year-old girl who had 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 paper 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 (1973:221) writes, "As an actor on the social scene, I can recognize my fellow-man not as 'something,' but as 'someone,' a 'someone like me'." 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 paper striking is that they are directed toward people who have often been denied their humanity by being defined as non-persons (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 (The 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, and we, are human by including, by accepting them rather than separating them out.

It is easy to dismiss the perspectives described in this paper. One might argue that the nondisabled people are deceiving or deluding themselves when they attribute these qualities and characteristics to people with severe and profound mental retardation and other disabilities. For example, some might consider the belief that such people can and do think as outlandish. Yet it is just as likely that those who dehumanize people with severe disabilities, dispute their human agency, and define them as non-persons 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 and who others, as well as we, are depends upon our relationships with them and what we choose to make of us.

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