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AUTHOR

Lutfiyya Zana Marie

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ABSTRACT

This paper examines the nature and extent of friendships between disabled and nondisabled people through a study of several pairs of such friends. Indepth interviews examined such questions as how the individuals met, the history of their relationship, how each individual perceives the friendship, and how this friendship compares to other relationships each person has. First, the four friendship pairs are described and characteristics of both the disabled and nondisabled partners summarized. Next, stages of the friendships are identified including meeting, initiating the friendship, becoming friends, and maintaining the friendships. Also discussed are the nature and number of other involvements, critical events, and the role of the disability. Meanings attributed to the friendships include that of "parent", of co-worker or mentor, and of volunteer. Stressed by informants is the importance of mutuality, of practical assistance and emotional support, of "breaking the rules," and of enjoyment. Also considered are responsibilities assumed by the nondisabled informants and the voluntary, private, and exclusive nature of friendship. The final section summarizes the major findings in the areas of: effects of living in the human service world; enhancing the possibilities for friendship between people with and without disabilities; and avoiding the romanticization of these friendships. Includes 76 references. (DB)

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Center on Human Policy

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April 1990

Zana Marie Lutfiyya
Center on Human Policy
Syracuse University
200 Huntington Hall, 2nd Floor
Syracuse, NY 13244-2340

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TABLE OF CONTENTS

SECTION I:	"A HOLDING IN THE HEART": PERSPECTIVES ON FRIENDS AND FRIENDSHIPS	1
SECTION II:	THE INFORMANTS	8
SECTION III:	"THE IDEA OF A JOURNEY": MOVING FROM THE INTRODUCTION TO THE FRIENDSHIP	27
SECTION IV:	THE CHARACTERISTICS OF FRIENDSHIP	47
SECTION V:	FRIENDSHIPS BETWEEN PEOPLE WITH AND WITHOUT DISABILITIES: SUMMARY AND IMPLICATIONS	64
	REFERENCES	78
APPENDIX A:	METHODOLOGY	86



SECTION I: "A HOLDING IN THE HEART": PERSPECTIVES ON FRIENDS AND FRIENDSHIPS

The interest in the nature and extent of friendships between disabled and nondisabled people is a relatively new phenomenon in the fields of special education and rehabilitation and appears to be a logical extension of the development of community based human services for people with mental retardation.

In recent years, attempts to establish regular contacts between people with disabilities and typical community members have increased (Bridge & Hutchison, 1988; Cormier, Grant, Hutchison, Johnson, & Martin, 1986). The goal of these interactions is to encourage close ties between disabled and nondisabled individuals and rests on the belief that such freely given relationships will promote a more complete assimilation of disabled people into society and extend to them the benefits of membership in that society (Johnson, 1985; O'Brien, 1987a; Reiter & Levi, 1980; Taylor, Racino, Knoll, & Lutfiyya, 1987; Wolfensberger & Thomas, 1983). Being recognized as a member of one's community indicates the acceptance and respect accorded that person, and represents the current understanding of being fully integrated. A member can call upon the community for certain benefits such as acceptance, assistance, and protection. In turn, members are expected to offer some sort of contribution to other members or to the community as a whole (Ignatieff, 1985).

These beliefs represent a divergence from the assumption that the most likely people to be friends with people with mental retardation are others with the same impairments. Whether consciously stated or not, many researchers assume this to be true and then examine the extent of such relationships, and the factors that may



influence the development of these relationships. Studies on the adjustment of people with mental retardation into the community--how well they fit in--often focus on these friendships to the exclusion of friendships with nondisabled people (Halpern, Close, & Nelson, 1986; Landesman-Dwyer, 1981; Landesman-Dwyer, Sackett, & Kleinman, 1980).

Helping someone to meet people and make friends can be difficult. Formal programmatic efforts to do so can contradict our society's notion of how relationships are formed. We do not like to think of ourselves as reliant upon arranged marriages or strict kinship obligations.

Planned introductions between people who might be "good for each other" do occur, such as those between potential business associates. There are also businesses which attempt to introduce compatible people who should "hit it off" with each other.

For many of us, arranged introductions may seem an artificial and heavy-handed way to establish relationships. And yet, some human service providers are trying to do just this in order to surround people with disabilities with a number of friends and close ties (Forest & Snow, 1983; Mount, Beeman, & Ducharme, 1988a, 1988b; O'Brien, 1987b; O'Connell, 1988; Strully & Bartholomew-Lorimer, 1988; Wolfensberger & Zauha, 1973). These efforts are made in order to overcome the barriers that are seen to prevent more naturally occurring relationships from taking place. There are two broad perspectives about what the major obstacles or barriers to naturally occurring relationships are between people with and without mental retardation. Both perspectives emphasize the lack of opportunities for socialization into the mainstream of society. The first perspective focuses on the necessity of



learning "prosocial skills," while the second perspective revolves around the effects of societal discrimination.

When the move to deinstitutionalization began, it was observed that many individuals with developmental disabilities did not know how to behave appropriately in a wide variety of social situations. In order to ready such individuals for a more typical life in the community, professionals believed that the inappropriate behaviours had to be extinguished. Once the problem was defined as a lack of social skills on the part of people with disabilities, a variety of teaching techniques and strategies was brought into play. Systematic efforts began in order to rid individuals of undesirable behaviours. Proponents of this perspective today suggest that disabled individuals will acquire the skills needed to fit successfully into the everyday world around them.

The social skills perspective rests on certain assumptions. While nondisabled individuals are seen as needing the chance to develop the skills that will increase their interactions with people with disabilities, the emphasis is on the disabled person to learn the necessary social skills to fit in. Second, people with disabilities need to acquire certain skills in order to interact with, get to know, and befriend others in meaningful ways. Third, especially for people with severe disabilities, these skills will be learned best through specialized instruction and structured interactions, and in situations where the nondisabled interactors are "responsive to social bids from handicapped people" (Breen, Haring, Pitts-Conway, & Gaylord-Ross, 1985, p.50).

The socio-cultural perspective shifts the focus away from the posited deficits of people with mental retardation and other disabilities to the response of a society to those individuals who are seen as different. According to this perspective, society



enforces its rules and norms and those who do not or cannot comply are seen and treated as deviant. It is the society that defines and creates deviant behaviour.

This perspective has been extended to the study of mental retardation. Even when individuals with disabilities live within a geographic community, the perception of and response to their deviance may result in a life that is separate from that of the so-called community. Because of their perceptions of people with disabilities, members of a given society discriminate against them and prevent them from assuming what should be their rightful position as citizens and members of the community.

Implications of the Two Perspectives

Proponents of both the social skills and the socio-cultural perspectives agree on common goals. The first is to establish more and more varied, freely given interpersonal relationships between people with and without disabilities. While there are not many such relationships documented by researchers, it cannot be denied that warm, reciprocal relationships between people with and without disabilities exist (Bogdan & Taylor, 1987; O'Connell, 1988; Taylor & Bogdan, 1989). People holding either of these perspectives think that such friendships are desirable, if not essential to the well-being of people with disabilities (Durner, 1985; Meyer, McQuarter, & Kishi, 1985; O'Brien & Lyle, 1987). Second, both perspectives view focused efforts as necessary to facilitate the desired relationships. But it is in how to best achieve the goal of increased friendships where the two perspectives differ. In the social skills context, the burden of change is placed upon the individuals with disabilities. The



emphasis is on the systematic instruction of people with disabilities and structured opportunities to practice their social skills. Within the socio-cultural approach, the burden of change is placed more on the society at large. In this framework, the society as a whole must begin to change and to accommodate itself to individuals with disabilities. Along with the recognition of the importance of such relationships come, depending on the approach, teachers and "integration facilitators" or "bridge-builders" (Mount, Beeman, & Ducharme, 1988b; Seward, 1987).

Little research, however, examines first hand accounts of actual relationships between nondisabled and disabled individuals. What is available is about a dozen case studies and testimonials that describe either the author's own friendship with a disabled person (Edwards & Dawson, 1983; Forest & Snow, 1983) or the friendships of which the author has direct personal knowledge. For example, Strully and Strully (1985a,b) and Strully and Bartholomew-Lorimer (1988) report on the friendship between Shawntell Strully and her friend Tanya. Perske (1988a) provides brief descriptions of several friendships between disabled and nondisabled individuals. But despite the current interest in this area, little is known about the meaning of these relationships to both partners (Kaufman, 1984).

The Research Question: Learning About the Friendships Between Disabled and Nondisabled People

Given the subtle segregation and outright exclusion of people with disabilities from our communities, how do people with disabilities and typical people meet, spend time with each other, and form friendships? From an earlier study (Lutfiyya, 1987), it appeared that the development of a friendship between a person with disabilities and



a nondisabled person was a dynamic and ongoing process of definition where both parties assumed an active role. What is not well understood is the specific meaning of this process of creating a personal relationship, and of the relationship itself to the participants. Do they share a common definition of friendship in general, and of their specific relationship with each other? What circumstances encourage and increase the chances that friendships will occur and continue over time? What factors come into play as a friendship is mutually acknowledged by the two people involved?

In order to learn more about the development of friendships between people with mental retardation and nondisabled individuals, I conducted indepth interviews with several pairs of friends. I also collected data by spending time with each pair of friends in activities that they typically did together. Each pair was made up of one person labelled mentally retarded and one nondisabled person. Both people in each pair identified themselves as friends with the other.

I tried to gather information to answer three broad sets of questions. The first set of questions reviewed how the two people met and what the story of their relationship was over time. This information established a chronology of events shared by the two individuals, and identified the activities and/or experiences they found crucial in getting to know each other. The histories of each relationship are presented. This is followed by a discussion on the process of establishing and maintaining a friendship.

The second set of questions tried to elicit information on how each person perceives their friendship, what it and the other person means to them. For the third area of investigation, informants compared this particular friendship to others they are



involved in. Initially, I wanted the informants to describe their typical styles of getting to know others. I thought that most people would meet and get to know others in certain ways, relying on patterns of interactions that are comfortable to them. Instead, the informants talked less about how they met and established friendships and more about the meanings of these various relationships. I learned about what they did with their friends, family, and colleagues, and what these relationships meant to them.

In Section II, I describe the informants of this study. In the third and fourth section, I present the themes about the characteristics of friendships that emerged from the interviews with the informants. In the fifth section, I review the implications of the findings of this study.

Little is known about the nature and meaning of friendships that do exist between nondisabled individuals and those with disabilities. In this study I tried to learn about these friendships directly from the people involved. By doing so, I hoped that their words, stories, and perspectives would contribute to our understanding about the creation and maintenance of affectionate bonds that exist between individuals.



SECTION II: THE INFORMANTS

When asked to describe their friendship, most of the informants began with a chronology of events. They told me how they had met each other and how the friendship developed and changed over time. This first layer of friendship is descriptive and at the level of introduction (i.e., we met at work, we belong to the same church; we both write). In one sense, this is the "public" part of the friendship -- information easily available to outsiders. At this level, both partners generally share the same understanding of what is going on or taking place within the friendship.

. In this section, I outline the public story of the friendships that I studied (all of the informants are referred to by pseudonyms). This is done in the form of brief, descriptive narratives.

Shirley and Kitty

Shirley and Kitty met each other at the office where they work. Kitty struck up a conversation with Shirley when the latter came in for a job interview. Once they began working in the same office, Kitty showed Shirley how to use the phone system and where to find things in the office. Kitty also invited Shirley out for lunch. As Shirley recalled,

At my other job I always went to lunch with the people that I worked with. When I first started here a lot of people didn't have structured lunch hours so when it came noon, nobody left. I got up and left and I went like about



a week without anybody to go to lunch with, and I felt kinda weird. ...She [Kitty] offered and so it was just her effering and that's how it got started.

During those first few months, Kitty and Shirley became friends. Now at work they have lunch together and Shirley has introduced Kitty to Mexican and Chinese food. They go shopping on occasion and bought plants and knick knacks for their work areas. Kitty spends time at Shirley's house with her husband and young son. Kitty has gone to the son's third birthday party and usually buys small gifts for him when she travels. Both women like to have a good time and they are involved in the planning for office parties and other celebrations.

About a year ago, Shirley was promoted to the position of office manager. Part of her job is to supervise Kitty directly. On her own initiative, Shirley started expanding Kitty's job and teaching her the skills that she needed. Kitty started working at the office on a part-time basis doing the xeroxing. She still works on a part-time basis, but her duties include maintaining the computerized mailing lists for the office and occasionally answering the phones. Shirley was responsible for teaching her how to do these additional tasks. Being able to teach Kitty new things is a source of satisfaction for Shirley.

She's so eager to learn that I get excited showing her things...you know I get a lift out of that.

This satisfaction is easy to observe. I came to the office once and saw Kitty sitting at someone else's desk, using the computer. Shirley was standing about 10 feet away, fists clenched, rocking back and forth slightly on the balls of her feet, watching Kitty



intently. As Kitty continues at the computer, accomplishing her task, Shirley nods to herself, saying, "Yes, yes, YEAH!" She breaks into a hop, skip and a jump over to Kitty. "Yes...you got it! I saw you get it. All right!" The two of them are laughing and hugging each other, relishing Kitty's success.

Kitty still lives at home with her parents who are now in their 70s. She attended the local parish school for Kindergarten and Grade 1, but was then transferred to a special education classroom that was located in a regular public school. She remained in special education classes until she was 21 when she left with a school attendance certificate. Kitty was subsequently placed in a sheltered workshop where she stayed for 14 years. Fed up with the assigned jobs and lack of work, Kitty sought help to locate what she called a "real job." A friend helped her secure the clerical position that she now holds. Shirley's family travelled a lot when she was growing up, but they eventually settled in the Syracuse area. She is now married with a 3 year old son and most of her free time is spent with her family and people she has met through her husband. One of her sisters suffered brain damage after a car accident at the age of 3, and Shirley has helped run a few recreational programs for adults with developmental disabilities. Although she and Kitty had never met prior to working at the same office, they learned that they know quite a few people in common -- those involved in the programs that Shirley used to run.

Today Shirley has assumed certain responsibilities for Kitty. These revolve entirely around helping Kitty do more at work, increasing the number of hours she works each week, and eventually, helping her become self-supporting. As Shirley states,



I also have taken it upon myself to worry about her as far as her livelihood...say if something happens to her parents...having her get the skills so that she could eventually go out and get a full time job and not having to rely as much as she does on other people. ...it's just something that I think about and I think that's one of the reasons why I'm motivated to show her different things....

To this end, Shirley has encouraged Kitty to take courses at a local community college, and even talked to the instructor of the course to see if it would be suitable for Kitty. Shirley tries to review each lesson with Kitty and gives her practice drills between classes. Shirley arranged for the company where they both work to pay Kitty's tuition for one of these courses. Shirley has also gotten Kitty to attend several in-service training events offered by the company where they work. Perhaps most significantly, Shirley gives Kitty the opportunity to use the office's word processors in order to complete her work.

John and Joe

John is a middle-aged man who runs his family auto refinishing business. Several years ago, recently following his divorce, John's parish priest suggested voluntary work to John. John saw the three men with disabilities from a group home in the congregation, and asked for an introduction. He thought this might be a good way to become less self-absorbed in his own problems. As John said,



Well, I saw these handicapped guys come to church every Sunday. I didn't know them, but then I noticed them....I asked the priest...I said that I wanted to help someone, and I was thinking of those guys.

The priest introduced John to one of the men with disabilities, Joe. Joe needed a sponsor so that he could complete his religious education and join the church. John agreed to be his sponsor. Joe has Down Syndrome and lives in a group home with five other people with disabilities. The two men started going out for breakfast together after Mass. They rode around on John's motorcycle. In fact, John tallies up the time that they have known each other by how many motorbikes he has owned since meeting Joe. John went over to Joe's house for a number of meetings about Joe, parties, and other social events.

This twosome expanded when John realized that two other men in Joe's house were anxious to join them. According to John,

I can't remember exactly. I probably picked Joe up for breakfast one day and saw those two guys looking remorseful 'cause they weren't going....

With Joe's permission, John invited Peter and Tom out to breakfast one Sunday and the pair became a foursome. This pattern was established as the four men attended church together and went out to different diners afterwards for breakfast. John admittedly enjoys spoiling the "Three Musketeers," (as he refers to Joe, Peter, and Tom), by stuffing them with food, flirting on their behalf with the waitress, and so on. Things changed again when John started dating Debbie. Their



first date was a Syracuse Chiefs baseball game -- and all the "guys" came along. As

John tells the story now, he knew that his bachelor days were numbered when Debbie

and the guys made such a good first impression on each other.

The group expanded to include Debbie. John and Debbie subsequently married and had a daughter, Emma. Debbie and John happily showed me photographs from their daughter's christening. One shows Joe holding Emma with Peter and Tom standing next to them. During the first set of interviews, the three men were very much a part of John and Debbie's family life. They saw each other every Sunday at church. Once a month John and Debbie attended a potluck dinner at the group home where the men live. They got together at Christmas to exchange gifts. Joe telephoned John every evening for a chat and to catch up on the day's happenings.

Throughout all of the "expansion," John insisted that he and Joe were still "palsy-walsy" and close with each other. This fact was recognized at the group home where Joe lives. John is invited only to Joe's annual meetings and not to those for Tom and Peter. A staff person close to Joe at the home did say that Joe had no choice but to accept the inclusion of Tom and Peter. According to her, that was better then going on no outings at all. But Debbie also acknowledges the relative closeness of Joe and John. She talked about the difficulties she had with Joe when she and John were first married. She likened them to two drinking buddies, no longer able to spend as much time gallivanting around with each other as they had in the past. John told me how he helped Joe spend time with his girlfriend, disobeying the requests of the staff at the home where Joe lives. Many of his stories about Joe



described the shenanigans that they have been up to. Along with sneaking visits to the girlfriend are tales of falling off the motorbike, flirting with the waitresses in the diners they frequent, and so on.

John and Debbie were full of stories about the three disabled men. They spoke about them with obvious delight and affection. But Debbie does chide John for the way he treats Joe, Peter, and Tom. She feels that he treats them as children and does not expect appropriate behaviour from them. As an example, she mentions the way Joe used to sit next to John, with his arm draped around John's shoulders. John answers that he wants to be nice to the guys; there is no harm in anything they do, and that they should be spoiled once in a while.

In some ways, John does patronize Joe. One evening when I was at John and Debbie's house for an interview, John told me how Joe used to call him every evening at about 8:00 p.m. John eventually asked the staff at the group home to limit Joe's calls to every other night, which they did. As John tells it, Joe never has much to say and asks John the same questions during every call. During my visit, Joe does indeed call, and John hands me the remote telephone so that I can listen in on the conversation. As Joe progresses through his stock questions, and John is giving his routine responses, John winks at me to confirm his earlier remarks. About halfway through the call, John finally tells Joe that I am listening in. The three of us chat briefly. As we hang up the telephones, John happily tells me, "I told you so," referring to the predictability of the conversation with Joe.

Seven months after this telephone conversation, many changes have occurred. Debbie and John, expecting their second child, sold their downtown apartment and



bought a house in a small town several miles away. A staff person at the group home where Joe lives could not remember when Joe and John had last gotten together. Joe has spoken to John on the phone once or twice since the early spring and John missed Joe's birthday this summer — for the first time since the two men met.

Christie and Joan

Christie is an English professor. An active feminist, she is involved in many projects that support women's causes. One of these was to teach a creative writing class to older women. The goal was to enable these women to write their own life stories and analyze some of the significant events in their lives. A year and a half ago, an acquaintance approached Christie and asked her if she would conduct such a class for adults with developmental disabilities. Christie readily agreed and the two women started setting up the course. An agency that offers evening and weekend classes to disabled adults agreed to sponsor the course, and it began a few months later.

A couple or weeks into the semester, Joan showed up at the class. She is in her mid 30s and still lives with her parents. Like Kitty, she attended special education classes in the regular public school system. Joan is well known by several of the local human service agencies. She has approached them in the past, often with unhappy results. In the past, she has spent one or two nights in a given residential facility (e.g., a group home, supported a partment, or a mental health hospital) only to return to her parents' home. This pattern continues with her forays into the world of



work. In addition to these experiences, Joan visits an incredible array of psychologists, psychiatrists, physicians, and other medical professionals. A capable woman in many ways, Joan sets up and drives herself to a plethora of appointments and meetings in order to receive therapy and/or talk about her most recent predicament. In between medical appointments and meetings, Joan does chores around her home and runs errands for her parents who own their own business.

Both Christie and Joan are unconventional women. Christie has been married twice, raised two sons and put herself through graduate school. Sometime before our interviews, Christie had become involved with another woman. During the course of our interviews, she and her lover were looking for a house to move into. Establishing this household was clearly her preoccupation that summer. Through her poetry and other writings, as well as her political involvements, Christie is known as a radical, left of center activist.

For all of her involvement with the medical and human service worlds, Joan is not a passive patient. She calls her own meetings, sets the agendas, switches doctors, and openly questions their findings. Joan possesses definite ideas about what she wants and should receive. Two winters ago, she led a spirited fight with the state's Department of Social Services in order to qualify for and receive what she referred to as a disability pension. Familiar with a variety of drugs and their effects on her, she told me how she haggles with her doctors to reduce or change her prescriptions. Loud and determined, Joan seems to manage by getting her own way or making her own way. Joan is the kind of person who causes others to roll their eyes heavenward at the mention of her name.



Unaware of this reputation, Christie met Joan the evening that Joan first showed up for the class. Christie recalled that at first Joan was quiet and closed, not sharing her feelings. As she continued to come to the class, Joan began to open up and talk about her feelings and frustrations. Classmates tried to offer advice and support. But Christie felt Joan truly started to open up when she tape recorded some of her past experiences. Christie tried to help Joan,

get around the stuff that she was presenting...to help her focus..on the things about her-self that were more positive...so that she could get a better sense of who she is.

Through this encouragement, Joan told Christie that she liked to sing in her synagogue. She invited Christie to a Passover service where she would be singing. Christie went to the service and had lunch with Joan and her parents afterwards. Since then, Joan and Christie speak frequently over the telephone and have gotten together two or three times. (When I first interviewed them, they had known each other 6 or 7 months. The class had ended 1 month before the interviews began). As Christie got to know Joan, she began to see her as a shy and capable woman. She credits Joan with a good sense of humor and suggests that these are things that most people don't know about Joan. Certainly Joan's reputation does not contain words such as shy, capable, and humorous.

In many ways, Christie's understanding and description of Joan is quite different from her reputation. Christie acknowledged that most people think Joan "comes on strong" and will try to take advantage of certain situations in order to talk about her problems. When the two talk, Joan, "usually starts out saying what's wrong



in her life." These problems include fights with others, moving out of her parents' house, upcoming social events, the latest appointment with her psychiatrist, and so on. For a while, Joan went through what Christie called "a suicidal period." She would tell Christie that she was thinking about taking an overdose of pills with some alcohol. "I can't continue, I can't stand living like this anymore...I want to kill myself" are among the things that she would tell Christie. Christie's response to this was to,

not take it up. I just decided not to focus on that.... And I just say, it's hard, I know. It's real hard...I just try to tell her that I'm sympathetic.

Christie describes herself as a "calming presence" in Joan's life. She asserts that in becoming friends with Joan, she has "taken on a big responsibility." When Joan's mother asked Christie if Joan could rent a room in Christie's new house, Christie realized that she would have to "set limits in my relationship with her...I am going to have to be clearer of the kinds of things I can afford to do, in reaction to her."

Preparing for a new semester, locating a new house, and moving in with someone are Christie's current preoccupations. Her new housemate is not keen about Joan's frequent calls each week.

Rhoda and Jim

Jim was a high school student in a special education class. He met Rhoda in November of his junior year. As part of his curriculum, he worked as a carpenter's helper at the New York State fairgrounds. But he had some difficulties in completing



the necessary work properly. The school district assigned him Rhoda as a job coach. Her job was to help Jim learn and complete his work in an acceptable manner. Jim had been working at the fairgrounds for 2 months when Rhoda appeared. He found it difficult to work with Rhoda as he resented the implication that his work wasn't good enough. They found those first few weeks difficult.

Just before Christmas, Rhoda learned that Jim was living with foster parents, but would be spending the holiday with his mother. Whenever he became difficult at work, she attributed this to the anxiety he must be feeling about the upcoming visit. She changed the way she acted with him.

if he was getting uptight...I would say, "Jim, just ease up..." and that's when he became responsive. Whenever I made a comment geared to his emotional state, that's when he was fine. And he would be less negative toward me.

Over the next few months, their relationship changed. Rhoda described a series of crises that she helped Jim face. The carpenter, Dan, that Jim had worked for at the fairgrounds left to have back surgery. During a confrontation with Jim about not doing his work, Rhoda learned that Jim missed Dan. So she arranged for the two of them to visit Dan at home. She did this because,

I knew that Jim had some emotional needs...so many separations...so with Dan, he didn't know if he was deserted or not.



Rhoda sees this event as the turning point in their relationship. While on the phone with Dan, getting directions to his home, she needed a pen. And while she rummaged in her bag for one, Jim offered her his own pen. Rhoda said:

not only did Jim give me a pen... he clicked it open for me. He held the little piece of paper down....Well, that might not sound like any big deal, but it was to me. Here was this kid who had been really obnoxious and was being helpful.

A few months later, Jim came to Rhoda and told her that he wanted to die and had asked a teacher to kill him. Confused, she confirmed his story and decided that Jim was in fact suicidal. That afternoon, she spoke with Jim and walked him to his school bus. She gave him a box of chocolates, grabbed hold of his arm and told him,

I don't want you to die. And I stood there. And he stood there and let me hold onto him...which he had never let me do before. So we made physical contact, right?

Together, Rhoda and Jim went to see the school psychologist, and Jim got the help that he needed. He later told the psychologist that it was Rhoda and what she had done that changed his mind. Subsequently, the two of them started spending more time together. Jim would visit Rhoda at her home over the summer. They went hiking once a month. After Jim spent a long weekend at her house, he asked Rhoda if she would become his foster mother. Due to her family situation, Rhoda turned him down.



After school ended and Rhoda was no longer Jim's job coach, she looked for a way to legitimize the friendship, especially in the eyes of Jim's foster family. She approached the Citizen Advocacy coordinator and soon Rhoda and Jim were listed as a "match." When school began again, Rhoda used her status as a citizen advocate to attend Jim's individual educational planning (IEP) meetings, meet with his teachers, and so on. She made sure that he stayed after school for tutoring and then drove him home, as he had missed the school bus. At the end of the initial interviews, Rhoda was balancing the time she spent with Jim and the time that she gives to her husband and son. She acknowledged that she often feels that by spending time with Jim, she was taking something away from her family life. But she continued the delicate balance because all three people were important to her. She likened her relationship with Jim as a "close, emotional connection...like an emotional adoption."

Six months later I learned from Rhoda how much has changed for both her and Jim. On a hot, muggy day in mid-July, the two of them had planned to spend a day together in New York City. They had each bought their own plane ticket and Jim wanted to visit the Statue of Liberty. Four days before they were to go, Jim was arrested and held without the possibility of bail. Rhoda first visited him in the city jail on the day they were to have been seeing the sights in the city.

Rhoda refused to tell me why Jim was arrested. She stated that she was honouring his specific request that she not share the details of what happened with anyone. But because he was already on probation, he was held in the city jail until his trial date. Convicted, he was sentenced to 9 months in prison. Rhoda expects that he will be released in 6 months because of his "good behaviour." Rhoda was the



only person who went to all three of his court appearances, and visited him as often as possible in both the city jail and the correctional facility where he was sent to serve his sentence.

At Jim's request, Rhoda arranged for his natural parents and sister to visit him. This included driving them about 80 miles from their home to the prison and then back home again. Rhoda keeps him supplied with cigarettes, magazines, and snacks. She is trying to get counselling provided for Jim and is also planning with others for an appropriate residence for him upon his expected release in January, 1989. As Rhoda described the events of the past few months, she spoke slowly and carefully. She seemed weary more than anything else. She said,

It hurts me a lot the way he is treated. I can't stop him or me from hurting. I still hurt when often he has moved past it....I have my finger in too many tragedies.

Characteristics of the Informants

There are some similarities of experience among the informants that seem worth noting. Overall, the informants received some public education. The level of education ranged from school attendance certificates to advanced college degrees. All of the informants are white and most are middle class. While Joe and Jim's families may be middle class, both men now live within and are totally supported by the human service system. It was difficult to identify blacks to participate in this study as none were nominated to me. It was also hard to identify men without disabilities



who were ir, a friendship with a person with disabilities. Only two men without disabilities had been brought to my attention.

The Informants With Disabilities

The four informants with disabilities have been labelled as being mentally retarded. Three of them, Joan, Kitty, and Jim were discovered and labelled by the school system while they were all in elementary school. Joe's Down Syndrome was identified shortly after he was born. Joe is thought of by the human service system as severely retarded. Despite this, he is familiar with the city's public transportation system and travels by himself across town every day. Joan would even be considered "dually diagnosed" (Racino & Knoll, 1988) as she has been labelled by and has received services from both the mental health and mental retardation systems. But being mentally retarded does not necessarily mean that the informants legal competence has been questioned. Joan has her driver's license and Jim was deemed fit to stand trial and serve a prison sentence.

While all of the informants are labelled as being mentally retarded, it is hard to determine what the term actually means. It is clear, though, that different societal institutions operate with different definitions of the term. While considered mentally retarded at school, at least some of the informants are not considered retarded by the criminal justice system or the Department of Motor Vehicles.

Despite their educational labels, all of these informants went to school. They all attended special education classes in regular public schools and received school attending certificates. In addition to special education, all of the four informants with



disabilities have had some kind of contact with the human service world. All receive Social Security Income (SSI) and Medicaid benefits. Kitty, Joan, and Joe are or have attended sheltered workshops. Jim, Joan, and Joe were placed in a variety of residential facilities, including group homes and supported apartment programs. Individually, the disabled informants have been involved with the mental health, child welfare, family court, and criminal justice systems. On the other hand, with the exception of Jim's prison sentence, none of the four informants with disabilities have ever lived in a large, congregate care facility known as a "total institution" (Goffman, 1961). For all of Joan's, Kitty's, and Joe's lives and for most of Jim's, they have lived in the community. Despite their physical presence in the community, in one way or another, Jim, Joan, Kitty, and Joe have been clients and their lives controlled to a greater or lesser extent by the human service system.

All of the informants with disabilities lived with their families as young children. Both Kitty and Joan still live with their parents today. Jim was removed from his family home when he was about 12 years old, although he has had infrequent contact with them since then. Joe has lived in a group home for the past 11 years and maintained regular contact with his mother until she died several years ago. Today he still sees his father, brothers, and sisters on important holidays.

Finally, three of the informants with disabilities have no obvious physical impairments or stigmata. From their physical appearance alone there is no image of them being disabled. Only by engaging in conversation might one suspect that these individuals have some difficulties in some way.



The Nondisabled Informants

The nondisabled informants have also had varying amounts of contact with the service world. Three, Shirley, Christie, and Rhoda have at least for a while, been identified as "staff people." Shirley ran some recreation programs for adults with mental retardation before she joined the organization where she now works. Christie had a fleeting experience while teaching the creative writing course for individuals with disabilities. This course was sponsored by an agency that organizes social and recreational activities for adults with disabilities. Rhoda continues her work as a job coach for people with disabilities, although she has not worked with Jim in this capacity for the past 2 years.

Interestingly, all of the nondisabled informants talked about or made reference to a variety of personal problems. These references were not made in response to any specific questions on my part, but did come out unsolicited during the interviews. These included their difficulties growing up, and a perceived lack of long-term connections or healthy family relationships. Except for Shirley, the other informants spent a lot of time describing the problems that they live with. John and Debbie openly talked about their history of alcoholism and their involvement with Alcoholics Anonymous (AA). They attend AA meetings and breakfast groups almost everyday, and other AA members constitute a large part of their social world. Christie has married twice and is now in a relationship with a woman. She referred to the oppression in her marriages and the inherent problems in having a relationship with a man.



Rhoda talked about herself as the "child of alcoholics" and carries a lot of unhappy family memories from her childhood. The nondisabled informants referred to these "personal problems" when talking about their relationships in general. For them, who they associate with, the ways that they relate to others is somehow influenced by these historical and/or current personal problems. Shirley did not talk about her personal problems in the same way as the other nondisabled informants. She moved around a lot as a youngster and credits this as the reason she received a poor education and has no long term friends or "childhood chums" as she calls them.

Shirley and Kitty met in the most "natural" or typical circumstances, without a social service agency's involvement. When people work, attend church, and conduct other aspects of their daily lives side by side, the possibilities for friendships to develop are enhanced. In some cases, a facilitator or an introducer may provide the initial impetus, as the priest did for John and Joe. While Christie and Joan were not specifically introduced to each other by an individual, they did met under the auspices of an arranged program. When people are in staff/client roles, as Rhoda and Jim were, it may be difficult for the individuals to establish a more personal relationship. Rhoda and Jim had to transcend these roles in order to begin their friendship. For all of the informants, their friendship grew out of a joint process of defining the other as a friend, and these relationships as a friendship. The next section describes how these individuals came to define themselves as friends.



SECTION III: "THE IDEA OF A JOURNEY": MOVING FROM THE INTRODUCTION TO THE FRIENDSHIP

The start of each friendship was a dynamic process, that the informants were aware had taken place: Over time, two people began to know each other and establish a friendship. Christie neatly summed up this process by describing it as starting a journey together. The metaphor of a journey is certainly not a new one when writing about relationships, but it is an apt one. And the first part of this journey is the chance to meet people, people who may possibly be interesting and interested enough to establish a friendship.

After having met, it was usually the informants with disabilities who initiated the friendship. They literally invited the nondisabled informant out, either for a meal or some other activity. In turn, the nondisabled informants accepted the invitation and reciprocated in some way. The process of creating and maintaining a friendship does not always follow a linear progression. That is, the friendships did not move in a straight path from two people getting to know each other, and then becoming closer as time passed. In such a progression, the friendship can either cool off and/or end, or continue to grow in depth of feeling and intimacy. During the early stages of analysis, I thought that this type of pattern might be the case. I also thought that at least some of the people had serial friendships. These I defined as friendships where a person has one intense friendship which ends, followed by another intense friendship and so on. While some friendships may follow these patterns, it became clear from the data that the course of friendships vary, and do not always move in such a fashion. Rhoda and Jim's friendship did become increasingly stronger over time and



as they faced certain crises together. And John and Joe's friendship appears to have ended. But for Christie and Joan, and Shirley and Kitty, their friendships have continued. While a greater degree of closeness did develop over time in these two friendships, they have not become increasingly more intimate. For these four women, they maintain ongoing contact with a level of closeness not much different than existed when the friendships were newer. Two people can define themselves as friends and then categorize their friendship. These categories include (but are not limited to) colleagues; confidantes; chums, buddies, and pals; companions; and intimates.

Opportunities to Meet

People can take advantage of many opportunities to meet and get to know others. We meet others through our families, neighbours, school/workplace, cultural, civic, and recreational events, church, synagogue. We also come into contact with innumerable individuals simply in conducting our daily affairs -- buying food, getting the car fixed, taking care of our health needs and so on. In our society, it requires an effort to avoid meeting new people.

For some people with disabilities, opportunities to meet nondisabled people are simply lacking. Many possess extremely limited opportunities to take part in activities and events where they can meet their nondisabled peers. We read of adults who did not know what rain was (Rothman & Rothman, 1985), or a woman who had never sat by a lighted fireplace (Bogdan & Taylor, 1982). Even when people with disabilities may be physically present in a community, a variety of circumstances



conspire to keep them apart from their neighbours. These can include program rules and restrictions, poverty, and transportation. Being moved from program to program, facility to facility can also interfere with opportunities to get to know people. As Joan said, "I have been to so many schools, so it was hard to make friends and [get into] cliques," in response to my question about her childhood friends.

Two sets of informants, Kitty and Shirley, and Joe and John, met each other in "regular" places where nondisabled people expect to meet others. Furthermore, Kitty and John were not under any immediate supervision of program staff, so they were not viewed/portrayed as somebody else's "business." Kitty was at her place of employment when she met Shirley, a new co-worker. John met Joe as a member of the same church congregation. For Kitty and John, their presence and participation at church and an office provided them with the opportunity to meet others and pursue a variety of possible relationships.

Joan met Christie by the two of them taking part in a "handicapped only" class at the local community college. Despite this label, Christie challenged Joan in her writing efforts, Joan invited Christie out, and the teacher accepted. Christie's broad definition of her role as a teacher and Joan's invitation helped these two women to pursue and accept a friendship with each other. Rhoda met Jim because she was hired to spend time with him. The story of their relationship is the story of two people who transcend their initial roles and relationship to each other and create a friendship which in turn established a deeper, stronger, and voluntary bond with each other.



Initiating the Friendship

In three out of the four pairs of informants, it was the disabled person who initiated the contact with the nondisabled person, and who set the stage for the beginnings of some kind of relationship. Kitty invited Shirley out for lunch and showed her around the office. These three partners (Christie, Rhoda, and Shirley) were aware that the person with a disability had indeed taken the initiative and started the ball rolling in each of their friendships. This finding confirmed my own earlier experiences with three disabled individuals (Lutfiyya, 1988c).

Becoming Friends

As the two people spent time with each other, these patterns of invitations and acceptances became a series of interactions. Over time, each pair of people established a history of activities and memories. For the informants, becoming friends was a process by which they came to jointly define the time spent with another person as a friendship.

Over time, the specific events may be lost or forgotten (i.e., it was difficult for John to remember how and when he met Joe) but something more than the sum of discrete interactions was created. This became the friendship between two individuals, an abstract thing that nevertheless carried meaning for each person involved, and was also recognized by outsiders as a friendship. Over time, and often imperceptibly, the friendship was shaped, nurtured, pruned, and defined by the two people involved. At least for the two friends, it was difficult to know when a specific set of interactions became a friendship. John remembered that he and Joe "hit it off right away." As



Shirley told me, "Well, then we just became friends." But all of the informants acknowledged that a change had taken place, and that they were in fact friends.

Maintaining the Friendships

Once the four friendships were established, it is most often the disabled person who does the most obvious maintenance of the relationship. These individuals do what might be called the day to day "work" of the friendship. They make the phone calls, suggest possible activities and events, and are most likely to remember holidays, anniversaries, and so on. Christie laughingly told me that she never calls Joan up -- as she never gets a chance to. In return, the nondisabled person provides transportation, occasionally money for activities, logistical arrangements (i.e., securing permission when necessary, material resources) and finally, facilitates interactions between their friend with disabilities and others. For example, John includes Joe in the banter with the waitress at the diner, Shirley introduces Kitty to other staff at training events.

Several other factors helped determine if and how the friendship was maintained. These include physical time, critical events, and the nature and number of other friendships that the individuals are involved in already.

Time. The first and most obvious factor that contributes to the maintenance of the friendships is sheer physical time. The longer two people spend time with each other, doing things with each other, caring for each other and so on, the longer a



joint history they have. Over time, two people come to define themselves as friends, at least in part because of the length of time they have known each other. Others, outsiders to the friendship, also identify the two as a "pair," "friends," and so on.

Each pair of informants had different ways of measuring the time that they had known each other. For instance, John calculated how long he had known Joe by remembering how many motorbikes he had owned that the two of them had ridden on together. Christie calibrates her world according to university semesters, and described events with Joan by relating them to whatever the semester had been.

Nature and Number of Other Involvements. Each of the four friendships included in this study is unique because it is based on ongoing and dynamic interactions between two individuals. For the informants with disabilities, the friendships I interviewed them about are one of the few, if not the only friendship in that person's life. They have far fewer friends than do the nondisabled people, and also have far fewer opportunities to meet others, disabled or not. Kitty has few other friends. She is close to her parents and a first cousin, but she defines these as family relationships and not as friendships. Although Kitty seems to get along with the other people in the office where she works, her only other friend is Sara, the woman who helped her locate her present job. Kitty and Sara now typically see each other only at office related events.

Joe was difficult to interview because he has few words with which to express himself. He simply does not talk very much. In interviews with a staff person from the group home where he lives, someone who has known Joe for the past 5 years, I learned that Joe has no friends outside or inside the group home. He does have



some brothers and sisters whom he sees on holidays. He does see his father, who lives in another state, about once a year. The staff person believes that due to some of his behaviours, Joe turns people, including potential friends, away. Whatever the reason, John was literally Joe's only friend.

Jim chummed around with a few guys when he was in high school. He was also dating one girl for several months before he was arrested and sentenced to prison. But his most intimate and personal relationships were with Rhoda and a couple of his high school teachers, one of whom he called dad. Today, aside from seeing Rhoda twice a week, his natural parents, and an assortment of social workers and psychologists "from the outside," all of whom have seen him only once or twice since going to jail, Jim remains in the company of the three other men on his unit and the correctional officers in the prison. Rhoda is Jim's only friend. Joan has her parents and sister. She is a regular member of her synagogue, and also knows the people at the law office where she works. She hangs out with about six or seven people in her free time, all of whom would be considered disabled. Because she has a car and can drive, she's sought after for certain activities and is often doing something with this group. Despite these social activities, Joan herself identifies only one member of the group, David, as a friend.

Three of the informants with disabilities have reputations as being difficult and unlikable individuals. Jim was seen by some of the staff in the apartment program as being a difficult person to work with. Rhoda mentioned that Jim was "a real ornery kid" when she first met him and that it was hard to break through that facade of his. The staff person in Joe's group home expressed surprise that John would want to



spend time with Joe, or in fact that anyone would even like Joe. And Joan had certainly gained a reputation among service providers as being an uncooperative person. It cannot be over-emphasized that while these friendships are but one of many friendships for the nondisabled informants, they are unusual for the informants with disabilities. These friendships are unusual for their sheer existence.

Critical Events. During the course of the four friendships, certain events took place that served the function of helping the partners examine and refine their understanding of this friendship to each other. These important events or "defining encounters" (Wiseman, 1986, 1987) served both as a way for people to mutually define themselves as friends in a friendship, and to define the nature of their friendship with each other. Consciously or not, these critical events and the informants' response to them helped to broaden and deepen a friendship or to narrow it. These critical events were usually the result of a crisis or simple reflection. Because friends do not progress through this process of becoming friends and defining the nature of their friendships in the same ways, there is a range in the closeness between people who are friends with each other.

The types of events that turn the defining encounters of the friendships differ between the informants. For the people with disabilities, their general life experiences and lack of other friendships and relationships resulted in a number of crises and a limited number of personal resources with which to face these situations. They find themselves needing assistance and support, and have relatively few people



to call on. For the nondisabled informants, the critical events were what might be considered normal life changes, such as moving, becoming involved in a serious relationship, and getting married.

The following examples illustrate the types of critical events faced by the nondisabled informants. For Christie, establishing a new household took up most of her time and energy when she was not working over one summer. This in itself might not have seriously affected her relationship with Joan. But the fact that Christie's roommate was not willing to accept Joan's many calls each day meant that Christie had to make a choice between the demands of two relationships. Christie decided to limit her telephone contacts with Joan.

John has gone through many changes since he first met Joe. He met and courted Debbie, they married and subsequently had a child. More recently, with a second child on the way, they bought a house and moved to a nearby town. At each of these junctures, John faced increasing demands on his time and loyalties. While friendships are often affected when one friend starts dating and/or marries, John was able to include Debbie in his friendship with Joe. It seemed that the move out of town, and not seeing each other at church each Sunday resulted in the two men not seeing each other for almost a year. Rhoda has also limited her contact with Jim as she balanced her family's needs with his. She turned him down when he asked her to be his foster mother, and she did not have him to her home every weekend as he had asked.



What constitutes a critical event is somewhat different for the informants with disabilities. At times they need assistance and support, and it is often their family nondisabled friends and acquaintances that they turn to for these things.

An example of the critical events that Jim and Rhoda have faced included Jim's suicide threat, and Jim asking Rhoda to be his foster mother. In response, Rhoda had organized services and resources for Jim, gotten other people to make commitments to him (i.e., a place to live, people to live with, a possible job). Rhoda and Jim have deepened and expanded their friendship over the course of time and events. Whenever Jim has faced a difficulty, Rhoda turns it into an opportunity to do something with Jim, or on his behalf. The critical events in Joan's life have also included a suicide threat and a period of depression.

On the face of it, Shirley and Kitty have not faced any obvious crossroads where they had to make a decision about their involvement with each other. Perhaps the only instance was when Shirley received a promotion and had the chance to redefine her relationship with Kitty once she was Kitty's supervisor at work. Shirley used her position and influence to try to increase opportunities for Kitty at the job and at work-related training events.

Disability and Friendship. While these friendships fit into the typical pattern and range of the nondisabled informants' friendships, this is not to say that these individuals deny or ignore the impairments of their friends and fail to acknowledge that it plays some role in their friendship. That is, the disability is not denied but



accepted and accommodated in certain ways (Bogdan & Taylor, 1987). All of the nondisabled partners (at least in the early stages of the friendship) saw their friend's disability as a potential difficulty or a problem in some way.

For example, Shirley recognized that it meant that Kitty takes longer to learn things and that repetition of instruction and practice is necessary. As she told me about their first meeting, "We started talking and you know, obviously it occurred to me that she did have some difficulties." Shirley reviews the lessons from Kitty's night classes with her, and occasionally gives her practice drills to do on the typewriter or word processor. As mentioned before, Shirley also quietly helps Kitty with the various office machines, decorating her desk, and getting Kitty out to staff training events, office parties, and so on. Kitty's disability has meant lower expectations held of her by others. This was especially true for the several years that she was at the sheltered workshop. Today, Kitty is not used to working an 8-hour day, having never had to do so. Shirley is consciously trying to build up Kitty's stamina by slowly getting her to increase her hours.

Shirley had also given Kitty some pointers on how to interact appropriately with her co-workers. Shirley recognizes that Kitty is, in her words, a "people person," and removed the divider that separated Kitty from the other secretaries in her office. Kitty was in the habit of joining conversations with people, and to Shirley's mind, not always appropriately. In these situations, Shirley began to pull Kitty aside.

You know, I told her, if it doesn't look good for you when you come out...if you really think about them and it's none of your business, you stay over in your little corner of the



world. And I said if it is something that you are really interested in and you have some comments that are of interest and are valuable, then go and do it.

As another example, Rhoda has played a key role in organizing resources and facilitating opportunities for Jim, recognizing that he could have difficulty in doing so himself. She made sure that he did his homework while he was in school. Concerned about his naivete and lack of judgment, she was blunt with him when she described the possibilities of prison life for good looking young men. And Rhoda began organizing supports for Jim's eventual release on the day that he was convicted. Throughout her efforts on Jim's behalf, she acknowledges his desire not to be labelled or thought of as retarded or disabled in any way.

"She's Like a Daughter to Me": Friendship has Many Meanings

In this study, it was easier to ascertain the perspectives of the nondisabled informants. Generally they were more articulate than their counterparts with disabilities. The nondisabled informants were both more clear and self-conscious about their categorization of the friendship studied and its comparison to their other friendships. While each of the four nondisabled informants refer to their relationship as a friendship, they all categorize this particular friendship in certain ways. The categories that emerged included that of parent, co-worker, mentor, and volunteer. Some of the meanings attributed to their friendships by the informants included more than one category.



Parent. It is not unusual for friends to compare at least some of their friendships to family or kin relationships. This comparison acknowledges the closeness that the friends feel with each other, and is often made when the two friends want to describe this closeness to an outsider to the relationship. As Rubin (1985) notes, "the idea of kin is so deeply and powerfully rooted within us that it is the most common metaphor for describing closeness" (p. 16). Bogdan and Taylor (1987) have also found examples of this comparison of friendships between disabled and nondisabled individuals to a familial relationship.

For the friends involved, such a comparison may provide legitimacy for a friendship that may in some ways be viewed as unusual by others. The perceived atypicalness of the friendship may come from a number of sources -- disparities in age, gender, intellect, education, and background. By defining a friendship that might otherwise be viewed as unusual or even suspect as a kin relationship provides a socially acceptable context for the friendship. As an example of this phenomenon, Rhoda told me that some people, including Jim's foster parents "wondered" about her friendship with Jim, implying that it was viewed by some as possessing romantic and/or sexual overtones. To me, Rhoda dismissed this notion with a shake of her head and the assertion that Jim was like a son to her. She took it upon herself to teach him domestic skills, follow his progress at school, make sure his homework is done, provide transportation, and chaperon visits with his girlfriend. Rhoda located and secured Jim's acceptance into the apartment living program. She attended all of his court appearances and has visited him weekly while he has been in prison. She has found a place for him to live once he is released, and located a possible job for



him. Rhoda is the one constant and consistent person in Jim's life and provides him with a great deal of emotional support. Although she is frustrated at the way he takes her for granted, she acknowledges that such a response is justified. She said:

But heaven help me...he does not have to call me on the phone, he knows that I'll be there. On the other hand, I maintain it. I say I do.

The unconditionality of her love for Jim is made poignant when she tells how, "he can give little things...presents...but can't give of [himself]. Maybe its because he is so fragile." But Rhoda's friendship with Jim remains. She is the mother that he never truly had. She shrugs her shoulders and concludes, "we're related, spiritually if not physically."

Christie had little difficulty in defining her friendship with Joan, and comparing her friendship with Joan to having a daughter.

That's nice for me because I always wanted one, I wanted a daughter, and I think that to some extent for me, women students are like that...so I see Joan in that way.

Christie is clear that while she defines Joan as a friend, "...I'm not using the term as I would for a peer...so it's a more limited sense of friendship." She compared her friendship to Joan as a teacher/student one in which the differences of age and experience preclude the "sense of equality" necessary in her mind for a peer friendship. But according to Christie, a few women students over the years have initiated a closer relationship with their teacher that extends beyond the parameters of the classroom and semester:



And there are always connections with these women that make it really positive for me...these women's lives are running parallel to mine. Y'know, I can see something about their journeys that comments on mine.

Christie broadly defines her role as a teacher. This allows her to be a mother/mentor in some ways to the younger women whom she finds interesting and intellectually active. For Christie, this handful of women students, including Joan, are the daughters that she never gave birth to. She enjoys making a contribution to their development and in turn learns from them. By placing Joan in the midst of these special student daughters, Christie does not focus on Joan's disabilities, but rather on her other qualities:

Part of the impulse is...to help her [Joan] connect with the part of herself that is beyond the label...a part of herself that...she can connect with that is more sustaining.

Co-worker/Mentor. Another assumption about friendship is that these relationships are generally formed on the basis of commonality. Individuals have similar interests, backgrounds, or take part in the same activities as do their friends (Bell, 1981; Bulmer, 1987; Fischer, 1982; Rubin, 1985). This commonality may arise from chosen interests and activities such as stamp collecting, folk dancing or athletics; or result more from other circumstances such as attending the same high school or working in the same office.

People whose friendships are rooted in similar contexts may confine their relationships to a narrowly defined sphere of interactions (i.e., a "work friend") or may



engage in activities outside of this sphere as well. Both patterns of involvement are still seen to be consistent with the meaning of friendship.

In many respects, Shirley and Kitty are co-workers who spend some time together after the work day is done. In terms of what they do together, Shirley and Kitty's friendship appears to have changed the least in the past year. Perhaps the biggest shift in these two women's friendship came when Shirley began providing Kitty with assistance, and teaching her new work-related things. When Shirley first came to the office, Kitty showed her around and facilitated her becoming a part of the staff. As Shirley describes it,

When I started [here] a year and a half ago, she was here about six months before that and just from my work, secretarial work, and the xeroxing and stuff, I began talking to her and she was one of the people who...helped me out a lot getting to know people, this and that. We just became friends and she would show me the places to eat, and we started going to lunch and then it evolved where she would start asking me for help and it just became natural that the two of us would work together and it blossomed to I became her superior and we are where we are.

Once a friendship was established between the two women, and Kitty began coming to Shirley for help, Shirley assumed a mentoring role vis-a-vis Kitty. She is concerned about Kitty's future and her ability to provide for herself. She searches for



opportunities that Kitty can take advantage of in order to improve her clerical skills. Shirley provides a lot of practical, informal, and largely unnoticed assistance to Kitty everyday. The following is a typical example of this. Kitty is at the xerox machine in the office fiddling with a paper jam and talking to herself in an annoyed tone of voice about the machine. Shirley, 10 feet away and on the other side of a partition, stops typing, cocks her head in Kitty's direction, and smiles. After a few moments, she gets up, walks over to Kitty, and puts her arms around Kitty's shoulders. In a tone of bemusement and affection, Shirley says, "What you bitchin' about Kitty?"

Kitty explains the problem and what she is trying to do to rectify it. Shirley, all business now, nods and together they clear out the paper jam. From this and other observations, I see that Shirley generally lets Kitty deal with the difficulties she faces in her job before stepping in. And when she does step in, Shirley uses it as a chance to teach Kitty how to do something for herself.

Volunteer. There is a prevalent societal context to view friendships between people with and without disabilities as being akin to traditional volunteer relationships. This probably arises from the belief that individuals with disabilities have certain deficits and needs for assistance that outweigh the possibilities for a reciprocal relationship (Guralnick, 1984). The volunteer (e.g., leisure buddy, foster grandparent, community companion, peer tutor) often has an allegiance to a program or an ideal rather than a personal connection with a specific person.

Volunteers are viewed as contributing the most to the relationship by providing some kind of assistance. Although it is recognized that the helper receives some kind of intangible reward for her/his activity, volunteers are often given honorariums,



plaques, and other forms of public recognition, course credits and other perks not viewed as acceptable within a friendship. Traditional volunteer relationships are more public in the sense that the relationship is not exclusive to the two friends. Others (e.g., staff) may claim some ownership over the relationship and what the two people do together. Some people who have made efforts to foster relationships between people with disabilities and nondisabled people have tried to specifically counteract the predisposition toward this type of volunteer-friendship (O'Brien, 1987b; Voeltz, 1984; Wolfensberger & Zauha, 1973).

For John, his involvement with Joe can be compared to a traditional volunteer relationship. First, his priest suggested that John do some volunteer work. Noticing Joe at church, John sought the relationship so that he could do "some work helping others, to forget about myself for a while." It was in this spirit that John asked the parish priest to introduce him to one of the men with handicaps. John was introduced to Joe in particular because the latter needed someone to sponsor his confirmation into the church. And although these two men got along well and found that they shared similar interests, it was not an exclusive friendship. Within the context of a helper and volunteer it was easy for John to include Peter and Tom in the weekly outings with Joe. They too had no one to spend time with and John had lots of time to fill. Hanging out with the guys was for John, "something for me to do. To give to someone, to help out."



Once John and Debbie began seeing each other, the group expanded to include her. It was unusual for John and Joe to do something just with each other. But John maintained that his relationship with Joe was "more special" than his connection to the other men. He said.

We do things together as a group. But Joe knows that we're really close. Like at his review meeting. All these people, psychiatrists, doctors, whatever, and Joe and me...they talk about him as if he wasn't there, but in a nice way... say how close we are and how important it is for Joe that we're friends.

Unlike the other friendships, this one began with a different premise. The first three pairs had no particular purpose in getting together beyond the initial short term invitation to lunch or whatever. There was no expectation of a friendship just the possibility of spending time together. John asked for an introduction to Joe in order to do some helping work. The friendship between the two men was not exclusive — that is, they did not have a friendship that included only them, a sense of "we." John, at least, relied on others to help him define his relationship to Joe as a friendship. And even though many friends see less of each other when one or both of the partners marries, starts a family, and/or moves, John and Joe have had no contact with each other for several months. This raises the question that although once defined as a friendship by John and Joe, their relationship may have been more like a "volunteer/receiver" relationship than anything else.



Friendships do not just happen, they are made. Individuals jointly create a friendship with each other by attaching certain symbolic meanings to the time that they spend with each other. The meanings of friendships that are created in this process of mutual definition are influenced by the length of time that the informants have known each other, the number and nature of their other interpersonal relationships, and the critical events that cause them to become more aware of their friendship. Although all of the informants saw themselves as friends, the personal meaning of these friendships differed across the informants. While friendship had many meanings for the informants, there were some common strands that ran through their definitions. The next section examines the common understandings of friendship that were held by the informants.



SECTION IV: THE CHARACTERISTICS OF FRIENDSHIP

While the specifics of each friendship are unique, the informants share similar ideas and expectations about the characteristics of friendship in general. For them, the characteristics of friendship include its mutual, exclusive, and voluntary nature; the rights, obligations, and responsibilities of friends to each other; and the positive regard or affection found between friends.

Mutuality: "A Feeling of Being Connected"

One of the most prevalent assumptions about friendship is that by definition it is a reciprocal relationship. Friends give and take a variety of resources from each other. These can include time, presence, material objects, practical assistance, comfort, and other forms of emotional support. The idea of the exchange is so essential to our notion of friendship that those relationships without an obvious reciprocity are generally not thought of as a friendship (Blau, 1964; Bogdan & Taylor, 1989; Field, 1984; Gold, 1986; Scott, 1985). The patterns of exchange between friends may vary over time, and may not be experienced by the partners as a straightforward exchange. But when one partner supports the other through a crisis or a difficult time, there is the expectation that the tables will be turned some day. In addition to this expectation is the hope that the giving and receiving of support or assistance will not be held against the "receiver" by the "giver" (Miller, 1983; Suttles, 1970).



A related assumption about friends is that in order for their friendship to be reciprocal, they must be each other's equals in some way, or have some sort of common ground between them (Bell, 1981; Bulmer, 1987; Scott, 1985). Reciprocity is not simply a characteristic of the friendship, but the ability to "be reciprocal" is seen as a necessary precondition for the possibility of friendship to develop. When this point of view is extended to people with disabilities, it gives rise to the assumption that people with mental retardation can be friends only with their likewise retarded peers. Several researchers make this assumption perhaps without being aware of it. Landesman-Dwyer, Berkson, and Romer (1980) suggest that larger residential facilities afford people with disabilities a greater chance of meeting a potential friend. Halpern, Close, and Nelson (1986) also assume that only people with disabilities can in fact be friends to other disabled people. In these studies, the authors simply do not consider or speculate upon the possibility of friendships between people with and without disabilities.

But not all researchers have reached the same conclusions. Edgerton's earlier studies (1967, 1984) delineate the key role played by nonretarded benefactors in the adjustment to life in the community by previously institutionalized individuals. For Edgerton, the benefactor wasn't a friend (despite the informants' claims that they were friends), but rather someone whose "assistance is necessary and not reciprocated" (p. 333). But by 1988, Edgerton found that his sample members,

were embedded in worlds of meaningful and reciprocal relationships with other people...these people gave to others every bit as much as they got from them. In addition to



small sums of money, they have shared useful information, emotional support, and affection.

Bogdan and Taylor (1989) also learned that many nondisabled individuals viewed their relationships with people with disabilities as reciprocal friendships.

Each of the pairs of people interviewed in this study defined their relationship as a friendship, and saw themselves as friends. For all of them, their personal definition of being friends incorporated the idea of mutuality. I have chosen the word mutuality to refer specifically to this as opposed to reciprocity. For the informants, mutuality means many things, but it was not confined to a strict view of a straightforward exchange of goods, presence, or services that is commonly thought to comprise "reciprocity" at least for the proponents of social exchange theory. According to the informants, what makes a friendship mutual differs within the context of each individual friendship. They are involved in different types of friendships where the expectations vary. Because of this, the meanings of mutuality vary across the informants' friendships. But there is a mutuality present in each of the four friendships I studied. The informants view their friendships as mutual, though not always between equals. The nondisabled friends acknowledge differences between themselves and their disabled friend and see the friendship as both similar and different from their other friendships, but also find a sense of mutuality in the friendship with disabled people.

For example, Christie articulated the difference as due to age and life experience. Christie's relationship with Joan typifies the special relationship she has with a few other female students. Joan benefits from Christie's "calming presence,"



her patience, her support while dealing with the psychologists, psychiatrists, and other professionals. Joan is recognized by Christie as a kindred spirit, is able to look past Joan's reputation and appreciate her for who she is. Christie is not bothered by Joan's loud voice and brash behaviour. She genuinely appreciates Joan's humor, feistiness, shyness, and competence. Christie is someone who likes Joan. And through her friendship with Christie, Joan is gaining a new reputation.

Friendship with a person with disabilities may be different than other friendships for a nondisabled person. But for the nondisabled informants in this study, the differences did not mean that the friendship was not mutual. As Christie says, echoing the sentiments of all of the nondisabled informants, "I don't consider myself just someone who is giving to her without getting anything."

I was able to identify five facets about the meanings of mutuality for the informants. These meanings included both the giving and receiving of emotional support, practical assistance, inspiration, rule-breaking and dispensations of certain societal norms, and the sheer enjoyment of being together.

Practical Assistance and Emotional Support

It was difficult to separate instances of practical assistance from those of emotional support between the friends. This was largely because the informants viewed the acts of practical aid (e.g., help with grocery shopping) as also supportive in other ways. So although the examples are somewhat arbitrarily differentiated as either assistance or support, for the informants, they were one and the same thing.



The informants often did practical things for each other, including ongoing forms of assistance or more occasional help. For example, Shirley has gotten Kitty involved in some after hours training courses. Shirley likes to encourage Kitty to continually try to succeed at new things, and she revels in Kitty's efforts. As Shirley said,

[Kitty's] so eager to learn that I get excited showing her things...you know I get a lot out of that. I want to see her do more than the basic xeroxing stuff because I know she has the potential of doing other things.

The informants provide various types of emotional support to each other. This took the form of advice, like Christie gave to Joan during a set of run-ins with Joan's psychiatrist; comfort, as John and Joe commiserated over Joe's loss of his girlfriend; lectures, as Rhoda gave to Jim before he entered prison to serve his sentence; and acting as an ally, as when Shirley went to the boss to get money for Kitty to take the word processing course, and Rhoda going to Jim's review meetings at his request. There are no parallel examples in the data illustrating how the informants without disabilities call on their friends with a disability for obvious assistance or support. That this is so does not detract from the feelings of mutuality regarding their friendship. While Rhoda provided Jim with a lot of practical assistance and emotional support, in return, she acquired a second son. She finds meaning in several of the small gestures that Jim has made. She related how this "real ornery kid" would reach over and put the sun visor down for her while she was driving, click a pen open before handing it to her or hold down a corner of notepaper while



Rhoda wrote on it. Jim also acted as a teaching assistant in a couple of the literacy courses that Rhoda taught one year.

Breaking the Rules

Another aspect of the feeling of mutuality between the informants was the breaking of rules. Denzin (1970, p. 71) asserts that the capacity to "validate, redefine, or make irrelevant rules from any other moral order" is one characteristic of friendships. Together, friends may jointly develop rules of conduct that they agree to follow within their friendship. Some of these rules may be at odds with the expectations of other individuals or organizations with whom the friends are involved.

John and Joe's friendship provides an example that relates to the meaning of mutuality. John accepts certain of Joe's behaviours that others find difficult to tolerate. Others, such as the staff and John's wife Debbie, do not appreciate Joe's ways of expressing affection like long hugs, keeping his arm around people's shoulders, and draping himself on people he sits next to. When chided by his wife for tolerating such behaviours, John shrugs his shoulders and chuckles. He sees Joe's behaviours as harmless and of no particular concern.

This breaking of rules is of benefit to John as well. When these men are out at a diner having breakfast, they flirt shamelessly with the waitress, guffaw at jokes, and they get a chance to show off a little. John gets to act in ways that his wife would not appreciate and Joe gets to do things not allowed to him under other circumstances. When they are together, these two men are able to act like two bad boys.



Rule-breaking does not have to revolve solely around having fun. Christie encouraged Joan's questioning of the mental health professionals that Joan was seeing (i.e., psychiatrist, psychologist, physician). Joan badgered them about the types and amounts of drugs that were or were not prescribed to her, and the advice that she was given. This alliance of friends to question and/or break someone else's rules served as one way to validate and strengthen their own ties to each other.

Inspiration

The disabled informants provide an inspiration to their nondisabled friends. Shirley talked about getting excited when she taught Kity new things, and was motivated to continue her efforts, even though they were not always dramatically rewarding. Christie was also impressed with the lessons she learned from Joan and some of the other disabled students that she has taught. She discovered their "courage in just living...their sense of interdependence...and a feeling of being connected." Christie admired the interdependence of Joan and the other disabled students in her class and relished the memory of giving her arm to a blind student and helping him get around.

Rhoda described how deeply touched she was when Jim credited her concern as his initial reason for not committing suicide. Something about Jim and his situation encouraged Rhoda to remain committed and faithful to their friendship.

John and Debbie told me many stories about how "the guys" helped each other out and stuck by each other, and how these gestures impressed them so much.



Enjoyment

One thread that runs through all of these expressions of mutuality is that of enjoyment. All of the informants genuinely enjoy spending time with each other. Outsiders may not see or appreciate the two way exchange of support, assistance, concern, and affection between the friends in these four relationships. But to the informants themselves, these friendships are mutual relationships. The friends do not keep a strict accounting of who contributes what. The respective contributions of a friend also vary within each of the friendships. But for the informants, this feeling of mutuality is present in their friendships.

Rights, Responsibilities, and Obligations: "I've Taken it Upon Myself"

Once a friendship is established, it is assumed that friends can make certain demands on each other and be assured of a response. Friends have a right to expect certain things from each other and an obligation to answer in some way. While these rights and obligations are voluntarily assumed in a friendship, they are considered mandatory in other types of interpersonal relationships, for example, family and/or business relationships. The capacity to ask for certain things from a friend is often taken for granted. Which friend gives something and which friend asks for something can change over time. Finally, the specific obligations that exist in any friendship are not understood or determined in advance, as they might be in a contractual arrangement. Rather, they are defined jointly between two people over time and are influenced by other circumstances (Bell, 1981; Bulmer, 1987; Fischer, 1982; Miller, 1983; Rubin, 1985).



When the informants jointly defined their relationship as a friendship, they chose to accept certain obligations towards their friend, and assumed that they in turn could call upon their friend for certain types of assistance and support. The disabled informants did not talk about assuming certain obligations for the relationship or toward their nondisabled friend. That this was the case may have been due to an inarticulateness on the part of the informants, or my inability as a researcher to ask questions in ways that the informants understood them. While the nondisabled informants are more articulate about this assumption of responsibilities in regard to their friend, the informants with disabilities have also taken on some of the responsibilities, especially in terms of keeping the friendship going.

Responsibilities Assumed by the Nondisabled Informants

All of the nondisabled informants referred to the obligations they had taken on by becoming friends to a person with a disability, expressed by taking on a particular role or roles. In addition to the other characteristics of each friendship, the nondisabled people took on a teaching, mentoring, caring, or protecting role with their friends with disabilities. These roles are not narrowly circumscribed and the nondisabled friends often would take on a combination of the above roles.

The nondisabled informants accepted certain responsibilities for their friends' overall welfare. While they acknowledged accepting similar types of obligations in all of their friendships, the nondisabled informants clearly listed specific responsibilities that they had assumed within their friendships with the disabled informants.



John spoke about sponsoring Joe into his church by helping Joe to prepare, praying for him, and making sure that Joe made the proper responses during the actual ceremony. John accepted the group home's designation of him as Joe's "special friend." To him, this meant an obligation to attend Joe's annual review meetings at the home and to help out at the group home when they were short staffed on a couple of occasions. But John did not define his obligations as complying totally with the requirements of the staff. He took Joe to visit his girlfriend and to do other prohibited things.

Shirley clearly articulated the obligation that she felt toward Kitty. Shirley worried about Kitty's future ability to support herself, and said, "I've taken it upon myself to worry about her future." Shirley's response was to try to help Kitty become more competent in the work that she does.

Having her get the skills so that she could eventually go out and get a full time job and not having to rely as much as she does on other people.

Christie also talks about the responsibility she has assumed in her friendship with Joan, "I realize that in trying to be her friend, I've taken on a big responsibility...you suspend your own stuff sometimes." Her response to Joan was to be "sympathetic, but I don't take it [the suicide threat] up." Christie described lengthy conversations where she would quietly redirect Joan's attention away from thoughts of self-destruction to other topics. She herself did not get upset or raise her voice.



These conversations were so demanding for Christie that she said she had to "balance being open with others" with caring for myself. "Joan has expectations that I can't meet."

Rhoda has assumed the most extensive amount of responsibility for her friend Jim. Over the past 2 years, Rhoda has stood by Jim through several crises. Most recently, she is preparing for his release from prison by locating a place for him to live, a possible job, and people who will support him during the next few months.

Responsibilities Assumed by the Informants With Disabilities

The informants with disabilities, although they do not talk about assuming certain responsibilities, do in fact fulfill certain obligations. They perform the more perfunctory responsibilities of the friendship. They do most of the maintaining of the relationships by making phone calls to their friend, suggesting possible activities and times to get together and so on.

"Positive Emotional Regard": From Companionship to Intimacy

Friends like each other. This "positive emotional regard" that friends carry for each other is described in innumerable ways, from love, like, satisfaction, support, acceptance, pleasure, joy, affirmation, tolerance, nurturance, and forgiveness. However it is expressed, friends are connected to each other through emotional and subjective bonds that provide the subtle shadings and tones to the palette of each friendship. What friends fee! toward each other changes over time, and is different within each friendship. The feelings that friends have for each other fluctuate in intensity and



content. Friends may or may not know exactly how their partner feels about them. Friends may take their own or their partner's feelings for granted or be unaware of these feelings (Bell, 1981; Bulmer, 1987; Field, 1984; Montaigne, 1949; Rubin, 1985).

While it is universally accepted that friends do carry some of these feelings for each other, it remains a problematic area of study for researchers. The feelings found in friendship, like in other interpersonal relationships, are private. However rich and meaningful, language cannot easily convey the extent of emotions experienced by friends for each other. Conventional wisdom simply reduces this dimension of friendship to "chemistry."

The affection and positive feelings that the informants had for one another were expressed in several ways. First was their behaviour with each other. Feelings were also demonstrated through their words. They showed, or tried to show, their feelings through their actions; how they addressed each other, and talked about each other to outsiders were all affirmations of their feelings. Simply by being friends, the informants were told that they meant something to another person, that in some ways they were special. This was especially important for the informants with disabilities who had few, or even no friends outside of the relationship considered in this study.

The friends accepted and tolerated each other. Christie chuckled as she told me how she had discovered that Joan had money after Christie had paid for Joan's lunch one day. Irritated as she was with Joan, she half-admired Joan's chutzpa, and merely shrugged her shoulders while she described how she had let Joan know about her irritation. John accepted some of Joe's behaviours that others apparently found inappropriate or even personally offensive, particularly Joe's excessively warm greetings



and the extent of his physical contact with others. While Debbie and the staff at Joe's group home complained about these behaviours, John shrugged his shoulders and said that he didn't know what all of the fuss was about.

However expressed, each partner had some positive feelings about their friend.

These feelings covered a wide range of emotions that fluctuated in intensity over time.

The Voluntary Nature of Friendship: Freely Chosen and Given

Montaigne (1949) characterized friendship as having a "free and voluntary familiarity." This voluntary nature of friendship makes it different from other relationships. In family relationships, the responsibilities of one member to another are expected and considered obligatory. But the assumptions and expectations held about friends and friendship are that this is a freely given and chosen relationship. Both friends choose each other, and a friendship continues as long as this voluntary bond remains.

A friend does not receive money or credit for being a friend. Friends are not supposed to exercise control over each other. The only proper exchange that takes place between friends is what they choose to share with each other. Although friends can call on each other for support and assistance, they assume that help will come voluntarily, albeit sometimes begrudgingly. Likewise, partners recognize that providing assistance in some way is a chosen obligation that allows the expression of the positive feelings of one friend to another.

It is often this voluntary aspect of friendship that friends regard as the amazing and wonderful part of their relationship. The knowledge that another person wants to



be with one, spend time and to do things together out of affection and by choice is a powerful affirmation of one's worth and value. Many friends are not able to describe why someone else likes them. Outsiders to a particular friendship are often unable to understand the nature of the bond between two people, although they acknowledge that such a bond does exist (Fischer, 1982; Suttles, 1970). The informants held certain expectations about the meaning of friendship in terms of its voluntary nature. They acknowledged that their friendships were both chosen and accepted. One expectation the informants had was that a friend does not receive money or some other form or reimbursement for being a friend. The nondisabled informants and Kitty all articulated the necessity that friendship be voluntary in order to be considered by them to be a friendship. Kitty recalled how the nondisabled staff at the sheltered workshop told her they couldn't get together with her on Saturdays as it was after working hours. Kitty continued, "Well, that was rich. They told me that what I wanted was friends. Well I did."

For a friend to continue in a friendship meant to play some role in maintaining it over time. The informants made a number of decisions that kept the relationships going. They agreed to continue as friends and actively defined the nature and extent of their involvement and commitment with each other.

The informants also believed that friends are not supposed to exercise control over each other. They believed that what takes place between two friends is what they choose to share. The informants shared their time, ear, advice, experience, or sheer presence with each other.



Finally, although as friends the informants often got together for specific activities and events, they assumed that there was no particular goal for their friendship other than the desire to be with each other, or the enjoyment of each other's company. Perhaps the clearest example of this was the consternation of the staff at the group home where Joe lived when he and John did things that the staff did not approve of. The staff had designated John as Joe's volunteer or special friend and had certain expectations for John. Specifically, they expected John to implement certain decisions that the staff made about Joe's activities and appropriate behaviours. Disappointed at John's disregard for programmatic requirements, a staff person told me,

We realized that we could not count on John to carry out our program goals. What's normalizing for us is not normalizing for John.

Although the informants did not fellow through on the expectations of others in regard to their friendships, they did choose to assume some responsibilities toward their friend. But these chosen obligations demonstrated the loyalty of the nondisabled informants to their friends with disabilities.

The Private and Exclusive Nature of Friendship

Although different friendships are similar in enough ways to be recognizable as such, each friendship is also unique and different in some way. A common element of the friendships examined in this study is that they have a recognizably exclusive and private aspect to them. That is, within the boundaries of each friendship is a



private relationship that is not accessible to others. The basis of this arises from their perspective that at least in some ways, they are more alike than different. The friends have a history and an understanding of their connection to each other that separates this from all of their other relationships.

For the informants, there always seemed to be some sort of tension involved in establishing the private boundaries of their friendship. One of Debbie's stories illustrates this characteristic of the friendships well. After she and John were already married, she saw John and Joe ride past her on the motorbike one day. Joe saw her and gave her what she called a contemptuous wave. She laughed as she said, "He knew he was on the motorbike, riding in my place and wearing my helmet. He really liked being able to rub that one in!"

John talked about the jealousy of his children regarding his friendship with Joe. Christie mentioned having to balance the expectations of her lover and of Joan. Rhoda regretted having to choose between Jim's and her family's demands upon her time and energy. The informants had to balance the effort they put into their personal relationships and this caused part of the tension. By having a friendship with one person, they effectively closed part of their life off from their spouses, lovers, children, and other friends. Of all of the informants, Shirley and Kitty seemed to experience the least amount of tension between their friendship and their other interpersonal relationships. This may be due to the fact that both women have strong family connections and have brought their two immediate families together for a couple of visits. They also see each other at work everyday, a time when their families do not expect access to them.



Friendships are a complex series of interpersonal relationships. Each of the five characteristics of the friendships influenced and constrained each other. The informants recognized that while at times their obligations to each other may have seemed onerous, they were in fact chosen responsibilities. While the friends may at times have been angry, hurt, or disappointed in each other, they still thought of each other with affection and appreciation.



SECTION V: FRIENDSHIPS BETWEEN PEOPLE WITH AND WITHOUT DISABILITIES: SUMMARY AND IMPLICATIONS

In this concluding section, I briefly summarize the major findings from this study and explore the implications for friendships between people who are disabled and those who are not.

From my analysis of the data, five major findings emerged. First, there is a possibility for genuine friendships between people with disabilities and people who are not disabled. Second, both the informants with disabilities and the nondisabled informants actively created their friendship with each other. Third, the informants played different roles vis-a-vis their friends even though they identified themselves as friends. Fourth, while the specifics of each friendship were unique, the informants shared similar ideas and expectations about the characteristics of friendship in general. These include the mutual, exclusive, and voluntary nature of friendship, the rights, obligations, and responsibilities of friends to each other, and the positive regard or affection found between friends. Finally, disability did play a role in the friendships. While both of the friends contributed something to their friendship, these contributions did differ according to whether the friend was disabled or not.

Implications of the Study

Three implications can be drawn from this study that are applicable not only to the informants with disabilities, but also to other individuals with disabilities as well.

These implications revolve around three areas: the effects of living in the human



service world, enhancing the possibilities for friendship between people with and without disabilities, and avoiding the romanticization of these friendships.

Living in the Human Service World

First, the majority of people the informants with disabilities knew were staff, and other individuals with disabilities. In addition, the clients may or may not have had contact with their families over the years, and the majority of the people in their lives were the people whom they conducted the daily business of their lives with: doctors, dentists, shopkeepers, and so on. Most human service programs (schools, residences, workshops, recreation programs) effectively set up barriers between people with disabilities and most people in the community. Surrounded by staff and others receiving the same services, people with disabilities are made into "clients," "service users," or "program participants." Family connections may be ignored or broken. Friends may be discouraged from keeping in touch. A person's history can be lost merely by entering a residential program. Bercovici (1983) found, for example, that a large number of adults with mental retardation did not view themselves as living in the "normal" community, but rather in a parallel, community-based but nevertheless institutional setting. Her informants compared their life in the community to that of the institution with the same staff, program structures, and hierarchy of control. Such occurrences are not infrequent. They take place so often that they form a pattern -the "normal" existence for people with disabilities (Blatt & Kaplan, 1966; Blatt, Ozolins, & McNally, 1977; Wolfensberger, 1975).



The heart of this matter lies in how most nondisabled people view their counterparts with disabilities. Over time, society has come to define people with disabilities as somehow different than the majority of people, and in need of specialized and unique care. The view that individuals with disabilities are in some ways essentially different from the rest of the world results in several types of experiences. People with disabilities are often separated from their families and communities, cast into roles of dependency and passivity, and even when physically present in some community settings, are kept at a social distance from others.

Separation. The historical pattern of the removal of people with disabilities from our society is well documented. Large numbers of individuals were placed into large congregate care facilities for the avowed purposes of education and training, medical care, family relief, or social control of unwanted segments of the population (MacMillan, 1982; Scheerenberger, 1983; Wolfensberger, 1975). Some concentrated efforts were also made to sterilize certain groups to prevent their propagation and also to kill them outright (Lusthaus, 1985; Wertham, 1973).

The enforced segregation of people with disabilities from the daily life of their communities reinforced the belief that some people are so different that they cannot fit in or successfully contribute to their society. Typica' community members lost the chance to meet, get to know, and be with individuals with disabilities. The opportunities for people in both groups to grow up together and form attachments with each other are often lost.



Clienthood. By entering a program, most people with disabilities are turned into clients. This happens when the program staff expect certain patterns of behaviour from the people who are receiving the service. During this process, a person is placed into a dependent relationship with the staff and other care-givers. Surrounded by specific expectations, the person then conforms and begins to act in the expected and reinforced ways (Scott, 1985). The person adopts (or is forced into) the role of a client. When the client role becomes life-defining, others see the person primarily in terms of his/her impairments, and emphasis is placed on the person's deficits, and the sense of the person as a whole being can be lost. Teachers, doctors, therapists, and other workers are hired to correct the problems seen as inherent in the disabled person. As a client, a person learns to show the acceptable behaviours at the right times in order to get the resources and supports that he/she might need. This socialization process works in two ways. This anecdote told to me by a staff person in Joe's group home serves as an illustration. This staff person told me that a relatively new staff person, Tony,

told us that he sees Joe as someone to be a friend with, nice to be with, someone who understands him, and vice versa. But Tony has a very poor self-image of himself. He does not mention any of Joe's behaviours. After he hears the others talk about the behaviours, then he acknowledges them. And he admits that yes, they bother him.



The new staff person was being taught the assumptions that he was expected to have of Joe, which was to see Joe as a man with certain behaviours that would make it difficult for Joe to have real friends.

As part of their jobs, the staff attempt to control the lives of their clients, who in turn try to maintain some control over their own lives. While the staff may define the client's behaviour as manipulative, self-destructive, or aggressive, the clients in turn may view the staff as capricious, inconsistent, or simply out to get them (Bogdan & Taylor, 1982; Lovett, 1985).

A common part of any client's life that is under the control of staff people are the individual's contacts and relationships with others. Adults may be restricted in who they can see, and when they can see them. Being a client can create barriers in the development of reciprocal and nourishing relationships with others; and through a rare or a complete lack of opportunities, people with disabilities become slowly desperate for connections with others that are not governed by control (McGee, Menousek, & Hobbs, 1987). As virtually all people served by human service agencies are in the client role, the area of relationships between people with disabilities and typical individuals needs to be addressed.

Other programs try to turn friendships between a typical person and a client into a formalized volunteer relationship. Such efforts make the volunteers responsible to the agency and weaken their bonds with their friends. Rhoda applied to become Jim's citizen advocate as she felt pressure to legitimize their relationship in a way that would be acceptable to human service agencies.



Opportunity. People who are not disabled can take advantage of many opportunities to meet and get to know other people. They meet others through their families, neighbors, school or work place, and church or synagogue congregations. They also come into contact with innumerable individuals simply in conducting their daily affairs such as buying food, getting the car fixed, taking care of their health needs, getting a haircut, and so on. For most people, it requires an effort to avoid meeting new people. Thus, Christie knows people through the college where she teaches, through her involvement as a volunteer teacher of adult education courses, and her membership in a women's health and information cooperative. She is known as a poet, has connections to other writers, and has her children and extended family connections as well. Christie is well connected to many different individuals and groups of people.

For many people with disabilities, such opportunities are simply lacking or they possess extremely limited chances to take part in activities and events where they can meet nondisabled people. But even when people with disabilities may be physically present in a community, a variety of circumstances may conspire to keep them apart from their nondisabled peers.

Continuity. Most people thrive on opportunities to meet new and interesting people. But along with meeting new people, they are sustained by those they have known for a long time. The continuity experienced in certain relationships over the years is an important source of security, comfort, and self-worth. Human beings learn to trust each other within long-term and stable relationships (Maslow, 1954; McGee, Menousek, & Hobbs, 1987).



Many people with disabilities do not enjoy the same continuity in their relationships. Children may leave their families for foster care or residential education programs. Staff people, social workers, and case managers can come and go frequently causing disruption in a person's life. Wolfensberger (personal communication, February 13, 1979) likens many people's experiences to a "relationship circus" where staff and professionals dance in and out of a person's life, each in turn demanding immediate trust from the person with disabilities. The author, after observing a supported apartment program, learned that 5 months of observations gave her some seniority over most of the support staff (Lutfiyya, 1987). For example, after leaving his parental home at the age of 13, Jim lived in several foster care situations; he lived in his last placement from the ages of 18 to 21. But he and his foster parents maintained no contact at all after he moved into the supported apartment program. As far as Rhoda and Jim know, his foster parents are not aware of his arrest, conviction, and prison sentence. Although Rhoda has kept in continuous touch with Jim over the past 2 1/2 to 3 years, no one else has done so. The other people that Jim has seen on occasion, including his biological parents and a couple of his high school teachers, all did so as a result of Rhoda's efforts.

For Joan and Kitty, the major source of continuity in their relationship have been their immediate families. Kitty also visits some of her mother's friends on a regular but infrequent basis. This includes seeing a couple of women who now live in the county's nursing home and having lunch with another woman who meets Kitty at her office. Joe sees his father once or twice a year and some of his siblings on major holidays. The main source of continuous relationships in Joe's life are the live-in staff



at his group home. These individuals change every 2 years or so, although one woman has lived in the same house with Joe for the past 5 years. Outside of their families, the disabled informants had very few long standing and stable relationships over the course of their lives.

Freely given and chosen relationships. For what may appear to be the most amazing reasons, individuals choose to like and love others because they want to. Our spouses, lovers, and friends all choose to be with us and we choose them. We are surrounded by people who accept, love, and tolerate us and we do the same for them. When this is not the case, something is thought to be wrong and the situation in need of rectification. Many people with disabilities enjoy few close relationships with others and even fewer unpaid relationships (Johnson, 1985; Wolfensberger, 1983). The main source of relationships for a lot of people with disabilities are their families, program staff, and other clients (Halpern, Close, & Nelson, 1986). This should not be a surprise given the lack of opportunity and support to become a part of the community and to meet others. It can be difficult to appreciate what life is like for people who know no single person who spends time with them because they want to not because they are paid to do so or are involuntarily placed in the same setting.

For example, Kitty also described her frustration in trying to befriend some of the staff at the sheltered workshop. She believed that the staff had been warned not to develop close connections with the disabled workers. As she put it, the staff were told,



Now you can be friends with these people, but don't get too close, or too attached. And so they didn't get too close, and they was friendly and alright, but you know, but, they just didn't want to get attached to a lot of these people.

Later on in the interview, the following exchange took place. When I asked Kitty about spending time socially with some of the staff at the workshop, she responded:

Yeah, like for example I'd say something to them, "Well, what are you doing for the weekend?"--"Oh, why, Kitty, what's that got to do with you?"--"Nothing really, but I just wondered what did you do for the weekend," you know, just asking a normal question like that and they look at you like, well, "It doesn't pertain to you, Kitty, what I done for the weekend."

While all of the four disabled informants did have some experience in a freely given and chosen relationship with someone, they did not enjoy the same number of such relationships as did the informants who were not disabled.

Diversity. Many people know a diverse range of people with differing backgrounds, interests, jobs, education, and so forth. People may not choose to associate with or become close to everyone they meet, but they have the opportunity to select their friends from a large number of people.

Unfortunately, the same cannot be said of many people with disabilities, especially those who are raised apart from their families and neighbourhoods.

Individuals served in both institutional and community based settings may have little



contact with people other than fellow clients and the staff. For example, before meeting Shirley, Kitty spent virtually all of her time with her parents and their friends. Through her friendship with Shirley, Kitty met some of Shirley's friends. These included Shirley's "really crazy and wild friends" who came to her son's birthday party. Kitty enjoyed meeting these people so much that she stayed at the party for several hours longer then she had intended to. Shirley also told me that a secondary reason she had encouraged Kitty to take the word processing course was "to have the opportunity to meet new people, maybe some people her own age." Shirley wanted Kitty to have a wider range of personal relationships. For the disabled informants, the most successful way to meet new and different types of individuals was to be introduced to them through their nondisabled friend.

Intimacy. The word intimacy may be confusing. It is used here as an expression of the closeness, comfort, and trust that people may feel for each other. Intimates can express thoughts and feelings that they share with no one else. Despite the difficulties in determining how people define those they are closest too, most people have or aspire to a few intimates (Rubin, 1985). In the current literature, it is recognized that many disabled individuals have few or no people with whom they share a close, intimate relationship (Mount, Beeman, & Ducharme, 1988a & 1988b; Strully & Bartholomew-Lorimer, 1988; Zetlin & Murtaugh, 1988). In this study, Rhoda and Jim's "emotional adoption" serves as the clearest example of a friendship that is intimate and intense.



The Possibilities for Friendship

The second implication of this study deals with the possibilities for friendships between people with and without disabilities. Despite the differences in opportunities and experiences, at least some people with disabilities have successfully formed friendships with nondisabled people. Through studying established friendships, we learn that both parties possess a respect for the other. The friends also experienced a mutuality in their interactions that may not be apparent to the outside observer. These feelings stem from a sense of identification between the two individuals. They come to see the "sameness" or commonalities between themselves and these serve as the basis of the relationship. Bogdan and Taylor (1987) suggest that several bases of identification held by the nondisabled person might account for their acceptance of people with disabilities. These include family ties, religious and/or humanitarian beliefs.

Despite the involvement of the individuals with disabilities in the human service system, and being cast into a client role, the nondisabled informants were able to identify with them. In some ways, the typical people saw in the person with disabilities a potential friend. Both the situations where the informants met and who the informants were contributed to this identification. But while the nondisabled informants were able to personally identify with their friends, they also viewed these same friends as being special in some way.

Situation. Three of the nondisabled informants met their future friend at a place where the disabled person was not identified primarily as being in the client role. For instance, Shirley saw Kitty primarily as a co-worker. Even though it



became clear to Shirley that Kitty had difficulty in doing and/or learning certain things, Shirley did not view Kitty as primarily a mentally retarded woman. Shirley rejected the notion that Kitty couldn't learn complex things such as use of a word processor, a stereotype often held about individuals labeled as mentally retarded (Wolfensberger, 1972). To Shirley, Kitty had lots of potential to learn, grow, and eventually become self-supporting. In this respect, Shirley distinguishes Kitty from the other people with disabilities that Shirley knows, including her own sister.

People. Something about the informants themselves as individuals encouraged the possibility of these friendships. Rhoda and Jim first met in a staff-client relationship. But something within these two people, or something that took place between them opened up the possibility of them seeing each other in a different way. Whatever that "chemistry" was, Rhoda was able to view Jim as an "ornery kid" who responded to someone taking a personal interest in him. Eventually, Rhoda identified Jim as part of her family, as an adopted son, even if a legal adoption did not take place. A similar process occurred within Jim so that he moved from defining Rhoda as a staff person whose role was to make him do things and give him trouble to someone who became a confidante and then like a mother.

Friends, not Heroes

The third implication that can be extrapolated from this study comes as a word of caution. Many people in the field of special education and rehabilitation today have a strong desire to help people with disabilities develop a wide variety of personal relationships, including friendships, with nondisabled individuals. It is



becoming more widely acknowledged that such relationships enrich the lives of both individuals and help make the person with a disability more a part of the community. But in the enthusiasm to support such friendships, there may be a tendency to inflate the existence of such friendships, to exaggerate the status of these friendships in the partner's lives, and to overemphasize the effect or influence of a specific friendship in a person's life. There are examples of incredible efforts on behalf of disabled people by their friends (Schwartz, McKnight, & Kendrick, 1987), for example, reuniting a family and building them a new house (Bogdan, 1987), or literally saving one woman's life by removing her from the abuse and neglect that she was receiving in a nursing home (Forest & Snow, 1983; Perske, 1988). These stories of heroic friendship have served as sources of inspiration to quite a few people, and have been used to illustrate the importance of friendship for people with disabilities. Judith Snow's story in particular has apparently been the impetus for others to develop circles of support around individuals with disabilities (Chapman & Zipperlin, personal communication, September, 1988).

While many would consider friendship in our lives as essential, it cannot serve as the panacea for all of the problems in a person's life. As in all other interpersonal relationships between human beings, friends disappoint and hurt each other. Friends fight with each other and do not always make up. Some friendships end while others may not meet the expectations and hopes of one or both of the people involved in the relationship. Christie felt cheated in some ways when she realized that Joan did have more than enough money to pay for her lunch. John and Joe's relationship, has, at least for the time being, ended. In the desire to encourage



friendships, and to publicize certain stories in order to serve as a model for others, the mystifying and mythologizing of the relationships that do exist must be avoided. To turn the real struggle of people's lives into fables is to strip the people of their reality and the true power of the friendships. For it is when friendships continue in spite of the pain and disappointment that something beautiful has been borne into existence.



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APPENDIX A: METHODOLOGY

This monograph is based on a research study conducted for my dissertation. This appendix outlines the qualitative research methodology that was used. A study using qualitative research methods begins with a broad outline and direction of approach rather than a specified study design. The development and maintenance of friendships between people with disabilities and those who are not disabled form the broad questions of this study. To gain an understanding of this process, I tried to learn the perspective of the people involved in such friendships--how they view their activities together and what their thoughts and feelings about their friendships are.

To limit the focus of this study, disabled partners with (or labelled as having) mental retardation were sought over partners with other disabilities. If potential informants had additional disabling conditions they were still considered (often, people, who are disabled receive a variety of labels over the course of their lifetime). I soon realized that almost twice as many women as men were brought to my attention as possible informants. This included both the nondisabled and disabled people in the friendships. I consciously chose two friendships where men were involved to try to learn more about the role of gender in the friendships I studied.

I met and interviewed informants who had been involved with each other for different lengths of time. At the time of the initial interviews, Christie and Joan had only met 9 months before. Shirley and Kitty had known each other for 2 1/2 years, John and Joe for 5 years, and Rhoda and Jim for 1 year when I began interviewing them.



The data for this study were collected primarily through a series of indepth interviews. I always met with the nondisabled person first, and then with their assistance arranged to interview their friend. All of the interviews were done singly. This reflected the preference of the informants. On the other hand, all of the participant observation sessions involved both friends. These sessions always revolved around a typical activity that the two people did together. These sessions turned out to be the most effective way to learn about the nature of interactions between the people in the friendships.

Most of the interviews were taped and later transcribed. I did not take notes or use a tape recorder during the participant observation sessions. I wrote traditional field notes after these outings. Eighteen interviews and six participant observation sessions spanning 55 hours of contact with the informants were conducted.

Approximately 670 double-spaced pages of transcripts and field notes resulted. The data were collected from June 1987-September 1988, although not on a continuous basis.

I did encounter some difficulties while conducting the interviews with the informants with disabilities. First, while they were interested in taking part in a study, Jim and Joan were not interested in answering my questions. They wanted to talk about other things in their lives, and found it difficult to focus on the questions that I was asking. This meant that I had to be patient, repeat several questions, and redirect the interview constantly. Second, another of the informants was not articulate. Joe simply does not speak a lot, appears to have a limited vocabulary and a speech impediment as well. I this case, I interviewed someone who has known him well for the past 5 years to collect the data that I needed.

