THE UNIVERSITY OF CALGARY

PERCEPTIONS OF FRIENDSHIP BASED ON THE VIEWS
OF PEOPLE WITH AND WITHOUT COGNITIVE DISABILITY

BY

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A THESIS

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Canada

March 8, 1990

Ms. R. Lehman
40 Carnarvon Way N.W.
Calgary, Alberta
T2K 1W4

Dear Ms. Lehman,

As per your request, enclosed are the following items, "Development of a Multidimensional Index for Assessing Social Support in Rehabilitation", "Social Support and Psychosocial Dysfunction after Stroke: Buffering Effects in a Community Sample" and the "Social Support Inventory for Disabled Persons" questionnaire. I want to thank you for your interest in our work. We would be most interested to hear of any application of this social measure that you undertake. We would also very much appreciate your feedback on the utility of the measure in your setting.

Kindest regards,

M.A. McColl
Director of Research
Lyndhurst Hospital

encls.

MAM/df

P.S. Scoring revisions are currently underway. Please let me know if you decide to use the SSIDP + want more scoring info.

M.

April 26, 1990

Ruth Lehman
40 Carnarvon Way N.W.
Calgary, Alberta
T2K 1W4

Dear Ms. Lehman,

In response to your letter of April 2nd, I am writing to share with you some of our findings around scoring and administration of the SSIDP. I hope these will be helpful, and I will be happy to discuss them with you further if you feel that would be useful. To begin with, regarding administration, we have made an observation that people do better on the SSIDP if they take a few moments at the out-set to out-line their network, as follows. Using three concentrik circles and two additional circles (as shown on the attached page), we now ask people to identify the intimate personal relationships, their family and close friends, their community contacts and groups and professionals in their network before beginning any questioning. We have found that subjects tend to have a slightly more comprehensive reference point for their network if they do this. It avoids them remembering halfway through section three someone who they wish they had included in section two. It also gives us a more complete picture of the size and composition of the network if we wish to analyse by those parameters.

With regard to scoring, we have tried several scoring methods, as they apply to specific projects. However, I will describe for you the most generic method, and scoring method referred to in the paper. We now score the five source categories according to quality and quantity. The quality dimension includes the closeness and the two satisfaction questions, and the quantity dimension includes the frequency and duration questions. This gives ten sub-scores', for example, personal quality, personal quantity, family/friend quality, family/friend quantity and so on. We have also computed a total quality and a total quantity sub-score by summing across the five sources on quantity and quality separately.

In addition there are several items you may wish to use descriptively; for example, whether or not the person lives with the source of support mentioned; whether or not that person is disabled; what sort of reciprocity is experienced in that relationship, etc. However, the only items that contribute to scoring are the item on frequency of contact, the item of average duration of contact, satisfaction with quality, satisfaction with quantity and closeness. All remaining items may therefore be included or excluded depending on their relevance in a descriptive sense. In addition, you may wish to add items for descriptive purposes, relative to your specific project.

Recently, in an effort to derive more detailed information about social networks of spinal cord injured individuals, we have added a more open ended section to the end of the questionnaire. This section has included items such as: who was the most helpful person to you following your injury; what types of support were most helpful to you. We have used House's (1981) taxomony of types of social support,(that is, instrumental, emotional, informational,) to explore the specific support functions that have been most helpful to people. This information has been used purely descriptively, and has considerably enhanced our understanding of the support systems of people we work with.

I hope this rather lengthy explanation has been helpful. As I am sure you will understand, the SSIDP is still very much in a developmental phase. I would suggest that if you use it in your study, you consider doing some psychometric confirmations of your own, such Cronbach's alpha and basic item analyses and descriptive statistics.

Best of luck with your work. I look forward to hearing more about your study. Please feel free to call me if you require any clarification or if you wish to discuss this further.
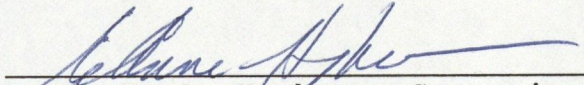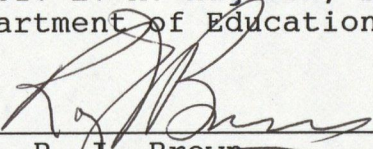
My best regards,

M.A. McColl

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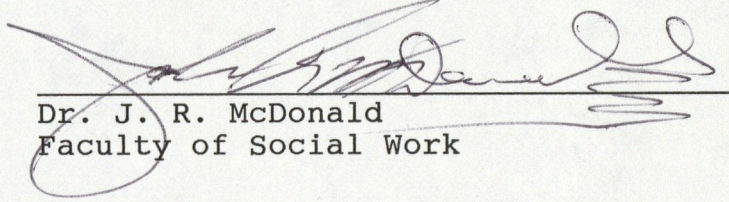
The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies for acceptance, a thesis entitled "Perceptions of Friendship Based on the Views of People with and without Cognitive Disability" submitted by Daphne Ruth Lehman in partial fulfillment of the requirements for the degree of Master of Science.

Prof. E. A. Hughson, Supervisor
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Date: Nov. 26/91

ii

ABSTRACT

Friendships are enjoyed universally by most people and are seen as contributing significantly to a life of quality. Many people with disabilities have only recently become physically present in the community and many remain socially isolated within their community settings.

The focus of this exploratory study was to examine some perceptions regarding friends and friendships as reported by twenty people with and without cognitive disabilities. All participants volunteered and were naturally paired by paid support roles prior to the study. All participants presented their own personal views and on rare occasions when a paid support person "corrected" the view of their partner, the stated opinion of the person with the disability was reported. This phenomenological research incorporated aspects of qualitative and quantitative methodologies and data was collected over two interview stages. The use of the dual methodologies was determined to be beneficial for the purposes of this exploration, however, the resulting limitations have been addressed.

Results from this investigation showed both similarities and differences between the two groups.

Indications were that people with disabilities reported perceptions and experiences regarding friends and friendships differently from their paid caregivers.

Discussion of these findings has led to implications for practice and research. While the people with disabilities in this study did not perceive themselves as socially isolated, their friendships were interpreted to be qualitatively different from their paid partners. In addition, this research highlighted the consistency and validity of information provided by the people with disabilities, confirming that they are the best source of information regarding circumstances affecting their lives. Further research and understanding, which is based on the perceptions of the people involved, is seen as a necessary component for future work in this area.

ACKNOWLEDGEMENTS

DEDICATION

I dedicate this thesis

- to the memory of my son and friend, Matthew Grant

- to my children, Kris, Allan, and Josie

- to my husband and friend, Terry

TABLE OF CONTENTS

LIST OF TABLES

CHAPTER I

INTRODUCTION AND LITERATURE REVIEW

INTRODUCTION

The last four decades have been witness to a multitude of changes that have affected the lives of people with cognitive disabilities. In spite of the progress that has been evident in many domains, people with cognitive disabilities have often remained isolated from the communities in which they live. One of the ways that people have come to feel accepted and experience a sense of connection in their social worlds is through their friendship relationships. As pointed out by Atkinson and Williams (1990), people establish who they are, and where they belong through their friendship relationships.

Aries and Johnson (1983) referred to friendship as a unique relationship characterized by voluntary association and affective ties. The Peerage Reference Dictionary (1980) defined a friend as a "person with whom one is on mutual terms of affection and respect....a helper or sympathizer" (p. 261), however each individual person attributes different qualities and emphasizes different aspects of friendship. There is also evidence which has suggested that men and women tend to experience friendship differently (Gilligan, 1982). If friendship is a major contributor to a meaningful life and if friendship is at the root of

developing caring communities (Strully & Strully, 1985),
then it is critical that an understanding be developed as to
how people with cognitive disabilities experience and
perceive friendship. Without such understanding, the quest
to integrate and include persons with cognitive disabilities
in the community can only result in partial success, and
while these individuals may indeed be physically present in
communities, they may share no meaningful personal
connection to that world. This study examined aspects of
friendship (and social life experiences) from the
perspectives of people with and without cognitive
disability.

The specific purpose of this project was to examine
friendship experiences and perceptions of friendship based
on the information provided by 20 people, 10 of whom were
individuals with cognitive disabilities. The remaining 10
people were all in positions of paid support roles to the
participant with the disability. The research design
incorporated both qualitative and quantitative methodologies
as the combination of these methods seemed well suited to
the area under investigation. The focus was to explore how
people define and experience friendship from a
phenomenological viewpoint.

Research has indicated that parents (or guardians) and
clients (people with cognitive disabilities) indicate
concerns regarding the nature of the (client) friendships

and it appears from this data that the interaction between clients and friends is often superficial (Brown, Bayer, & MacFarlane, 1989; Garvey & Kroese, 1991). Brown et al. (1989) used the term "spectator friendship" to describe the type of relationships often observed amongst many individuals with cognitive disabilities, suggesting a lack of active involvement. Lutfiyya (1988), in reference to a training session with residential staff, relates that these staff, when thinking of the persons they worked with (all of whom had cognitive disabilities), determined that none had "best friends". It was expected that an increased understanding of the personal perceptions of friendship would raise questions and provide suggestions for further exploration on this and related topics. Although it was anticipated that patterns and trends would emerge as the research progressed, it was not known whether the trends would be across the groups or unique to each group.

REVIEW OF LITERATURE

History

At the turn of the century, the majority of people with disabilities were hidden from public view and regarded as "unproductive burdens" (Driedger, 1989, p.7). With the advent of World War 1 this attitude began to shift. Many young men were engaged in fighting the war thus increasing

demands for productivity on all persons who remained "at home", including those with disabilities (Brown & Hughson, 1987). It was not until after World War 11 that major changes began to emerge. Prior to this time most services were available only from hospitals or institutions, and typically the institutions were located away from communities (Lord, 1984). Protection and care were vital concerns and included not only the protection and care of the individual with disabilities but also the society. Clarke and Clarke (1975) suggested that although humane attitudes towards persons with disabilities contributed to the concern for care and protection, protection of society was the main objective of services in the early part of this century. Baroff (1974) has referred to the attitudes of society towards persons with cognitive disabilities as varied and cyclic, at certain times ignoring the needs of these people and at other times showing a high degree of compassion.

During the first half of this century, the medical model was most influential. Baldwin (1985) identified five separate, though not necessarily mutually exclusive, models of service delivery to persons with cognitive disabilities. These included the developmental model, the social-ecological model, the psycho-educational model, the behavioural model, and the medical model. Differing fundamental attitudes, beliefs, and values underlie the

models and have had impact on service delivery.

The medical model has continued to impact on the lives of people with disabilities. Underlying the medical model is a conceptual framework of physical illness (Baldwin, 1985), consequently people with disabilities served by this model were viewed as sick or frail. As most disabilities are permanent in nature, the individuals could not become "well" and therefore, could not participate in the mainstream of society. In a sense, the medical model provided a rationale for excluding people from their communities and encouraged an attitude of pity toward persons with disabilities. This model also helped to maintain the societal attitude that people with disabilities are "different" and should be set apart thus denying their shared humanity. The term "rehabilitation" has its roots in this model and while it is partially defined as a restoration of "rights, privileges, [or] reputation", the definition also includes a restoration to "proper condition" (Oxford Dictionary, 1960, p. 682).

During the 1950s parent groups began to advocate for needed community services for their children. Specialized education services, although typically segregated from mainstream educational services, were introduced. Parents were responsible for the early development of many of the volunteer organizations that exist today. Boards were founded, and initially private funding was attained which

allowed the groups to hire professionals to deliver the
needed services. Most organizations had a single disability
focus during this time and groups were formed on the basis
of parental and professional advocacy rather than self-
advocacy.

History shows a series of situations where people with
disabilities were excluded from any self-representation and
eventually these people began to form their own
organizations. Although some groups had formed their own
organizations as early as 1960, one of the first groups to
emerge in the area of cognitive disability was People First
in 1974 (Driedger, 1989). It should be noted that although
people with disabilities share some common history, there
are also specific aspects of history which are unique to
each disability group. For example, it has been many years
since a person with epilepsy has been institutionalized
solely because of the impairment, yet the possibility of
institutionalization still remains for a person with a
cognitive disability.

People with cognitive disabilities have only recently
become visible in the community and many individuals remain
in large and small institutional settings, where individual
behaviours are learned and reinforced "that further distance
[them]...from the broader community" (Taylor & Bogdan, 1989,
p. 24). As these people move into the community, the value
of personal relationships (often apparent due to their

absence) has taken on new meaning.

Movement to the Community

As previously mentioned, parents were responsible for
the creation of many societies for persons with cognitive
disabilities and these parents hired professionals to
deliver services that provided an alternative to
institutional care. The professional model (which could fit
into any of the aforementioned models, but assumes that the
professional "knows best") to which parents
looked for guidance and service eventually led to the
acknowledgement that the model often did not take into
account the wealth of information that families could have
provided. Typically, the emotional attachments between
family members and the roles of the individual family
members were negated or ignored in the efforts of the
professionals to provide service to the person with the
disability. The professional model did not usually attempt
to meet the needs of the "whole" person but focussed on the
remediation of specific "problem" areas. Although families
were usually the "experts" in terms of knowing and
understanding the needs and strengths of their family member
with a disability, this model did not usually incorporate
their views.

Darling (1991) has used the concept of worldview to
explain this phenomena. Members of the same cultural group

tend to view the world in a similar way, however, these views can be quite divergent depending on the extent to which the life experiences have differed. The life experiences and consequent expectations of parents differed from those of professionals which resulted in strained parent-professional interactions where "conflict is a common outcome" (Darling, 1991, p. 120).

Parents believed that the professionals had solutions to some of the problems they encountered but it became evident that the professional group did not have "all the answers". As confidence in the medical and professional models began to wane, more and more consideration was given by service planners and operators to families and other caregivers. Developers of service began to listen to families in the 1970s and the services were developed based on what families (and other caregivers) felt that they needed in order to assist them in their role. This enabled families to be heard and public funding became available to provide services for individuals with disabilities who remained in the community. Although more of a partnership was emerging between families and the people who provided services to the individual with a disability, the person with the disability was not included in this relationship. Nevertheless, the changes in attitudes and services enabled people with cognitive disabilities to remain in their communities.

Normalization

A concept that has had a major influence on attitudes
and the development of services is that of normalization.
Bank-Mikkelson (1980), Nirje (1980), and Wolfensberger
(1980a) have all had considerable impact on the defining and
implementation of normalization. Bank-Mikkelson first
stated that normalization involved "letting the mentally
retarded obtain an existence as close to the normal as
possible" (Wolfensberger, 1980a, p. 7). Nirje
(Wolfensberger, 1980a) has been credited with having written
the first systematic statement of normalization and
Wolfensberger elaborated further on the principles,
attempting to broaden the scope to include all devalued
persons rather than being limited to any particular group.
Wolfensberger (1980a) has defined normalization as the "use
of culturally normative means to offer persons life
conditions at least as good as that of average citizens, and
to as much as possible enhance or support their behavior,
appearances, experiences, status and reputation" (p. 8). By
1983, Wolfensberger had coined the term social role-
valorization to replace normalization, further emphasizing
his conviction that the aim of normalization was to enable
culturally valued means to achieve socially valued roles.

While this ideology has had enormous impact,
Wolfensberger (1980b) gives examples of what he terms

outright perversions of the concept, including
"normalization is making the institution as normal as
possible" (p. 101).

Nirje (1980) determined that being labelled "mentally
retarded" has involved dealing with three handicaps. The
cognitive impairment itself has led to varying degrees of
disability within the societal context. This impairment has
also presented difficulties for individuals in terms of
understanding self and personal growth. The third area
involved "imposed or acquired retardation" (Nirje, 1980, p.
32) and reflected the impact of deficiencies in the
environment or society. Although the three areas were
interrelated, the latter was openly available to change.

While changes in the attitudes and values of society
have not eliminated the impairment of the individual, they
have had impact on the degree of disability and handicap.
The World Health Organization (1980) has clarified the terms
impairment, disability, and handicap in the following way:

> Impairment: Any loss or abnormality of
> psychological, physiological, or anatomical
> structure or function.
>
> Disability: Any restriction or lack (resulting
> from an impairment) of ability to perform an
> activity in the manner or within the range
> considered normal for a human being.
>
> Handicap: A disadvantage for a given individual,
> resulting from an impairment or disability, that
> limits or prevents the fulfilment of a role that
> is normal, depending on age, sex, social and
> cultural factors, for that individual. (p. 14)

The World Programme of Action Concerning Disabled

Persons (1983) pointed out that handicap is therefore a function of the relationship between persons with disabilities and their environments and includes the loss or limitation of opportunities to take part in the life of the community on an "equal level with others" (p. 3).

The principle of normalization has provided a means whereby the handicaps imposed by society and its members can be identified and, hopefully, reduced. It has meant "making available to all mentally retarded people patterns of life and conditions of everyday living which are as close as possible to the regular circumstances and ways of life of society" (Nirje, 1980, p. 33).

This movement has had a profound effect on the attitudes of people towards persons with disabilities, particularly with regard to how and where these individuals have lived their lives. Most individuals with cognitive disabilities have been set apart and seen as objects of pity or as "less than human". As humans, we typically relate to and form relationships with people that we value, and for people with disabilities, the status of being viewed as fully human has been rarely accorded. As these individuals with disabilities became more visible in communities, the possibility of being recognized as valued people began to develop. In having accepted the ideology of normalization, the cultural norms (such as living in a community of "typical" people) have been applied to all members of

society, including those who have traditionally been seen as having no value. Normalization had set the stage for previously devalued people to meet and form relationships with valued members of society.

The Changing Nature of Services

Brown and Hughson (1987) have described the historical development of services as having moved from structured to less structured and from concrete to more abstract forms of service delivery. For example, the institutional care model which was prevalent in the 1950s, was designed to provide all necessary services to the individual. Thirty years later, services had been developed in community settings which included not only group home living and vocational training, but also provided assistance for the development of home living, social, and leisure skills. While these more abstract and less structured program models have certainly improved the lives of people with disabilities, the structured institutional model has not been eliminated, but has existed along with the newer developments.

An even more recent development in Canada began in the late 1970s and the early 1980s when groups of parents founded societies whereby people with disabilities can live in their own homes with the necessary paid supports. The concept of home ownership, particularly for individuals with severe disabilities, has been an indication of the changing

attitudes toward persons with disabilities.

Although people with disabilities had been living in the community prior to this movement, they were typically living in group homes or family settings. The ownership of these homes varied (private, government, agency) but did not include the individuals who were served. Individuals with disabilities who lived in these settings were typically placed according to specific criteria and could be moved at any time.

The concept of ownership not only guaranteed personal choice of living accommodation but also built in a degree of stability and security. Inherent within this concept was a subtle change in attitude. Rather than "staff" going to work at the group home, they now went to "a person's" home to provide support. Often these situations allowed the people served to take part in the selection of staff, further emphasizing the rights of individuals with disabilities to speak for themselves in a meaningful way and according them the dignity of choice. In many cases, the person providing service under these circumstances moved away from the "staff" role and into a "support" role which involved a caring relationship with another human being.

McKnight (1985) has commented that "care is a special relationship characterized by consent rather than control" (p. 8) and for individuals with disabilities this change has provided opportunities for developing some meaningful

connections, at least in the context of their homes.

Quality of Life

The emphasis on understanding the needs and describing the lives of persons with disabilities has, in recent years, largely revolved around "quality of life" issues. Emerson (1985) defined quality of life as the "satisfaction of an individual's values, goals, and needs through the actualization of their abilities or lifestyle" (p. 282). In a subjective definition, Walker (1988) stated "for me, quality of life not only embraces where I live and work, but also includes the ability to make choices in my environment" (p. 255). Brown et al. (1989) have provided two interrelated definitions which include the discrepancy between a person's achieved and unmet needs and desires as well as the extent to which an individual gains increasing control over aspects of life. It has been suggested that no precise definition can be given for quality of life (Brown et al., 1989) but it has been generally accepted that quality of life is a very personal and individualized issue that involves an interaction between the person and the environment.

As was the case with the concept of normalization, outright perversions of the application of the quality of life concept have also occurred. One example came from a large institutional setting in Western Canada where

individual program plans included in their objectives a section on Quality of Life. For Jeff (not his real name), this meant the he would be "given access to materials and dormitory [and] will make 12 beds in small dorm" and Jeff would also be "given mop and pail containing water and cleanser [and] will mop washroom floor after supper every night, leaving no excess water on floor" (L. Pfaff, personal communication, 1988). Jeff was also to receive 1 cent for every bed that he had made correctly.

Quality of life has encompassed not only the subjective viewpoint of an individual (as two different individuals may regard the same aspect of life as a contributor to or inhibitor of the quality) but has also allowed for the development of a comprehensive approach. Measures of quality of life have included both objective and subjective measures as well as combinations of the two. Objective measures can be attained by evaluating areas such as health, the physical environment, or skill attainment levels, whereas subjective measures have included areas relating to the perceptions of the individual (Brown et al., 1989). Within this context, "personal relationships in love, belonging, hate, respect and responsibility should be evaluated" (Brown et al., 1989, p. 60). Quality of life must address all areas of an individual's life as life quality is not viewed as a function of any one domain. The "enhancement of the quality of life of developmentally

handicapped individuals is the ultimate goal of the philosophy of normalization" (Brown et al., 1989, p. 67).

O'Brien (1987) identified five essential outcomes that constitute a quality of life and suggested that when these are jointly considered, they define the principle of normalization. Included in this framework are community presence, community participation, choice (in small, everyday matters as well as large, life-defining matters), respect (having a valued place among people), and competence (the opportunity to perform functional and meaningful activities with whatever assistance is required).

Rowitz (1989) predicted that the developing concerns regarding quality of life would become one of the trends of the 1990s. The problems and confusion associated with defining the term, the identification of the positive and negative factors associated with quality, and the subjective and objective determinants of quality of life are some of the issues that must be explored (Rowitz, 1989).

A conceptual model has been used to illustrate some of the domains which affect quality of life and the interrelatedness and importance of both subjective and objective measures (Brown et al., 1989). Subjective measures included life satisfaction as well as psychological well-being and objective measures included the areas of health, economic stability, growth and mastery, and the quality of the environment. High quality of life would be

reflected by high measures on the domains outlined.

One aspect of life which can have great impact on the majority of domains outlined is that of social support.

Social Support

Social Adjustment

Social adjustment has been recognized as a major factor in successful community living (Romer & Heller, 1983) and has been defined as "the ability to initiate and maintain positive social relationships, friendships, and enduring patterns of affiliation with social agencies in the environment (Walker & Calkins, 1986, p. 49). The topic of social adjustment is one that has been researched extensively and has led to at least two major intervention approaches: social skills training and social-ecological support (Romer & Heller, 1983).

Social Skills Training

Social skills training had its roots in the psychology of learning and assumed that social adaptation was a function of cognitive and behavioural abilities. Poor social adjustment has been assumed to result from a deficiency in these abilities and training was the means of overcoming the deficiencies (Romer & Heller, 1983). As people with cognitive disabilities began to move from institutional settings into the community, it was observed

that many of these individuals did not know how to conduct themselves in a variety of social situations and the social skills approach was often used as an intervention technique. While there were some benefits to this approach, there were certain limitations. People with learning difficulties have found it difficult to transfer skills they have acquired to new environments, therefore, teaching a social skill in one setting (which has been typical) may not have any impact on the other settings that the individual encounters. Further to this, generalization has been a major problem for many individuals with cognitive disabilities. Distinguishing between stimuli that are reasonably similar has presented difficulties for these individuals (Brown & Hughson, 1987). Given the wide variety of possible social interactions (and skills required), it is not surprising that social skills training has been less than totally successful when used as a method of intervention in achieving community adjustment or in the development of relationships that could lead to meaningful community inclusion.

Social-Ecological Approach

Social skills training has placed emphasis on the deficits of the individual whereas the social-ecological approach has its roots in the interactionist tradition in personality theory (Romer & Heller, 1983) and has emphasized the joint influence of the person and the environment on

motivation and behaviour. Within this context, the fit between the individual and their environment has been viewed as determining the success of social adjustment. The better the match between these two components, the better the degree of social adjustment. A critical concept in the latter approach has been the notion of social networks.

Social Support Networks

Social networks have referred to human interactions, which may or may not provide social support (Israel & Antonucci, 1987). Social support can be understood as a metaconstruct involving three subsidiary constructs; support network resources, supportive behavior, and subjective appraisals of support (Vaux, Riedel, & Stewart, 1987). Further, social support may be comprised of different types of help or assistance and Vaux et al. (1987) have suggested that "a consensus is emerging as to a set of some four to six major modes of support" (p. 210). Cobb (1976) has identified three modes of social support which include emotional support, esteem support, and belonging to a network of mutual obligation that is common and shared. Gottlieb's (1989) typologies of support also included emotional and esteem support, along with support derived from cognitive guidance, material/tangible support, socializing/companionship, milieu reliability (referring to someone who can be counted on when needed), and belonging

support.

According to Gesten & Jason (1987) there were 450 studies on social support published in the psychological literature in the two year period following the entry of "Social Support Networks" as an index term. It has been reported that problems of measurement, definition, & research inconsistencies abound (Alloway & Bebbington, 1987; Barrera, 1986; McColl & Skinner, 1988).

Social Support Definitions

Social support definitions may focus on the emotional aspects of support, the instrumental, informational, or practical components of support, goal attainment, esteem components, or belonging aspects (McColl & Skinner, 1988). Gottlieb (1988) has reported "that a meeting of researchers on social support, convened by the US National Institute of Mental Health to agree on specific criteria for it's definition, only made progress in their discussions when they stopped trying to define social support" (O'Brien and O'Brien, in press). O'Connor (1983) has stated that:

> In its simplest sense, social support is made up
> of the emotional, informational and material
> support provided by friends, relatives, neighbors,
> service providers, and others with whom one has an
> ongoing relationship and to whom one can turn in
> times of need or crisis. (p. 187)

Although the definitions all contained the concept that social relationships have beneficial aspects, the subtle variations that have existed become problematic when

attempts are made to operationalize the definition.

Social Support Measures

Many measures have been introduced, all based on unique definitions of social support and Antonucci (1985) suggested that the intuitive nature of social support has prompted conceptualizations that are not necessarily empirically supported.

Gottlieb (1985) reported that three different categories can be identified that reflect differences in the measurement of social support and the first category, which he referred to as the macrolevel of analysis, revealed only that those persons who were more socially embedded tended to fare better than those who were not socially embedded. Individuals were seen as embedded in sets of interpersonal relationships which provided support when the individual experienced stress (Romer & Heller, 1983). This category looked primarily at the number and frequency of social contacts and revealed quantitative information regarding the degree of social integration and participation (Gottlieb, 1985).

The analysis and examination of the structure and supportive functions of social networks occurred at the mezzolevel and concerned itself with the people that an individual saw on a regular basis and considered to be close peers. Information regarding the properties of these

relationships (e.g. material assistance, companionship) can be attained as well as information about the network as a whole, such as density (or the interconnections between network members) and cohesion. Networks which were very dense tended to be very cohesive and resulted in greater opportunities for sharing information and receiving social feedback (Gottlieb, 1985).

Finally, the microlevel of analysis included the quality or content of close or intimate relationships. This category of analysis was based on the belief that social support "essentially stems from the deep emotional nurturance which only a select few can provide, [and] it is an approach that attends more to the quality or content of social relationships" (Gottlieb, 1985, p. 12). While Gottlieb (1980, 1988) has looked at numerous social support strategies across a variety of sample populations, there were no examples of studies which included people who have been labelled as "mentally retarded".

There has been a cautionary note in terms of viewing social ties as only supportive as this denies the complexity of social interaction which can also be conflicting and non-supportive (Starker, 1986).

Social Support Models

Cohen & Wills (1985) outlined two models of the support process: as a main effect (or embeddedness in a network) or as a stress buffer, which may intervene at two different points after the occurrence of a stressful event. If an individual has strong social support, the impact of stress will be less threatening to the individual when it occurs and the presence of this support will prevent exposure to certain stressors. A further benefit of the main effect process has been described as the sense of well-being experienced by individuals with good social support (Gottlieb, 1980).

In describing the buffering aspects, Cohen and Wills (1985) determined that the first intervention point arises from the influence of social support between the stressful event and a stressful reaction, thus preventing stress appraisal. This was similar to Gottlieb's (1980) description of the main effect process whereby an individual is less threatened by a stressful occurrence, but is distinguished by the fact that the stressful occurrence is not interpreted as a stressor as a result of the impact of the support network. The second point at which the buffering model could have an impact was between a stressful event and the pathological outcome, resulting in actions which prevented or reduced the stress reaction thereby influencing physiological processes (Cohen & Wills, 1985).

Gottlieb (1980) described the benefits of the buffering effect of social support as preserving feelings of self esteem, providing a sense of mastery when exposed to adversity, and as a protection against depression when stressful reactions occur. It was determined that both models show evidence of association between social support and well-being although each represents a different process, with enhanced well-being as an outcome.

Social Support and People with Disabilities

The importance of social support with respect to mental and physical well-being in the general population has been well-documented (Rosen & Burchard, 1990), but very little attention has been directed toward the social support patterns of people with cognitive disabilities. O'Brien and O'Brien (1991) speak of social support in terms of membership and identify 4 distinct experiences which contribute to this:

- Feeling attached to emotionally important other people
- Have the opportunity to engage in shared activities
- Being a part of a network of people who can approach one another for information and assistance
- Having a place and playing a variety of roles in economic and civil life

The concept of membership has provided a useful framework for envisioning social support.

O'Brien and O'Brien (1991) have reported that friendships are uniquely shaped by each individual's culture and personal history which results in a variety of kinds of

"belonging" that constitute the basis for social support. People who belonged, or who were recognized as members of social networks, have benefited from "everyday exchanges of support that create opportunities to play socially valued roles and chances to form personally significant 74relationships. People excluded from membership risk loneliness, isolation, and powerlessness" (O'Brien & O'Brien, 1991). Reference was made to the difficulties of speaking in terms of shared membership as words do not adequately describe feelings of belonging or exclusion and it was suggested that this is a reflection of the cultural devaluation of relationships (Gilligan, 1982).

Within the context of shared membership O'Brien and O'Brien have stated that it is critical that all citizens come to recognize that we are all "members of each other". As people with cognitive disabilities become more visible and active in the shared physical places that define community life, recognition of this membership will continue to develop and grow for those people that society has labelled as "different".

Friendship

Informal social support has typically included friends, family, and neighbors (Denoff, 1982). These relationships have been seen as vital in determining overall quality of life (Donegan & Potts, 1988; Krauss & Erickson, 1988).

People with friends were reported to be more likely to have: a) reassurance of their worth and value, b) a sense of belonging, c) opportunity for community and social integration, and d) opportunity to receive and provide assistance and support (Stainback & Stainback, 1987). Informal supports were viewed as moderating the effects of life stress (Romer & Heller, 1984) and individuals who experienced stressful life events were reported to be less susceptible to illness if social support was available (Starker, 1986). Schulz and Decker (1985) found that network size and satisfaction with social support were inversely related to depression, life satisfaction, and psychological well-being.

"Researchers have been slow to investigate friendship" (Aukett, Ritchie, & Mill, 1988, p. 57) and research on "friendship and people who are mentally retarded is very sparse" (Rhoades, Browning, & Thorin, 1986, p.4). The qualities of friendship have also been elusive and difficult to define. Further, investigations have rarely attempted to determine how the frequency and range of activities compare between adults with and adults without cognitive disabilities living in similar communities (Rosen & Burchard, 1990). Alfred North Whitehead (1932) stated that it is the familiar things, like friendships, that are the hardest to research. Involvement in a friendship requires social behaviour and this term has covered a number of

variables such as social skills, interpersonal behaviour, personality characteristics, and emotional stability (Reiter & Levi, 1981). The complexity and variability of social behaviour has rendered it a difficult topic for research (Edgerton & Bercovici, 1976; Reiter & Levi, 1981). Also, it has been suggested that gender affects relationships and it has been noted that these gender differences have been observed in children.

Friendship and Gender

Furman and Buhrmester (1985) discovered that female children demonstrated greater intimacy (which increased with age) than their male counterparts and that companionship was the most important aspect of friendship for children (Reid, Landesman, Treder, & Jaccard, 1989). Male and female friendships in adulthood have been reported as qualitatively different (Aries & Johnson, 1983; Davidson & Duberman, 1982; Hess, 1982; Williams, 1985) and these differences tended to be related to the degree of intimacy between the friends. Although there has been no research specific to gender, disability, and friendship, Atkinson and Williams (1990) have noted gender differences in the stories told by men and women with disabilities. Where the men were at ease with a chronological life-story approach, the women's stories were usually about people who mattered and their relationships with them, as opposed to a systematic account of life

events.

Friendship and Disability

O'Connor (1983) suggested that individuals with cognitive disabilities tended to socialize primarily with other individuals with cognitive disabilities and she stated that this was a matter of choice rather than a result of lack of opportunity to have "normal" friends. Results of a previous investigation (Lehman, 1989) certainly indicated that although friends tended to have disabilities, there was no reason to believe that this was necessarily a matter of choice. It has been reported that having a friend without a disability was viewed as an achievement and a valued acquisition, and was not only a useful resource, but also provided for wider social engagements (Atkinson, 1986; Edgerton, 1967). Further to this, Kaufman (1984) reported that having one or more reciprocal normal friends was associated with high satisfaction and Reiter & Levi (1981) asserted that "mentally retarded people in the community have a compelling need for normal friends" (p. 83).

It was interesting to note that individual intelligence has appeared to be related to sociability only if individuals were segregated according to ability (Romer & Heller, 1983). Although it has been noted (McAndrew & Edgerton, 1964) that residential staff members' ratings of residents' sociability were positively correlated with IQ,

the possibility exists that the correlation is illusory "given the positive halo [effect] associated with both sociability and IQ" (Romer & Heller, 1983, p. 307). More recent research (Landesman-Dwyer, Berkson, & Romer, 1979; Romer & Berkson, 1980a) has shown either no correlation between IQ and sociability or the correlations were attributable to ecological constraints such as being segregated in programs according to the degree of disability (Romer & Heller, 1983). It has been noted that individuals with cognitive disabilities, when asked to report on their friendships, also failed to confirm an IQ- sociability relation (Romer & Heller, 1983).

Heller, Berkson, and Romer (1981) found that an individual's tendency to develop peer relationships appeared to be influenced by the sociability of their milieu. Settings with individuals who were exclusively of lower IQ tended to be less sociable than in settings where a wider range of IQ was represented (Romer & Heller, 1983), suggesting that perhaps the environmental conditions may have inhibited the development of social networks, particularly for those individuals with lower IQ's. There was also evidence which suggested that individuals preferred to associate with those of differing intellectual ability. (Romer & Berkson, 1980b). Also, although content of social behavior can be predicted by intelligence quotient measures, the extensiveness, intensity, and the number of friendships

cannot be predicted (O'Connor, 1983).

Causby and York (1991), when looking at predictors of success in community placement, found no relationship between intelligence levels and success. These factors suggest that there is a question as to whether or not individuals have had choice and opportunity in their selection of friends. A previous study (Lehman, 1989) indicated that persons with cognitive disabilities not only experienced a lack of involvement in non-segregated settings, but many people had no involvement at all, thus seriously limiting the chance of any friendships developing. Further, "special social club(s) for retarded persons seem to fulfill the functions of a sheltered framework without preparing the participants for social integration" (Reiter & Levi, 1981, p. 253). Yet, as Kaufman (1984) found, for those who do not attend sheltered workshops or social activities for persons with a cognitive disability, social opportunities are generally limited.

This topic becomes further complicated when residence is taken into account. For persons with cognitive disabilities who lived within the family residence, the family has been seen as forming a basis for social interaction and increasing opportunities for social integration. Family members were found to play a pivotal and somewhat exclusive role in the lives of their relatives with a disability (Krauss & Erickson, 1988), which suggested

a limited friendship circle.

Flynn and Saleem (1986) found that only one of the twelve individuals they interviewed saw friends aside from contact at the facility, and none of the individuals reported having normal friends. Landesman-Dwyer (1981) discovered that even if the individuals moved to a group home setting, if active contact was maintained with the family, there could be an increased risk of social isolation. As it has been noted (Jones, 1986) that contact with families is fairly frequent in group home settings, it appears that family presence may limit outside friendships and that congregated, segregated living arrangements may limit choice and opportunities for the development of relationships in general.

According to Wight-Felske (1984) people with disabilities have responded that "in their experience housing has not been a choice, but a concrete service dictated by government funding" (p. 61). Until quite recently people with disabilities had very little control or choice in most areas of their lives including residential setting, roommates, and paid support persons. Although friendships can be retained and were meaningful even after the friends had been separated as a result of a transfer (Berkson & Romer, 1980), very little attention has been paid to the consequences of separation. The "decision to move an individual to a new home or program is usually based only on

the quality of the new setting" (Landesman-Dwyer, 1981, p. 230). A previous study (Lehman, 1989) suggested that people do not retain friendships after they have moved, with only one person in twenty retaining such a friend.

Rhoades et al. (1986) reported that as people move into the community, they rely on friends and benefactors as an important source of social contact. Edgerton and Bercovici (1976) found that the availability of "nonretarded benefactors" determined success of community adjustment more than "any measurable skill, attitude, training, or experience" (p. 485), and the development and retention of friendships influenced whether self-identity would be as a stigmatized or socially valued person (Rhoades et al., 1986). These factors have emphasized the importance of what Atkinson (1986) referred to as "competent others" (p. 83) in the lives of people in determining social contact, success of community adjustment, and self-identity.

Friendship and Community Services

For many years, people with disabilities have been receiving services in the community and have been involved in a broad range of programs that have touched on most aspects of daily life. McKnight (1985) has described how the professionally administered services have usually been called "comprehensive, multidisciplinary, coordinated, · inter-agency service system[s]" (p. 4) and commented that

these systems have acted as the equivalent of institutionalization without walls, which has resulted in the creation of a totally dependent service system consumer. With regard to the social lives of people with disabilities, programs have been developed for social skills training, social-educational training, and social relations training.

While people with disabilities may have often required support in order to develop and maintain friendships, this support has not always been provided in the past. With the growing recognition that people with disabilities do not seem to have many friends in their lives, the concern has been expressed that friendship may become yet another service to be provided (Biersdorff, Young, & McClelland, 1991). As pointed out by O'Brien (1987), services alone are not enough and the benefits of friendship "cannot be purchased at any price" (p. 176).

Friendships are seen as mutually agreed upon relationships of a voluntary nature that develop naturally for most people. For people with disabilities, the paid caregivers have had a major influence on the social lives of the people they care for and this interaction must be understood and incorporated into the training that is provided for workers in this field.

Caregivers

The relationships that have existed between paid

caregivers and the people they serve have impacted on both parties in the relationship. Brown and Smith (1990) have presented the argument that a parallel exists between women and people with disabilities. Both have had the experience of being "rendered invisible" (p. 17) and both have suffered from varying degrees of devaluation.

The majority of paid caregivers have been women and the provision of care has been seen as part of "women's work". This work has often been devalued "both in an economic and in a social sense" (Munford, 1990, p. 26). The devaluation of both the work and of the people who have needed the care has affected the quality of care received as well as the types of relationships that have developed. For example, caregivers may have inadvertently restricted the people they have served in the name of protection. Further, the continued devaluation of the work has helped to perpetuate the devaluation of the people in need of care.

These factors have had implications for the training of caregivers. An awareness of the difficulties that have arisen as a result of the multiple devaluations may assist in the identification and remediation of related concerns.

People with disabilities have had a parade of people in their lives who have acted as caregivers. Often these caregivers have been intimately involved in the life of the person they served. When the caregiver decided to leave the paid role, they often left the person as well. The impact

of this interaction between caregivers and people with disabilities must be taken into account in the understanding of the lives of people with disabilities.   Over the past decades, rehabilitation practice has moved more and more into a less structured realm (ie. from institutional environments to the community) with more emphasis on abstract concepts. Initially, deinstitutionalization was seen as the answer to normalized living but difficulties have been most apparent.   It has become increasingly obvious that living in the community has not guaranteed that the person is a part of the community (Rosen & Burchard, 1990).   It seemed essential that the role of the paid caregiver, in determining the overall quality of life for the person with a disability, be better understood. Quality of life issues have not been resolved simply by moving a person to a community setting and physical presence has not ensured connections to or within the social environment.   Paid caregivers have had enormous impact on the social lives of the people they have served and an exploration of this interaction appeared necessary to the understanding of the social lives of the people with disabilities.

Discovering a Voice

In the last decade, advocacy roles, self-help groups and independent living centers have enabled individuals with

disabilities to represent themselves, and, as consumers of services, to have a voice in their own lives. Prior to the 1960s few civil or human rights were upheld for persons with cognitive disabilities (Walker, 1988). Since that time people with disabilities and their advocates have insisted that all people are entitled to basic human rights and that no-one can be discriminated against on the basis of disability. Great progress has been made in many areas relating to the lives of people with cognitive disabilities over the past few decades. Nevertheless, having the opportunity to live in and become a part of the community have continued to present challenges, not only to the individuals and to those who develop and deliver services, but also to the community at large.

Self-advocacy has allowed people with disabilities to speak and be heard for the first time in history. Society has traditionally expected these people to be passive and submissive and has regarded them as unable to contribute to decision-making that affected their lives (Siegel & Kantor, 1982). As a result, the people with disabilities became accustomed to decisions being made on their behalves, which further encouraged a "dependent" status. Opinions of people with disabilities have increasingly been sought by service providers and service planners and "researchers have begun to recognise the value of including the views of people with mental handicaps" (Atkinson, 1989, p. 63).

Although it has become more widely accepted that people with disabilities could be valued, contributing, full members of their societies, the abstract realm of relationships has remained elusive. Wolfensberger (1988) has described how the role of human service workers has been "to help, to be competent, and/or in a place of authority vis-a-vis the competency impaired person" (p. 70) and has suggested that human pride may have prevented these workers, who have placed value on independence and intelligence, from being aware of the value of the people they serve. Further, Wolfensberger (1988) has stated that some people have refused to acknowledge the assets of people with cognitive disabilities as a result of their participation in the devaluation of these individuals.

These factors have contributed to the types of relationships experienced by people with disabilities. If people who have provided services to these individuals have been unable to accept their value as human beings, the broader community is even less likely to have been able to value and welcome the people who have been classified as "different". While people with disabilities have begun to have a voice, until value is placed on the people behind the voice, their words have little meaning. Research has relied on the voice of caregivers and/or professionals when seeking information regarding the lives of people with cognitive disabilities. As friendship has been uniquely experienced

by each individual in the relationship, it is only the individual who can provided meaningful information on the experience of the friendship. Incorporating the voice of people with cognitive disabilities and their paid caregivers was determined to be a necessary component of research designed to explore personal perceptions of friends and friendships.

Research Issues

The exploratory nature of this research led to the decision to proceed with both qualitative and quantitative methodologies. According to Eisner (1977) using qualitative and quantitative methods together can provide a depth of perception that neither could provide alone. Given the lack of available research on friendship and disability, it was hoped that the combining of the two methods would allow for a broad base of data that could lead to the emergence of trends or patterns worthy of future consideration. While the topic of this project was well-suited to a qualitative design, the reporting of the results and the comparison of the two participant groups were seen as more reflective of a quantitative approach.

The quantitative approach allowed for the description of the measurable features of friendship and the phenomenological aspects of the study permitted the examination of the views of the participants. The views of

the participants were critical to this research as it was within their lives and experiences that the relationships existed. Research has not traditionally incorporated the voice of people with disabilities (Atkinson, 1989), but, for the purposes of this study, the views and perceptions of the individual participants were seen as the only valid source of information.

The use of the qualitative method encouraged the use of natural settings for data collection and allowed for more detailed descriptions of the participants (Lincoln & Guba, 1985; Pearsol, 1985; Stainback & Stainback, 1988). These aspects were seen as useful to the research question and were incorporated into the research design.

It was hoped that the exploration of the similarities and differences among the participants on their perceptions and experiences of friends and friendships would provide some information on the impact of paid caregivers on the social lives of the people they were paid to support.

Summary

There appear to be a number of factors which have influenced relationships in the lives of people with disabilities. Segregation, lack of choices and control, lack of support and encouragement, and family presence may all be relevant issues. It was hoped that by examining the nature of friendships within a social and ecological

framework, constructs would emerge that would be of assistance in both determining the major inhibitors and contributors to building friendships, as well as providing insights into the perceptions of friendship.

The aim of this study is to gain an understanding of how people with cognitive disabilities perceive the friendship relationships in their lives and this information can only be provided by the people themselves. People without disabilities were included to allow for a comparison of differences and similarities in the perceptions of the participants. Paid caregivers were chosen based on the interaction that occurs between the caregiver and the person with the disability, and the resulting influence on the social life of the person receiving care. It was determined that the most useful approach for addressing these aspects would be through the combining of qualitative and quantitative methods within a phenomenological framework.

CHAPTER II

METHODOLOGY

<u>INTRODUCTION</u>

General Information

Perske (1988) has commented that friendships are such
an everyday thing that we take them for granted in the same
way as we do clothing. To take the parallel further, one
could argue that friendship, like clothing, has many forms
and meets different needs at different times. The variety
of elements that has contributed to friendship is evident
when one looks at popular folklore in this area. Friendship
cards, friendship bracelets, books and booklets on
friendship are readily available in the community and
reflect the diversity of attitudes toward this everyday
phenomenon.

Anais Nin has stated that "each friend represents a
world in us, a world possibly not born until they arrive,
and it is only by this meeting that a new world is born"
(Friendship, 1989, p. 89). Ayn Rand commented that "love
and friendship are profoundly personal, selfish values...an
expression and assertion of self-esteem, a response to one's
own values in the person of another" (Friendship, 1989, p.
57). Another viewpoint was that "friendship is unnecessary,

like philosophy, like art...it has no survival value; rather it is one of those things that give value to survival" (C. S. Lewis in Friendship, 1989, p. 82).

In accepting the diversity and unique aspects of people's views on friendships it was clear that for research to be meaningful in this area, friendship must be understood from the perspective of the person involved. Phenomenological research, which underlies a qualitative approach, has allowed for this understanding and encouraged a discovery orientation (Pearsol, 1985; Stainback & Stainback, 1988). An emphasis on discovery as opposed to prediction and control was a necessary component of this research design. The emphasis of phenomenology has been on the subjective viewpoint and "the phenomenologist views human behavior, what people say and do, as a product of how people define (or interpret) their world" (Taylor & Bogdan, 1984, p. 8-9). From this framework, reality has been understood only in the form in which it has been perceived, and people's perceptions can and do influence their actions. Although previous research has indicated many reasons (e.g., lack of social skills) for the apparent lack of friendship relationships in the lives of people with cognitive disabilities, an understanding as to how this group perceives and interprets friendship has been lacking.

Recently, the opinions of people with cognitive disabilities have come to be recognized as valuable,

particularly in areas of research which directly touch their lives (Atkinson, 1989; Edgerton & Bercovici, 1976). Within the context of this investigation, the participants were seen as the experts with respect to the friendship experiences in their lives. The aim of this study was to gather information about how the participants report their experiences of friendship through the use of both qualitative and quantitative methods.

Combining Methodologies

Reichardt and Cook (1979) have commented that far from being antagonistic, "the two types of knowing (methods) are complementary" (p. 110). A caution is noted in that the differing theoretical perspectives of the methods must be taken into account (Taylor & Bogdan, 1984). For example, within the quantitative method, the purpose of the research has been to seek causes and effects of human behaviour, whereas the qualitative method has sought to understand people's interpretations and perceptions (Stainback & Stainback, 1988). Given that qualitative research has typically involved a single person or a small group of people, the question of generalizability or representativeness has often been seen as difficult to achieve. People's perceptions, interpretations, and situations change over time, therefore generalizations have not been likely to be true across different individuals and

settings. This has not been seen as reducing the value of qualitative research. Taylor and Bogdan (1984) have suggested that questions relating to generalization or representativeness can best be answered by other studies, either by the collection and consolidation of the findings in other studies, or by conducting a series of less intense mini-studies.

Cronbach (1975) has recommended that findings from qualitative research be regarded as working hypotheses. These hypotheses can then be evaluated as to their applicability to other areas depending upon the similarity of conditions present in the old and new situations. It is clear from this example that the caution noted by Taylor and Bogdan (1984) is of critical importance if research from either method is to be meaningful.

Differences in Qualitative and Quantitative Methods

Stainback and Stainback (1988) provided a summary of differences between qualitative and quantitative research designs based on ten dimensions including purpose, reality, viewpoint, values, focus, orientation, data, instrumentation, conditions, and results. Based on this analysis of differences, the paradigm used in this study is predominantly qualitative in nature, however, the dimensions relating to data, instrumentation, and results incorporated quantitative methods. While the data reflected the

perceptions of the participants, the interviews were relatively structured, in that the questions to be asked were predetermined, thus allowing for some comparison across the groups.

One stage of the data collection involved the administration of the Social Support Inventory for Disabled Persons (SSIDP) which was designed to provide both quantitative and qualitative data (see Appendix A). Actual taped transcripts were used as a basis for data analysis for a small portion of the data that was collected, but the majority of data was hand written and was analyzed and reported by use of descriptive statistics.

Within qualitative research, the data has typically been organized into categories, and these categories have evolved out of grounded theory. However, in this design the data was organized according to predetermined categories based on the structured questions. When all of the data had been collected and analyzed, the integration of data required a more qualitative approach. Categories that were indicative of overall themes or trends were dictated by the information received as opposed to being predetermined.

It should also be noted that the qualitative approach has often involved the participants in the actual analysis and interpretation of the data that has been collected. None of the participants in this study were involved in the analysis nor in the interpretation of the data. The

research in this area is developing and further methods will need to be examined that can lead to participant involvement in these domains for such populations.

Although in qualitative research, approaches to selection have generally evolved as the investigation progressed (i.e., snowballing techniques), this was not seen as necessary given the focus of the study. Stainback and Stainback (1988) have pointed out the danger in being focused on a small group of people as this may preclude a comprehensive understanding of the topic in question. Since friendship has been uniquely experienced by each person, there should not be a danger of assuming that all participants shared the same perspective. The personal experiences of the participants within their social worlds were expected to be reflections of unique relationships between people. Stainback and Stainback (1988) have also stressed the importance of including detailed descriptions in qualitative research reports to assist readers in their understanding of the findings.

The rationales for the numbers of participants chosen for this study were based both on time restrictions and a desire to attain enough information to explore trends. It was felt that more than 20 participants could restrict the depth of the study and that less than 20 could limit the ability to determine trends that emerged from the data. The repeated patterns or trends that emerged from the data were

seen as a means of validating the descriptions and interpretations.

The concepts of validity and reliability have been interpreted uniquely within the qualitative research method. Validity is judged by the degree to which there is a fit between what was intended to be studied and what was actually studied (Stainback & Stainback, 1988). Some aspects that have enhanced the validity of qualitative research include the degree to which rapport has been developed between the participants and the researcher and the degree to which the interpretations were consistent with repeated patterns in the data.

Reliability was reflected in the degree of fit between what occurred in the setting under study and what was recorded as data. Stainback and Stainback (1988) stated that to define reliability in terms of the "consistency of findings over time is in direct opposition to the nature of the data collected with qualitative methods" (p. 101). Within the qualitative method, it has been reported as unlikely that two researchers would produce the same findings on the same topic of inquiry (Stainback & Stainback, 1988), although both sets of findings could be considered accurate. Corroboration techniques can be used which help to ensure that the research findings have accurately reflected the perceptions of the participants.

This study incorporated several aspects of

corroboration. The questions used in the data collection were designed, in part, to gain information on the same topic but from differing perspectives. For example, the Social Support Inventory for Disabled People (SSIDP) which was used in the first interview, asked for the names of people that the participants felt very close to, and the second interviews asked participants to provide information about the people in their lives that they felt were important. This was not viewed as a method of confirming that the perceptions of the participants were "accurate", but rather as a means of assisting the researcher to increase her understanding. Stainback and Stainback (1988) have pointed out that increased understanding of the perceptions of participants is one aim of corroboration, but corroboration also increases the probability that the findings will be seen as credible or worthy of consideration by others.

Prior knowledge of the participants contributed to the ability of the researcher to accurately reflect participant perceptions. For example, if a participant mentioned the name of a "friend", it was likely that the researcher had previous knowledge of the relationship. In these cases, particularly for the individuals with disabilities, this allowed for an understanding of the situation that would not have been possible without prior knowledge.

Typically, people with disabilities have been regarded

as unable to provide information about themselves. In spite of the prior knowledge of the researcher and the presence of the paired partner during the second interviews, there was no evidence to suggest that these individuals were not fully capable of participating in this type of research. Any of the information provided by the participants with disabilities appeared to accurately reflect their lives. The only time that "corrections" were made by the paired partner without a disability, they related to personal perceptions. For example, there were occasions when a person with a disability was told that the person that they had just mentioned was "not really a friend" or that a particular family member was "not really as close as" another family member. In all cases where this occurred, the response of the person with the disability was recorded.

ETHICAL CONSIDERATIONS

After the details of involvement were fully explained verbally and in written form, all participants (and legal guardians where appropriate) signed a consent form (see Appendix B). Extra time was taken to ensure that individuals with disabilities fully understood the nature of their involvement, with particular emphasis on the voluntary nature of their commitment (i.e., they could withdraw at any time). Although all participants received a small

reimbursement for their participation, approval for the thesis research grant of an honorarium for participants was not received until after the data collection was complete and therefore had no influence on an individual's decision to take part. Each participant was paid within two months after the data had been collected.

Confidentiality was guaranteed and participants were advised that all of the data would be destroyed when the research was complete. All of the participants were informed that the results of the study would be available for them to access. No participant left the study after data collection began.

PARTICIPANTS

Selection

All of the participants were known to the researcher prior to the study and all voluntarily agreed to take part when approached. People were asked to volunteer in pairs, with each pair including one person with a cognitive disability and one person whose role was that of paid support worker to the other. The participants determined with whom they would be paired. Individuals were accepted on a first come, first serve basis up to a total of 10 pairs (20 participants) and all participants were over the age of 18 years. With one exception, all of the pairs were of the

same gender and included four male pairs and five female pairs. Only those persons who were able to verbally communicate with the researcher were approached for this study in order that third party interpretations could be avoided.

General Information about Participants

The total number of participants in the study was 20 and included 10 people without cognitive disabilities and 10 people with cognitive disabilities. All of the participants lived in a large city in a community setting in typical homes (i.e. single family dwellings, duplexes) and all of the situations involved individualized service and funding. Each participant was able to verbally communicate with the researcher and, with the exception of one person without a disability who was raised in England, all participants were born in Canada.

Description of Support Service Operations

At the beginning of this study all of the people involved were supported and directed by a local brokerage and support service group. The concept of brokerage has evolved to include different approaches and Maclean and Marlett (1987) outline four models of service brokerage including agency brokerage, placement brokerage, government official, and independent service brokerage. The

participants with cognitive disabilities in this study were

served by a model similar to the last. For the participants

in this study, brokerage was defined as:

>A technical support role which seeks to empower
>the person served. The role varies according to
>the person's life situation. It often includes:
>
>- assessment of the person's service needs and
> desirable lifestyle
>- assessment of the community's ability to respond
> to the above
>- planning with the person and his/her significant
> others toward achieving the desired lifestyle
>- negotiating with potential service providers
> and/or funders
>- creation of service delivery and/or funding
> sources
>
>(Leep Brokerage and Support Services,
>personal communication, 1988)

Within the context of this model, planning for a person

may include all aspects of the person's life, as was the

case for all of the participants with cognitive disabilities

involved in this research. Funding was considered to be

"individualized", as it was directly tied to the service

needs of the person. This concept influenced the study as

the participants had the benefit of receiving services that

had been "customized" to suit them as opposed to block

funding where the individual must fit the service. All of

the participants without disabilities were supported in

their service delivery role by the same brokerage and

support services group. Between the first and second

interviews the brokerage and support service group

discontinued its service, yet all of the participants

remained stable throughout the research project (i.e. none of the paid relationships changed). Most of these situations were operating on an "independent" basis throughout the time of the second interviews, and some retained this status. Others affiliated with different service operators in the city. In one situation, an individual did change his residence but this did not affect the relationship between the paired participants.

Description of Support Roles

A variety of support roles have been referred to and were indicative of the type of paid relationship that existed between the paired participants. Most of the people without disabilities were in a paid residential support role, which included providing any supports necessary to enable the person with the disability to live in their home. The intensity of support varied according to the need, but typically the residential support person had complete responsibility for ensuring that attention was paid to all aspects of home living and personal care.

Vocational support roles referred to any person whose role included support provided during "working hours". Two of the paired participants were involved in this way through an alternative day program and the third pair was set up independently (i.e. no attachment to any program or facility). The role involved providing personal support as

required but the focus was to enable the individual with disabilities to be involved in meaningful daytime activities.

One of the pairs was involved in a relationship where the participant without a disability was the personal monitor to his partner. This role involved knowing the person with the disability well enough to be able to evaluate and report on the individual's well-being to the guardian, service provider, and government agency. Support was provided to the person with the disability in the sense that the monitor's alliance rested with the person rather than with any particular service group or funding operation. This role was the least intensive of all of the support roles, but the individuals knew each other well from a previous paid residential support relationship.

Table 2.1 describes some features of the relationships between pairs of participants:

Table 2.1

Basic Descriptive Information

Relating to the Paired Participants

Descriptors

Participants	1	2	3	4	5
A1	20	M	22.5	2.0	Residential
A2	35	M			
B1	43	F	21.0	4.0	Residential
B2	38	F			
C1	32	F	30.0	0.7	Residential
C2	25	F			
D1	28	M	17.5	7.0	Vocational
D2	19	M			
E1	42	F	40.0	4.0	Vocational
E2	36	M			
F1	25	F	40.0	3.5	Residential
F2	34	F			
G1	45	F	1.5	2.0	Relief
G2	28	F			
H1	43	F	12.0	3.0	Relief
H2	48	F			
I1	23	M	0.5	4.0	Personal
I2	30	M			Monitor
J1	31	M	15.0	0.8	Vocational
J2	43	M			

Note. Descriptor 1 = Age in years as of January, 1991.
      Descriptor 2 = Gender.
      Descriptor 3 = Average number of hours spent together
                     each week.
      Descriptor 4 = Length of time in years that the
                     participants have known each other.
      Descriptor 5 = Type of support role.

      Letters have been used to designate the pairs.
      Numbers have been used to designate the person with
      the disability (1) and the person without the
      disability (2).

<u>Work Activities</u>

The two general classifications that have been used to describe the daytime activities for the participants with cognitive disabilities are the sheltered workshop and alternative work programs. The sheltered workshop environments provided some work experience within a facility-based service and on occasion work contracts were carried out in community settings. The three people who attended sheltered workshops spent the majority of their days in the company of other "clients". The opportunity for wages to be earned was very limited for any of the people in these programs and none of the individuals in the study who attended the sheltered workshops were in the same program.

The alternative work program designation referred to two separate day programs. One of these programs shared some of the aspects of the sheltered workshop environment, but differed in that there appeared to be a greater opportunity for individualized approaches. This was partly a result of individualized funding. Although the program was segregated and facility-based, there was a greater degree of flexibility, possibly due to the relatively small size of the program. Two of the participants were involved in this type of work setting.

The other alternative program was originally developed for one of the participants who did not fit any existing service and had expanded to include several other

service and had expanded to include several other individuals. The program was not facility-based and was completely individualized. Opportunities for earning wages existed as the organizers of the program sought out a variety of jobs in the community such as housecleaning or yard work and any money that was earned was shared by the individuals in the program. Volunteer work was also a part of the program and typically involved activities such as shopping for people who were restricted in mobility. Two participants were involved with this alternative.

One of the participants was employed on a work crew. Supports that were provided included transportation to and from the work site and active supervision while working. Two of the participants were unemployed at the beginning of the data collection, but one of these individuals had found competitive employment by the time of the second interview.

The people without disabilities were employed only in human services work during the interview times. Only one participant worked exclusively with their paired partner and had no other job responsibility or place of employment. Five of the participants worked directly with their paired partner, but also served other individuals with disabilities who shared either a home or a place of work with the paired partner. Of these five people, two were also employed in other work situations. The four remaining participants without disabilities were employed to serve only their

paired partner (i.e. no responsibilities to other individuals), but all of these participants were employed in other capacities (e.g. teaching assistant or other paid support positions).

Specific Information about Participants

As the people all volunteered in pairs, it seemed fitting to describe each individual, at least partially, in the context of their shared relationship. All names have been changed to protect anonymity. Wherever letter designations (i.e. A -J) have been used, they consistently reflect the same pairs of individuals. It should be noted that where individuals with disabilities have reported a grade level, it was likely that this reflected specialized education levels which are not equivalent to the regular system.

Where the term "significant other" has been used, it refers to married persons (1), common-law arrangements (6), or self-described, long-standing relationships of at least 2 years duration (4). In the one case, where Bill lived with his girlfriend for a short period of time, the relationship has been categorized as long-standing. Ages have been reported in the context of young (18 - 30 years of age) or middle aged (31 - 48 years of age).

Paired Participants (A)

Don was a young man with mild cognitive and physical impairments who was reported to have a sexual disorder that was the result of a genetic syndrome. Don has been in therapy to treat his sexual disorder since his first sexual offense at the age of 13 and was incarcerated in restrictive settings for six years prior to his unsupported release to the community. Don has been judged to be a high risk to others in the community and the potential for long term re-institutionalization was reported as high. Don reported that he has completed Grade 9 and that he has been involved in the past with a vocational rehabilitation program. He was not working when the first interview was conducted. By the time of the second interview he was competitively employed in the community and had no contact with any programs. According to Don, he found this job on his own with the support of his partners.

Although initially there were no supports in place for Don, through brokerage services, a 24 hour funding model was approved and implemented. This support was seen as necessary both for the protection of Don as well as for the protection of the community. The support role involved teaching the skills required to live independently, companionship, and monitoring Don's whereabouts (a condition of probation). The latter has reduced significantly over time as the combination of support, therapy, and medication

seem to have decreased the risk of another offence being committed by Don.

Don's paired partner was Cameron, a middle-aged man, whose previous work experience included work as a cook and as a bartender. Cameron reported a Grade 11 education and he lived with his significant other when he was not providing support to Don. Cameron lived in Don's home during the week and was replaced by relief staff on the weekends. This situation has been stable for over 2 years.

Paired Participants (B)

Ellie was a somewhat shy middle-aged woman with moderate cognitive and speech impairments. She was reported to be quite fearful in most new situations, especially when males were present. Ellie spent 38 years in a large institutional setting which she was admitted to at the age of 5 years. Ellie was not reported to present risk to others, but was viewed as vulnerable due to her lack of skills and experience. She attended an alternative day program and reported no educational background. Ellie lived in her own home which was shared with two female roommates. Support has been provided to Ellie on a 24 hour basis which has enabled her to live safely in the community and has included almost all aspects of daily living. Although Ellie has changed her residence once since moving to the community in 1988, most of the people involved in her life have

remained the same.

Ellie's partner, Doreen, was a middle-aged woman with two children and a significant other. She has a university degree and has always worked in human services.

Paired Participants (C)

Lana was a middle aged woman with moderate cognitive impairments who has experienced some behavioural difficulties. There were concerns with regard to mental health issues prior to her move to the community, but Lana has exhibited no difficulties in this regard in her community home. Lana can be difficult to understand but her speech has improved dramatically over the past couple of years. From the age of 3 years, Lana lived in a large institutional setting and she reported no educational background. Lana was seen as presenting no risk to others, but was seen as vulnerable due to her lack of skills and experience. Lana moved to the community in 1989 where she has lived in her own rented duplex with a female roommate. During the day Lana attended a sheltered workshop. Although there have been some changes in the paid support roles, Lana's roommate, Vicky, has remained stable.

Cathy, Lana's partner, was a young woman with a university degree whose previous jobs have included waitressing and day care. She lived alone and provided residential support which has enabled Lana to live in her

own home in the community and this support has included most aspects of daily living.

Paired Participants (D)

Richard was a young man with a moderate cognitive impairment. Mental health, emotional problems, and behavioural issues have been reported. Richard has a slight speech impairment and has been diagnosed as having mild cerebral palsy. He was institutionalized at the age of 6 years and reported that he has never recovered from this traumatic experience. While he was moved to a community (behavioural) group home during the 1980s, he did not progress well and presented sexual danger to children on several occasions. Richard's potential risk to himself and to others has been reported as moderate. In 1988, Richard left the group home environment and moved to a home in the community where he was living in a family setting. Richard reported his level of education at Grade 3 and although he was not employed, he attended an alternative work program on an irregular basis. Richard was able to travel independently and used this skill daily. Although he had 24 hour support available, he did not always choose it and often preferred to wander. Supports were geared to all aspects of daily living. The support provided has some elements of protection, both of Richard and of the community, but to date there have been no serious legal

encounters.

Mark, the paired partner, was a young man with no previous work experience, although he had been involved in human services as a volunteer. Mark has completed Grade 12 and left his family home fairly recently to live with his significant other. On those occasions when Richard attended the day program, Mark provided support related to day activities and employment.

Paired Participants (E)

Penny was a middle-aged woman with moderate cognitive impairments and a moderate speech impairment. Penny was triple brain-injured. Her original injury occurred in an automobile accident and resulted in severe self-injurious and assaultive behaviours. Treatment efforts included two brain surgeries (partial frontal lobotomy and cranial surgery). Unfortunately, these surgeries did not appear to change her behaviours. The severity of her assaults have diminished in her own home and the reported risk that Penny presents to herself and others was considered moderate. Penny reported no educational background and she lived in a large institutional setting from the age of 8 years until she was moved to a specialized (behavioural) group home in the 1980s. In 1988, she began to be served by the brokerage model and moved into a family setting. This situation did not work out and Penny moved to her own home in the

community with two female roommates. She was attending an alternative day program where she received support from her partner, Colin. Support for Penny was provided on a 24 hour basis and included all areas of daily life.

Colin was a middle-aged man with some university education who lived with his significant other. He has previously been employed as a cook, as a carpenter, and has done fencing work. He provided support to Penny in her work program and they were involved in a number of activities, including lawn work, cleaning homes, and shopping for people.

Paired Participants (F)

Linda was a young woman who suffered from uncontrolled seizures and has a mild cognitive impairment. She has experienced behavioural and emotional difficulties on occasion and it was reported that she could present a high risk to herself at these times. Linda was traumatized as a child and was permanently removed from her natural family home around the age of 6 years after which she was placed in a series of foster homes. At some point during her teenage years she was placed in a series of specialized treatment facilities where she remained until she moved to a family home in 1988. Linda reported a Grade 9 education and she was living in a family setting. Linda attended a sheltered workshop where possibilities for community work were being

explored. Linda travels independently in the community but has encountered problems from time to time. Support was available to Linda on a 24 hour basis and a large component of this support involved counselling and guidance.

Donna, Linda's partner, was a middle-aged woman with small children who lived with her significant other and Linda. She has a university degree and has always worked in human services. The support role to Linda included many aspects of daily living. This situation has been stable since Linda moved in with the family.

Paired Participants (G)

Vicky was a middle-aged woman with mental health difficulties and a moderate cognitive impairment. She spent almost 30 years in a large institutional setting and has presented no risk to others except when her emotional health was unstable. Apparently Vicky received some schooling in a segregated setting, but she was unable to report an educational level. Vicky moved to the community in 1989 where she has shared her home with another female. Vicky attended a sheltered workshop which she seemed to enjoy most of the time. Support has been provided to Vicky on a 24 hour basis to enable her to live in the community and most aspects of daily life have been supported.

Elsie was a young woman who provided relief support to Vicky. Up until the summer of 1990, Elsie's role was that

of residential support partner but she had found other

employment and was in the process of slowly phasing out her

support role during the course of the study. Elsie has a

university degree and has always worked in human services.

She lived alone but reported that she spent a great deal of

her time with her significant other.

Paired Participants (H)

Leslie was a middle-aged woman with mental health

involvements and a mild cognitive disability. She suffered

from severe asthma and has a speech impairment. Leslie

reported several unresolved traumas in her earlier life.

She was seen as presenting no risk to others but can

jeopardize her own health and safety as evidenced by 21

suicide attempts. Leslie lived at home until the age of 16

years when she became involved with the mental health

system. She has spent about 6 years in large institutional

settings and the remainder of her time in group home

environments. Leslie moved to her own home in the community

in 1987 which she shared with the same roommate until 1991.

She recently moved into another home which she was sharing

with a support partner. Leslie reported a Grade 6 education

and she attended an alternative work program where

employment opportunities were being explored. Support was

available to Leslie on a 24 hour basis. Although Leslie was

quite independent, she needed assistance with many aspects

of daily living, particularly if her emotional state was
unstable.

Janet was a paid support partner who provided relief
services to Leslie. She was a middle-aged woman who shared
her home with another woman with disabilities. Janet has a
Grade 11 education and her previous work experience has been
in the area of office and secretarial work.

Paired Participants (I)

Bill was a young man with a mild cognitive impairment,
emotional and behavioural difficulties and unstable mental
health. He has been assaultive and has been incarcerated.
He reported several traumas from his early childhood. He
lived at home until the age of 5 years when he was
permanently removed from his family and placed in a series
of foster homes. Bill's risk to himself and to others has
varied from non-existent to high and when the risk factors
are high he has required intensive support. While still
fairly young, he was placed in a series of treatment centers
and eventually group homes. In 1988, Bill moved to his own
apartment but the situation deteriorated and he was
hospitalized. Upon his release he lived with his paired
partner, Bob, until he was sufficiently recovered and could
plan for and develop a new living arrangement. Bill went on
to live with his significant other for about 6 months but
found the situation to be too stressful and moved to an

approved home setting. Bill reported a Grade 8 education
and was employed on a work crew during the research process.
Bill was a very independent young man who carried a fairly
negative attitude toward "staff". Bill did not have 24 hour
support during the interview times, but did have regular
contact with a support worker.

Bill's partner, Bob, was a young man with some
university education and he has worked in human services, as
well as in banks and at the liquor control board. He was
living with his significant other and a young man with
disabilities. During the research, Bob was involved with
Bill as his personal monitor.

Paired Participants (J)

Brian was a middle-aged man with insulin dependent
diabetes, mild to severe mental health difficulties, several
specific learning disabilities, and a mild cognitive
impairment. Brian's physical health problems have triggered
acute mental health issues. He was reported as presenting
little or no risk to others but can present a high risk to
himself. Brian lived at home for most of his early years
and has spent approximately 6 or 7 years in mental health
facilities. He reported a Grade 8 education and was
unemployed during his involvement with this study. He was
living with his parents at the time of the interviews.
Although Brian was quite independent, he required support on

a regular basis to ensure that his basic health needs were
met. When the stability of Brian's mental health is an
issue, increased support has been critical to his well-being
and safety.

Martin, the paired partner, was a middle-aged man who
lived with his significant other. He has a college diploma
and human service work experience. The support role of
Martin to Brian was to enable Brian to find work or
activities in the community.

DATA COLLECTION

Nature of Data Collected

First Stage

The first stage of the data collection was designed to
gather a large amount of information. The Social Support
Inventory for Disabled Persons (SSIDP), developed by McColl
and Friedland (1989, see Appendix A for the SSIDP) was used
to collect information on people's perceptions of the social
support in their lives, and also provided information
regarding the quality and quantity of social support.
Although this study was not primarily interested in the
broad aspects of social support, this information was seen
as valuable both from the perspective of allowing the
researcher to obtain a broader base of information about the
participants, as well as permitting a structure from which a

range of interview questions could be developed.

The SSIDP was chosen based on the authors' report that it could be adapted, with minor modifications, for use with any population with disabilities (McColl & Friedland, 1989; McColl & Skinner, 1988). It was initially developed for use with stroke survivors and this necessitated the alteration of one question on the questionnaire. The original form asked "Did you know this person before your injury or illness?" and this was altered in each of the five sections to read "How long have you known this person?" (see Appendix A for permission to alter).

McColl and Skinner (1988) also examined the usefulness of twelve selected measures of social support with regard to rehabilitative settings. In their review the following items were determined to be issues of importance for measuring social support among people with disabilities:

    (a) sensitivity to non-traditional forms of support that may be necessitated by the physical constraints
    (b) ability to assess support by type (i.e., emotional, instrumental, or informational)
    (c) ability to assess by source
    (d) ability to examine source-type interactions
    (e) ability to capture change in support since discharge
    (f) awareness of the demands on network members and the importance of the concept of reciprocity
    (g) recognition of the importance of perceived support

                  (McColl & Skinner, 1988, p. 102)

In their comparison of measures on these items, the

SSIDP scored most favourably reflecting 6 of the 7 criteria.

Originally developed by Friedland and McColl (SSISS; 1987) the SSIDP was composed of five sections corresponding to sources of support. Each section contained between 9 and 11 questions dealing with both qualitative and quantitative aspects of support. Internal consistency reliability was estimated at .85 and test-retest reliability at .91 (after one week). Correlations with the Interview Schedule for Social Interaction (ISSI; Henderson, Duncan-Jones, Byrne, & Scott, 1980) supported criterion validity and construct validity was supported by a significant correlation with psychological health (McColl & Friedland, 1989). Overall, it was felt that this particular inventory was best suited to the area under investigation both because it was designed to provide information from the perspective of the participants, and also because it was specifically designed for populations with disabilities.

Although in this study, the questionnaire was used with participants with and without disabilities, this was not seen as problematic given the high correlation reported (McColl & Skinner, 1988) with the ISSI (which was not designed for any particular population).

The first semi-structured interviews, following the administration of the SSIDP, incorporated questions regarding community participation and community presence based on John O'Brien's (1987) work in this area (see

Appendix C). Community presence referred to the sharing of ordinary places that define community life and included activities such as going to the mall, swimming at the local pool, or dining at a restaurant. Community participation related to the experience of being part of a growing network of personal relationships that included close friends and provided information regarding people and their relationships.

Both of these areas were seen as necessary in order that the researcher gain an understanding of the opportunities (or lack of) for interaction with others and perhaps to gain insights into the similarities or differences that may have existed in the lives of the participants. Information from the community participation section also allowed for some corroborative measures.

During the first interviews participants were asked about family contact and also to define what "friend" and "friendship" meant to them. During this phase of data collection, all responses were recorded by hand by the researcher.

Second Stage

The second round of interviews was designed on the basis of information gathered during the first interviews. Although the SSIDP provided information about people's perceptions of the social support in their lives, it was a

structured format and a more in-depth look at the social lives of the individuals was seen as necessary in order to gain understanding. For example, the SSIDP permitted the participant to provide information on only one "friend" or "family member" and the information could vary depending upon whom the participant had chosen to report. While this information was valuable, it did not permit a complete picture of the social lives of the participants. This approach also allowed for further corroboration of the earlier data and provided a means for examining the stability of relationships over time as the shortest interval between interviews was 85 days.

The majority of the questions that formed the second interviews were based on Benjamin Gottlieb's approach as described in a hand-out from a local workshop conducted in December, 1989 in Calgary (see Appendix D). This approach identified the important people in one's life that were seen weekly, as well as other important people who may or may not have been in regular (weekly) contact with the person. Methods for categorizing the types of support were provided and participants were expected to identify which supporters fitted which categories. The categories of types of support included (a) esteem support (someone who gives you feedback about your performance or yourself), (b) material/tangible support (someone who gives or lends you goods), (c) milieu reliability (someone you can turn to or count on when

needed), (d) belonging support (someone, or a group, who makes you feel included - reliable alliance), (e) emotional support (someone who can listen when you need to talk about your feelings), (f) cognitive guidance (someone who gives you advice and guidance, especially about decisions), and (g) socializing/companionship (someone you can go out and have fun with).

Although attempts were made to connect the support typologies to the individuals named as part of the social network, participants with cognitive disabilities had great difficulty following the instructions in a reasonable amount of time. Therefore, the fourth question ("I'd like to know whether any of the people in your social circle give you any of the following types of help and support?") was discarded from the analysis. Gottlieb (1989) also provided a method of mapping social circles which reflected the degree of density in the networks.

The final section of the second interviews included questions suggested by Gottlieb (1989) along with questions that had arisen as a result of the analysis of data from the first interviews (see Appendix D). The latter included gathering information about the early friendship experiences of people and questions pertaining to perceived differences in support depending on gender or family relations. Questions suggested by Gottlieb (1989) included information about the expressed satisfaction of people with regard to

their network size and information as to whether there were people that the participants wished to be more intimate with or, conversely, from whom they would like more distance. Information was also provided regarding the participants perceptions pertaining to the existence of one person above all others in whom they felt they could confide.

Interviews

The first set of interviews took six weeks to complete and the second set took three and one half weeks to complete. The average time between the two interviews was 119 days. This reflects a range from 85 days to 141 days.

During the first round of data collection, all of the individuals were interviewed separately. In most cases (12) only the participant and researcher were present but in 8 instances other people were in the vicinity, although not actively involved. This did not seem to have any negative effect on the process as all of the participants chose the time and place for the interviews and appeared to be very comfortable in their chosen environment.

The second round of interviews were conducted jointly with both of the paired participants. Once again, the times and places for these interviews were determined by the participants. Giving the participants the choice of time and place for the interview was seen as an important factor in enabling the participants to feel as comfortable and

secure as possible. As Stainback and Stainback (1988) pointed out, these aspects are critical in order that the participants feel "at ease enough to speak openly about their point of view" (p. 53).

As was the case in the first interviews, the majority of these interviews (6 out of 10) involved only the participants and the researcher. In the remaining cases, others were present but not usually involved. There was one occasion where another paid support person, who was not a part of the study, did involve herself in the final section of the interview. This was not seen as problematic in any way, and, in fact, the interchange provided insight on the topic under discussion.

As previously mentioned, creating an atmosphere that was conducive to the open sharing of information was desirable and contributed to the validity of the study. In the majority of interviews, it was felt that this goal was achieved.

There were a few situations where other factors came into play and may have affected the openness of response. One non-disabled person felt that some of the questions asked were really "stupid" and freely commented on this in both interviews! In another case, during the second interview, there appeared to be a problem between the two participants. This did not seem to greatly affect the responsiveness of the participants to the researcher, but

the general atmosphere was not as comfortable as desired and may have had impact on the openness of response.

As most of the interviews took up to 2 hours to complete, some of the participants with disabilities appeared to be quite tired by the end of the interview and this may have had some influence on their responses. There were no occasions where the researcher felt uncomfortable and participants generally went out of their way to ensure that she felt welcome and at ease as evidenced by the offering of refreshments and on some occasions an invitation to share a meal.

Eleven of the first interviews were conducted in the homes of the participants. Of these 11, 6 were participants with disabilities (pwd) and 5 were participants without disabilities (pwod). Five interviews were conducted at the home of one of the paired participants, 3 at the home of the pwd and 2 at the home of the persons without disabilities. Of the remaining four interviews, two were conducted at the home of the researcher (one pwd and one pwod), one was conducted at the persons' place of work (pwod), and one was conducted at a restaurant (pwd).

The second interviews, which were all conducted with both participants present, took place either in the home of the person with a disability (5) or in the home of the person without a disability (4). In one situation the two people lived together and the interview was conducted in

their home.

ROLE OF THE RESEARCHER

In qualitative research it has been suggested that the nature of the relationships between the participants and the researcher be clearly examined (Atkinson, 1989; Stainback & Stainback, 1988). Not only could the validity of the study be affected by this relationship, but ethical considerations required attention. The researcher had known all of the participants prior to the study for varying lengths of time. The researcher had developed a relationship with all of the participants with disabilities as a result of her paid role of personal monitor to those individuals, and all of these individuals had been visited a minimum of nine times.

In the role of personal monitor, it was necessary to come to know the person fairly well as part of the responsibility of the monitor was to determine, largely from the perspective of the individual, whether the services they were receiving were meeting their needs. Although not all of the people were personally monitored by the researcher immediately prior to the study, all personal monitoring work was discontinued one month prior to data collection.

The participants without disabilities were also known to the researcher through the personal monitoring role although not in nearly as much depth. Of these 10 people, 3

had minimal contact (two or three visits) with the researcher and the remaining 7 had been visited at least nine times. This allowed the researcher to be in a very privileged position. Rapport, a critical component of the qualitative approach, had already been well established and, given the time limitations for this research, prior personal knowledge of the people was extremely helpful in the data collection phase as well as in the analysis of the data.

While it was important that the participants trusted and valued the researcher enough to be willing to provide personal and sometimes intimate thoughts, it was also incumbent upon the researcher to determine ethically how much should or should not be disclosed. Although this did not present any great difficulties, there were several situations where people indicated a desire to share very personal information but were reluctant to do so in front of their paired partner.

In all cases, the researcher assured the individuals that they were under no obligation to reveal any information that made them feel uneasy. These people were also told that if they wished to discuss the topic privately they could call the researcher at any time. Due to the nature of the questions and the established trust relationship, it was felt that people must be given the opportunity for further contact if they felt it to be necessary. None of the participants initiated this contact.

There were also occasions where people shared information that could affect their well-being. As this information did not relate directly to the research, it was not used in the analysis or interpretation. It was important to consider the relationships that had developed between the researcher and the participants, as the potential for harm and benefit existed.

Researcher Bias

Another facet that must be examined are the biases that the researcher brought into the study and their potential influences on the process. Despite the fact that the role of the researcher was that of learner and the participants were the experts, the researcher recognized that she held strong beliefs about the necessity of friends in the lives of all people.

Without friendship, a life of quality is not possible. Initially this was the only self-acknowledged bias, but, as the investigation progressed, the researcher discovered that she also believed in the concept of the ensembled individual (Sampson, 1988). Within this framework, boundaries between the self and others are seen as fluid and the cultural location of power and control have included the person but go well beyond. As Sampson (1988) pointed out:

> Confucian thought...further illustrates the
> fluidity of the self-other boundary and the

embedding of the person in a larger field of
forces: Individuals do not define themselves as
detached from their family and society; persons'
obligations are to sustain harmony within the
social order. (p. 17)

Gilligan (1982) further illustrated this point in her

writings which described how women seemed to confront the

world and the terms under which they framed their

understanding. Connections and relationships were critical

components rather than boundaries and separations. The

inclusive concept of the person, which has been central to

ensembled individualism has purported that "who I am is

defined in and through my relations with others; I am

completed through these relations and do not exist apart

from them" (Sampson, 1988. p. 20).

As this concept became clear to the researcher, she

realized the importance of seeing and speaking to the fields

of influence. Within the area of friendship, the researcher

identified several influences as important and these

included the personality of the individual, their past

experiences, and their current circumstances.

While personality was seen by the researcher as mainly

having an influence on the size of personal networks, past

experiences of the participants were seen as having a

profound affect on their current social lives, particularly

from a developmental perspective.

Personality factors were not studied as the size of

networks were not considered to be as important as the

degree of satisfaction expressed by participants regarding the size. Current circumstances were seen as critical by the researcher as opportunity, accessibility, choice, and other factors all have impact on this domain. The interactions between people with disabilities and their paid caregivers were also seen as having considerable influence. Attempts were made to cover these specific aspects in the interviews.

A final recognized bias on the part of the researcher related to the belief that the individual is always the best source of information in matters pertaining to his or her own life. It was also acknowledged that this value statement applied not only to typical persons in the community, but to all persons, including those who have traditionally been seen as incapable of providing this type of information. This bias was a determining factor in the decision to incorporate the phenomenological approach within the combined methodologies.

CHAPTER III

RESULTS

INTRODUCTION

The results chapter has been organized in the following manner. The two interviews provided specific information on a variety of topics and included:

1. Basic descriptive information regarding the participants which was presented in Chapter 2.

2. Data from the SSIDP which examined the perceptions of the participants with respect to the quantity of time spent with people and the perceived quality of this time.

3. Information provided by participants with regard to community presence.

4. Information provided by the participants with regard to community participation.

5. Information provided by the participants on family contact.

6. Participant perceptions regarding the meanings of friends and friendships.

7. Social network characteristics from the perspective of the types of relationships within the networks as described by the participants in Interview 1 and Interview 2 as well as a comparison of the relationship types.

8. Social network characteristics as analyzed by changes in the networks over time.

9. The degree of density which existed in the network.

10. Participants reported satisfaction with the size of their networks.

11. Information regarding individuals that the participants reported that they would have liked either more intimacy with or from whom they would like more distance.

12. Information regarding perceptions of the existence of one person, above all others, that the participants felt they could confide in (i.e. best friend).

13. Information provided by participants regarding perceived differences in support received from family members as compared to friends.

14. Information provided by participants regarding perceived differences in support received from male as compared to female friends.

15. Early memories of friends.

Given the rather diverse information provided, a systematic presentation of each subject area is provided. The discussion section will be reserved for the presentation of identified themes or trends arising from the integration of all of the findings. As pointed out by Kidder and Judd (1986), "there is no such thing as a pure results section without any accompanying discussion" (p. 438). Further to this, Stainback and Stainback (1988) cautioned against

separating data analysis (or results) from interpretation (or discussion) as analytic interpretation may not be grounded or supported by the data collected. The analysis and brief discussion of each of the 15 identified areas in the study concurs with this method of reporting results.

Social Support Inventory for Disabled Persons (SSIDP)

The SSIDP provided information from five sources (personal, friends/family, community, group, and professional) on both quality and quantity dimensions. Unless otherwise specified, all calculations were based on the inclusion of each participant's response, even if there was no response (i.e. no involvement) on that section. The terms "pwd" and "pwod" have been used to discriminate between the groups and may reflect the singular or plural form (person or people) depending on the context.

Quantity Dimension

These responses were derived from two questions on the SSIDP in each source category: About how often do you see _____ ? and; About how much time do you spend with _____ on the average?. Each participant had to choose from one of several possible responses for each question. For example, on the personal source category, the possible choices of response for how often the participant saw their friend included (a) every day, (b) a couple of times a week, (c)

once a week, and (d) less than once a week. Each separate
response had a number value attached for purposes
of scoring. These number values ranged from 1 to 4 with the
lower number reflecting responses indicative of lower
quantity. Two questions from the quantity dimension
reflected values ranging from 1 to 5 rather than from 1 to
4. An individual score of 4 on the quantity dimension for
the personal source category could indicate that the persons
involved had contact once a week for a couple of hours,
twice a week for less than 2 hours, or contact less than
once a week for half of a day.

The results indicated that the people with and without
disabilities reported similarly with regard to the quantity
of time spent with people. The range of individual
responses on the quantitative section was from 13 to 30.5
(possible total of 42) with a total mean average score of
24.2. The mean average scores for people with disabilities
(pwd) and for people without disabilities (pwod) were 24.3
and 24.1 respectively, and the pwd showed a lower variation
in responses than did the pwod (s^2 = 7.46 as compared to s^2
= 29.14). These results indicated that although pwd and
pwod report similarly with respect to the quantity of time
spent with the people mentioned on the SSIDP, pwd varied
less in their responses regarding the amount of time spent
with the people mentioned.

The average scores for pwd and pwod on the one

dimension from the personal source category were 4.15 and 6.65 respectively. Examples of the meaning of an individual score of 6 could include contact every day for a couple of hours or contact once a week for an entire day. It was important to take note of the discrepancy between pwd and pwod on this one source category as it reflected the quantity of time spent with an individual whom the participant perceived as a very close friend. Although the overall average scores were indicative of fairly equal quantities of time, it was apparent that the pwd reported spending less time with their close friends than did the pwod.

Quality Dimension

The quality dimension was reflected by the following questions from the five source categories on the SSIDP:

1. How happy are you with the amount of time spent?

2. How happy are you with the way you and _____ get along together at present?

3. How close do you feel to _____ ?

Each question was accompanied by four possible choices of response with a range from 1 to 4. Responses were interpreted in the same manner as on the quantity dimension where lower numbers indicated lower perceptions of quality. The highest quality score possible was 60 for the entire quality dimension, or 12 for any particular source category.

In this area, people with disabilities reported higher quality than people without disabilities with mean averages scores of 47.2 (pwd) and 38.4 (pwod). In contrast with the quantity scores, the pwd showed higher variance (s^2 = 74.01) than did the pwod (s^2 = 25.42).

It was determined that it would be useful to examine the results by placing the participant scores into four groups, based on both disability and gender. The statistic used was the Kruskal-Wallis one-way analysis of variance by ranks, a non-parametric test which is analogous to a one-way anova. This statistic was chosen based on its ability to determine whether the groups came from the same or different populations. The results from this analysis indicated significance with $\underline{H}$ (3, $\underline{N}$ = 20) = 8.41, $\underline{p}$ < .05. In attempting to look more closely at the differences, the following information emerged.

When mean scores over the personal (source) on the quality dimension were examined, it appeared that there was little difference between pwd and pwod (mean of 10.6 for pwd and 10.5 for pwod). However, when looking at the male/female and disability/non-disability aspects, it was evident that females with disabilities reported the highest scores and men with disabilities reported the lowest for the first three source categories (see Table 3.1).

Table 3.1

Mean Scores On the Quality Dimension from the SSIDP

for all Participants by Gender and Disability

Social Support Source Category	Male PWD ($\underline{n}$=4)	Male PWOD ($\underline{n}$=5)	Female PWD ($\underline{n}$=6)	Female PWOD ($\underline{n}$=5)
Personal	9.8 (4)	10.6 (5)	11.2 (6)	10.4 (5)
Friends/Family	7.4 (3)	10.2 (5)	10.9 (6)	9.4 (5)
Community	6.3 (3)	8.8 (5)	10.8 (6)	8.2 (5)
Group	7 (3)	5.4 (3)	8.5 (5)	3.2 (2)
Professional	10.3 (4)	2.4 (2)	10.2 (6)	8.3 (5)

Note. Parentheses have been used to indicate the actual number of respondents for the source category. When no response was given for a particular source category, the participant received a score of zero.

PWD = People with Disabilities
PWOD = People without Disabilities

A different profile emerged for the group category, with pwd reporting higher quality compared to pwod. This also reflected involvement as 5 out of 10 pwod did not participate in groups therefore there was no score recorded. Only 2 out of 10 pwd reported no involvement. This reflected the typical grouping patterns for people with cognitive disabilities, as all of the group involvement reflected participation in activities such as Special

Olympics or attendance at segregated dances. The professional category also reflected a higher involvement for pwd. Three out of 5 male pwod reported no involvement with professionals.

An average individual score of 9 on any of the source categories reflected a "quite happy" state and an average individual score of 6 reflected a "not that happy" state, therefore, with the exception of men with disabilities, the other participants were close overall to the quite happy score for the first three source categories. This was due in part to the fact that only male pwd did not respond on the categories for friend/family and community.

It was noted that the patterns across the quality dimension were similar for all of the participants on the first three source categories. Personal source quality scores were higher than those for the friends/family source, and community quality scores were lower than the friends/family source quality scores.

The people who were listed on the personal source category represented predominantly significant others (8) for pwod and the two remaining people were female friends. For pwd, one half of the responses referred to other people with cognitive disabilities and three referred to paid caregivers. The remaining two responses included a family member (mom) and a female friend without disabilities. The total numbers of people mentioned appeared similar for

the two groups with a range of responses from 3 (female with disabilities) to 13 (female with disabilities). People mentioned on the questionnaire totalled 84 for people with disabilities and 86 for people without disabilities which reflected similar sizes of networks.

Quality Dimension and Gender

Although the initial difference appeared to be indicative of people with disabilities reporting a higher quality of social support in their lives, upon closer examination it was apparent that it was the women within this group that contributed the highest quality scores on four of the source categories (personal, friends/family, community, and group). With the exception of the group category, where men with disabilities reported the second highest quality score, and the professional category, where male pwd reported the highest quality score, the men with disabilities reported the lowest quality scores for the other three sources of support.

All women in the study perceived the lowest quality in the group source category and the highest quality in the personal source category whereas men without disabilities perceived the personal source as the highest and the professional category as the lowest. As women in general have been reported to be more likely to seek professional help than men, it was not surprising that men without

disabilities showed the least involvement and therefore the lowest quality scores.

Men with disabilities showed a very different perception from any of the other groups with the professional source category reflecting the highest quality scores and the community source category reflecting the lowest. These results appeared to imply a possible gender difference with regard to the perceived quality of support, particularly among the pwd, although also evident in the responses of pwod in the latter three source categories.

Summary of Quality Dimension

It appeared that women with disabilities were (on self-report) the happiest with the amount of time spent with the people they identified, how well they got along with these people, and their perceived closeness to them. For males with disabilities the reverse was true (i.e. they were the unhappiest) except for the professional and group source categories. It was encouraging that all of the people reported the existence of some form of self-identified social support in their lives and that everyone was able to name one individual with whom they felt close.

Community Presence

All of the people interviewed indicated a presence in the community. Overall, the places most often mentioned by

the participants ($\underline{N}$ = 20) were malls (18 people) and restaurants (18 people). The two people who did not mention these were both men with disabilities. Following malls and restaurants, were movies (15 people), parks (12 people), and bars (7 people). The top four places for males were movies (9), restaurants (7), malls (7), and parks (4) ($\underline{n}$ = 9) and for females were restaurants (11), malls (11), parks (8), and movies (6) ($\underline{n}$ = 11). The top four places for pwd were restaurants (8), malls (8), movies (8), and segregated dances (4) and for pwod were restaurants (10), malls (10), parks (8), and movies (7) ($\underline{n}$ = 10 for both groups). Only pwd reported dances, otherwise the responses were similar for all participants. All of the participants reported that they had presence in public places in the community a minimum of twice a week.

Only one person with a disability spoke of having encountered problems or difficulties in the community and this person said that he was able to resolve the problem. However, 7 out of 10 pwod reported problems. Of these 7, 3 referred to difficulties arising from the presence of a person with a disability (one referred to seizures, another to being 'stared at' and one to physical access).

With respect to places you would like to go, but can't or don't, pwd mentioned the following obstacles; a) don't know how (2); b) money (2); c) told it was unsafe (1); and d) restricted privileges due to probation status (1). Three

people reported no problems and one person was unable to answer due to the inability of the researcher to present the question in an understandable way.

Three pwod also reported no problems. Restrictions that were mentioned included a) money (5); b) difficulties arising from the presence of a person with a disability (3); c) time restrictions (2); d) sexist regulations (1); and e) lack of companion (1). Although both groups showed similarities in that 3 out of 10 reported no problems and both groups cited financial restrictions, a difference emerged in the life worlds. No person without a disability was restricted by lack of knowledge nor by reasons relating to safety or legalities. Further, lack of companion, time, and sexist restrictions were found only in the responses of pwod.

In another part of the interview (when participants were asked if they go alone or with someone), the following comments were made by people with disabilities and shed further light on this matter. These comments included: "nobody to go with", "I went alone because I couldn't find someone", and "I wouldn't want to go alone". People without disabilities made the following comments: "limited only by the availability of others", "I choose to go alone", "I prefer to go alone", "I go alone by choice", and "I'm not allowed to go alone" (this referred to specific places that a significant other felt strongly about). Although pwd did

not refer to lack of companionship when specifically asked about places they would like to use but can't or don't, the above comments reflected that persons with disabilities have experienced some difficulties in this area, although the person did not report feeling restricted and activities were not necessarily cancelled as a result.

Some people with disabilities were always in the company of others. No choice was involved here but this did not appear to be problematic to the individuals concerned. This did raise the question as to whether the contacts in the community were the choice of the pwd or the choice of the paid support person. One person with a disability commented that they would not like to go anywhere alone.

Both groups mentioned not being able to find someone to go with therefore they went alone. It did seem that this was more of a temporary inconvenience for people without disabilities ("limited only by availability of others") whereas it appeared to be more of a longstanding problem for pwd ("I went alone because I couldn't find someone"). Also, pwod referred to choosing to go alone (4 out of 5 females). This reflected a difference as none of the people with disabilities indicated that they would choose to go somewhere alone.

Summary

From these data it was apparent that all of the

participants enjoyed a degree of community presence, although often the people with disabilities were accompanied by paid support people. When not in the company of paid support people, the pwd were often alone or in segregated groups such as the dances or Special Olympics. Persons without disabilities perceived greater difficulties in the community than did people with disabilities and people without disabilities seemed to be more sensitive to problems for the people with disabilities than were the people with disabilities themselves. This could also be interpreted as indicative of the people without disabilities being uncomfortable ("seizures", "stared at") or inconvenienced ("no physical access") rather than sensitive. People with disabilities may not have reported difficulties in the community (arising from their disability) for a number of reasons. These individuals have lived as devalued and stigmatized people for much of their lives and their life experiences may have led them to expect this treatment rather than to perceive it as a problem or difficulty. It was also possible that the people with disabilities did not perceive problems in this area because they were protected by the people with them and in fact were unaware of the situation and the implications.

Community Participation

When examining with whom people spent most of their

time, a different picture emerged for the two groups. Seven out of 10 pwod listed their significant others as the people with whom they spent most of their time. In the group with disabilities, only 3 out of 10 listed significant others and two of these relationships were in the process of ending by the time of the second interview.

It was also interesting that all of the 7 pwod who mentioned spending most of their time with their significant others, also reported that these people were their "best friends". (The "best friend" category came from the SSIDP question which asked if there was someone in your life that you felt particularly close to, and from the question in the second interview which asked if there was one person above all others in your network in whom you could confide.) Of the two people with disabilities who mentioned spending most of their time with their significant others, neither reported that these people were their best friends. For pwd, only half (five people) said that their best friends knew them really well. Of these five people, three were males and represented 75% of the men with disabilities. Only one person reported spending most of their time with their reported best friend and, in this case, the friend was also a roommate who was not reported as knowing the participant well. All people without disabilities, if they agreed that anyone "knew them", listed their best friends (2 out of 10 said that no-one knew them). For pwod, 7 out of

10 reported spending most of their time with their best friends, who were also the people they reported as knowing them really well.

Each group had one person who listed a person that they spent most of their time with, yet this person was not mentioned on any of the source categories of the SSIDP. One was a female pwod who identified her roommate/friend as the person she spent most of her time with, but did not mention the person on the social support inventory, perhaps indicating that the roommate/friend was not perceived as a source of support. The other was a male pwd who listed his significant other as the person he spent most time with but he did not mention her on the support inventory. It was quite unlikely that this response was a result of a lack of understanding of the questions. It seemed most likely that the person may have been responding to a problem within the relationship at the time.

On at least two occasions, pwd responded to questions as they pertained to the situation at the moment, as opposed to giving an overall picture of the relationship. For example, if the pwd was upset with someone who was important to them, they may not have mentioned that person while they were upset. People with disabilities appeared to find it difficult to be able to put the immediate problem aside and give a response that would reflect the overall nature of the relationship. The privileged position of the researcher, in

terms of knowing these individuals over time, was evident here. If people had only been seen once, or if the contact had been brief, the data could well be more a reflection of the participant's mood at the time rather than a realistic overall picture.

All people with disabilities reported having an advocate or someone who would speak on their behalf. People without disabilities also made reference to having an advocate (4 out of 10). In fact, they seemed to be referring more to a person who may be a mentor as they made reference to someone who assisted them in their ability to represent themselves (or the person they served) rather than someone who actually spoke for them.

People with disabilities reported having adequate support in their lives when they were able to answer (2 out of 10 were unable to answer due to the researcher's inability to put questions in an understandable manner). One woman with disabilities commented that she didn't "know if she had adequate support...[and that] sometimes I'm lonely and people tell me not to be". People without disabilities responded that they received adequate support 7 out of 10 times. The remaining three responses included "yes, now", "not always", and "not professionally". When the pwd were asked why they felt that they had adequate support, they referred to having "people". They did not mention "friends" whereas people without disabilities did

refer to "friends" as the reason that they felt adequately supported.

This raised an important question about how people experienced support. It seemed likely that pwod experience support in terms of the friendship relationships in their lives whereas people with disabilities experienced support in a different way. For example, the people with disabilities never referred to friends in this context, but commented that they saw "a lot of people" or had enough "people" in their lives.

When asked about improvements that people might like to see in the area of support, 6 out of 20 saw no need for improvements. Of these six, three were pwd and three were pwod. Three pwd were unable to respond due to the inability of the researcher to present the question in an understandable manner. Of the 4 pwd who would like improvements, three specifically referred to areas of independence. Two men wanted to live alone and one female wanted to be able to go for sleepovers at the home of a male friend. The fourth response related to wanting more time with her partner which may also be related to independence, but given this particular situation, it seemed to be more indicative of a social need. People without disabilities tended to respond with "it's O.K. but......". None of the responses indicated that anyone without disabilities was unhappy enough that they would actually try to change

anything in their lives.

Summary

Generally speaking, it seems as though the information from this section indicated a difference in the social worlds of people with and without disabilities. People without disabilities appeared to experience social relationships that were more connected (best friend knew them well, a lot of time spent with the best friend) than were the relationships of the pwd and this group perceived that it was the friends in their lives that enabled them to feel adequately supported.

People with disabilities appeared to experience friendship in a more disconnected way as evidenced by their reports that they do not spend as much time together as the pwod reported and because the best friends were not always perceived as knowing them well.

For people with disabilities the overall impression was that of being powerless to influence or initiate any change. Although they were able to voice their opinions, the people around them and the availability of feasible options determined both where and with whom the participation could take place. This lack of choice has affected not only the people with disabilities, but also their paid caregivers. The lack of options has not only restricted the choices for the pwd, but has often placed the onus of responsibility on

caregivers who have attempted to meet the needs of the people they serve.

Family Contact

All people, except for one person with a disability, had some contact with their families. Both groups mentioned the existence of immediate family members with whom there was very little or no contact, with 7 out of 10 individuals with disabilities and 3 out of 10 individuals without disabilities reporting these circumstances. There was a difference in that the individuals without disabilities reported that the lack of contact was a matter of mutual choice. People with disabilities, with the exception of one male, reported that they would like the contact but the other party was not interested. The majority of participants (18) had regular, often weekly, contact with a family member.

Friends and Friendships

All participants were asked to tell the researcher what the words friend and friendship meant to them. Generally speaking, the people with disabilities had difficulty with defining friendship. The total number of descriptors given was 138, 45 of which were descriptions from people with disabilities. It was determined that a useful way to analyze this material would be to code the responses

according to Gottlieb's (1989) support typologies.

A total of four coders, including the researcher, were asked to categorize the responses into one of the seven categories outlined. Any responses where three of the four coders agreed on the category type were kept for further analysis. There were six occasions when the coders agreed that the item could not be classified and this reduced the total to 132 responses. This resulted in a total of 94 items to be analyzed (30 of which were responses from people with disabilities), and a total of 38 items that were discarded.

The category most often chosen by pwd was socializing and companionship, and this was also the category type that received the highest number of individual responses.

For pwod, the category that received the highest number of individual responses was that of emotional support. This group mentioned two category types equally often (7 of the 10 people having responses placed in these categories) and these were emotional support and milieu reliability. The results of this analysis are shown in Tables 3.2 and 3.3:

Table 3.2

Cumulative Coded Responses Regarding Friends/Friendships

to Gottlieb's (1989) Support Typologies

for Persons with Disabilities

Support Typologies	Participants with Disabilities										
	(A)	B	C	(D)	E	F	G	H	(I)	(J)	TTL
Esteem Support						1					1
Material/ Tangible Support					1		1				2
Cognitive Guidance	(1)										1
Emotional Support					1			3	(1)	(1)	6
Belonging Support			1			1					2
Socializing/ Companionship	(1)		1	(1)		1		3	(2)	(3)	12
Milieu Reliability	(1)	1			1				(1)	(2)	6

Note. Parentheses indicate male responses.

TTL: Total number of responses for each support typology.

The numbers in the columns represent participant responses. For example, the score of 2 indicates that the participant made two references to this support typology.

Table 3.3

Cumulative Coded Responses Regarding Friends/Friendships to Gottlieb's (1989) Support Typologies for Persons without Disabilities

Support Typologies	Participants without Disabilities										
	(A)	B	C	(D)	E	F	G	H	(I)	(J)	TTL
Esteem Support	(2)	2	1		(2)	2				(1)	10
Material/ Tangible Support	(1)										1
Cognitive Guidance	(1)										1
Emotional Support	(5)			(1)	(2)	3	2		(1)	(4)	18
Belonging Support	(1)	2					1		(1)	(1)	6
Socializing/ Companionship	(1)	3	2		(3)		1			(3)	13
Milieu Reliability			1	(1)		2	4	2	(1)	(4)	15

Note. Parentheses indicate male responses.

TTL: Total number of responses for each support typology.

The numbers in the columns represent participant responses. For example, the score of 2 indicates that the participant made two references to this support typology.

The responses that were discarded from the above analysis were examined and yielded interesting findings. A total of 24 responses came from the pwod and 14 from pwd. Although there was no identifiable trend within the responses from the pwd, some of these responses were very different from any response given by a pwod. Examples of comments from pwd included: "lets me listen to my radio", "not afraid of", and "don't hide from people". A definite pattern existed in the responses of pwod relating to the concept of reciprocity. Over half (13) of the discarded responses could be classified in this manner and examples include: "do things for each other", "care for each other", "give and receive", "mutual support", and "equal".

When viewed from this perspective, it appeared that pwd did not perceive reciprocity as an important aspect of friendship. Only one person with a disability mentioned this concept at all ("care for each other"), whereas every person without a disability referred to reciprocity, establishing it as the category most often mentioned when compared to the responses originally classified.

Summary

The way in which people with and without disabilities perceive and experience friends and friendships appeared to be quite different, at least amongst these 20 participants. Reciprocity, which has often been defined in terms of

mutuality, is a critical component of friendship relationships for the pwod whereas the most important aspect of friendship for pwd appeared to be related to socializing and companionship. This may be related to the presence of paid support relationships in the lives of the pwd. The support workers may be more accessible and better equipped to meet the emotional support needs of the pwd. Indeed, meeting these needs was often a part of the "job".

The area of esteem support also showed a discrepancy between the groups. Perhaps this was another area where paid support has had impact. As people with disabilities constantly received feedback about their performance this may not be interpreted as a part of friendship. In terms of the support typologies used, neither pwd nor pwod felt that cognitive guidance, belonging support, or material/tangible support were important aspects of friendship.

Social Network Characteristics: Relationship Types and Comparisons

The first comparison that was made related to the "best friend" category on the SSIDP. People with disabilities mentioned five people with disabilities (one person was reported as a significant other), three paid support persons, one family member, and one "typical" person. The term "typical" has been used to describe relationships with a person that is neither a family member nor a person with a

disability (paid or unpaid). People without disabilities all reported typical people, eight of whom were significant others.

Relationships were analyzed from the perspective of (a) how often participants mentioned a paid support relationship as a friendship, (b) how often participants mentioned a family member, (c) how often participants mention people with disabilities as friends when no paid support role was involved, and (d) how often "typical" people were mentioned.

For pwd, 96% (Interview 1) and 91% (Interview 2) of the friends mentioned fall into categories a, b, or c, as compared to 28% (Interview 1) and 53% (Interview 2) for pwod. In the first interview, the remaining 4% for pwd reflected 3 people who had previously been in a paid role. In the second interview the remaining 10% for pwd reflected 3 people who were previously in a paid role and 11 typical friends. It was noted that of these 11 people, 7 were reported by one male and the individual had access to them only at their place of work. For example, the individual had no way to call them at home and had never seen them outside of their work environment.

In the first interview for pwod, 72% of the relationships were not in the three categories (family, paid, or other people with disabilities) and this dropped to 46% in the second interviews. This may be a reflection of the fact that second interviews were conducted jointly and

perhaps people were sensitive to mentioning their friends with disabilities. The second interviews also picked up on people that were seen on a weekly basis that were important to them.

A difference was seen in the lifeworlds when examining the nature of relationships between pwd and pwod. Only one person without a disability mentioned a friend with a disability when there was not a paid role and this occurred only in the first interview. By comparison, pwd mentioned other disabled persons as friends much more frequently. In the first interview, 40% of the responses of pwd reflected other people with disabilities as compared to 1% of pwod (when no paid role was involved). The second interview showed 25% (pwd) and 0% (pwod).

In the first interview, 43% of the friends mentioned by pwd were paid support relationships as compared to 8% of pwod responses. Over the three months between interviews, the percentage remained fairly constant for the pwd (45%) but the pwod group now mentioned people they were paid to support more frequently (19%).

Family "friends" accounted for 13% (pwd) and 19% (pwod) in the first interview and 21% (pwd) and 34% (pwod) in the second interview. This increase could have been related to the more open ended format of the second interviews. It was also possible that participants felt more comfortable with the second interview as they were more familiar with the

format. Table 3.4 summarizes these results.

Table 3.4

The Percentage of People Reported in each of Four
Categories of Relationships over the Two
Interview Stages for all Participants

Relationship Categories	First Interviews		Second Interviews	
	Participants			
	PWD (n=10)	PWOD (n=10)	PWD (n=10)	PWOD (n=10)
Paid	43% (36)	8% (7)	45% (63)	19% (24)
Family	13% (11)	19% (16)	21% (29)	34% (43)
Other Persons with Disabilities	40% (34)	1% (1)	25% (35)	0% (0)
Typical	4% (3)	72% (62)	10% (14)	46% (58)
Total Number of People Mentioned	84	86	141	125

Note. All percentages were rounded to the nearest whole
number.
The actual numbers of people in each category are identified
by parentheses. People mentioned in the first interviews
may or may not be mentioned again in the second interviews.
The average time between the two interviews was 17 weeks.
PWD = People with Disabilities
PWOD = People without Disabilities

When looking at percentages, the following trends were

seen. For people with disabilities, most of the friendship

relationships fell into the paid support category, followed

by other people with disabilities, family, and finally typical people. People without disabilities reported typical friends as the most prevalent friendship type, followed by family, paid support, and other people with disabilities.

The "paid support" category referred to any relationship where one person was paid to be with the other. This category also included people who were related to the paid support person. In the first and second interviews, this accounted for 3 people and 9 people respectively. People in this category included children of the caregiver or significant others, and it was felt that these individuals would be unlikely to have a relationship with the person with the disability if it were not for the paid support relationship. "Other people with disabilities" referred to any person with a disability that was not involved in a paid relationship. The trends regarding the relationship types remained constant over both interviews.

The main findings from this section were not surprising with regard to the types of friendship relationships experienced by pwd and pwod. It was noted that pwod did not tend to perceive the people with whom they worked as sources of support or as friends, yet often in other contexts they indicated that the pwd was their friend.

Social Network Characteristics: Changes over Time

Overall, people mentioned greater numbers of persons in the second interviews. There were 3 exceptions to this, one male and one female with disabilities (4 to 2 people and 9 to 8 people respectively) and one male without disabilities (7 to 5 people). All of the other participants mentioned more people with a range of increase from 1 to 11 and the average network sizes for participants in the second interviews were 13 (pwod) and 14 (pwd). The average total increase in numbers of people mentioned was 6. People with disabilities mentioned more people in all categories except "other", and people without disabilities mentioned more people in all categories except "other" and typical. The areas that showed the greatest increase for people with and without disabilities were paid support relationships and family relationships respectively. The analysis of the similarities and differences in the relationships mentioned in the two interviews was done in the following manner. The SSIDP allowed people to place individuals in their social circles into 4 distinct categories that included personal (or best friend), family and friends, community, and professional. The group category was eliminated from this analysis as it did not elicit the names of specific individuals but indicated group membership. All persons that were mentioned on the SSIDP were listed according to the categories and then the data from the second interviews

was matched to see (a) if the people were mentioned again in the second interview, and (b) where changes occurred. For the group with disabilities, 20 people listed as community (n = 31), 8 from family/friends (n = 40), and 2 from personal or best friend (n = 10) were not mentioned again. The group without disabilities did not mention 25 people from the community section (n = 36) and 10 people from the family/friends category (n = 40). Gender showed a slight tendency toward females mentioning people less often in the second interviews with a total number of 39 people not mentioned as compared to a total of 26 for men. It should be noted that there were more females (11) than males (9) in the study.

In looking at the people who were mentioned again, the patterns were the same for the two groups with respect to all people being more likely to lose (or not mention) persons from the community category and being more likely to retain (or mention again) people from the family/friends and personal categories.

Table 3.5

Consistency of Reporting the Same People in both the
First Interviews and in the Second Interviews
by Source Categories (SSIDP)

	Participants	
Source Category of Repeats	People with Disabilities (n=10)	People without Disabilities (n=10)
Personal	80% (8/10)	100% (10/10)
Family/Friends	80% (32/40)	75% (30/40)
Community	35% (11/31)	31% (11/36)
Professional	30% (3/10)	0% (0/7)

Note. The ratio of people mentioned out of the total possible number of people that could be mentioned have been identified in parentheses.

As illustrated in Table 3.5, a difference in the two groups was apparent in the professional category, which applied only to the group with disabilities, and it is only pwd that failed to mention people from the personal or best friend category. This was seen as important to include as only the people with disabilities mentioned professionals in the later context of their social circles. It was not expected that people would report individuals that they perceived as professionals as a part of their social lives, yet this form of support is reportedly experienced by some

people with disabilities.

With the exception of one male with disabilities, all of the participants failed to mention at least one person in the second interviews. There was also one instance (a second male with a disability) where only two people were mentioned in the second interview (both previously mentioned) and where no new people were introduced. In all other cases there were new people reported on the second occasion and previously mentioned people who were not mentioned again.

Degree of Density

The density (cohesion or connectedness) of the social network was examined using the method described by Gottlieb (1989) for determining characteristics of a person's primary social circle. Participants were asked to choose up to 10 people who they considered to be important in their lives, and to write their names in a circle (drawn by the researcher) according to the perceived closeness of the relationship. A central point in the circle represented the participant. Separate circles were drawn for family and for friends, although a family member who was also considered a friend could be placed in both circles. All participants were told that they need not list 10 people and that, in fact, there may be just one or two people that they felt were very important in their lives at the time. The

participants were then asked to draw lines to indicate which of the people in the primary social circle had relationships with each other that were independent of the participant.

All of the pwod, with the exception of one male who mentions only family, listed a mixture of friends and family members. Within these primary social circles, there were varying degrees of connectedness (or people that enjoyed a relationship that was independent of their relationship with the participant), but in all cases, there was evidence that the participant was part of a social circle where people enjoyed both communal and private relationships.

For the pwd, three of the participants mentioned only friends and two mentioned only family. In the latter group, although the family members had relationships that were independent of the participant, the opportunity for being a part of these social circles was limited as only one person (an aging parent) lived in the same geographical area. For the remaining participants, who mentioned friends only or who mentioned a mixture of friends and family, there was very little evidence to suggest that these were connected in the same way as were the social circles of the pwod.

On the surface it appeared that there were similar connections but when the roles of the people mentioned were defined, they were usually the paid caregivers or family members. Both the family members and the paid support persons tended to know each other but these relationships

were not really independent, rather, they existed because of the pwd and could be considered more as working relationships as opposed to a social circle.

Within the friendship area, six of the participants with disabilities revealed social circles that appeared to be connected but in reality these circles consisted of paid support people who "know each other". While some of these individuals may have indeed been friends and enjoyed a relationship beyond their working role, the participants seemed to be central in the circle as a result of their support needs. There were three cases where pwd mentioned people who were a part of their paid support persons social circle but none of the pwd reported having contact with these individuals apart from their paid support person, again indicating a qualitative difference between the groups.

In one of the second interviews, a pwod commented to the pwd that the people the pwd was mentioning were not her friends, but rather were the friends of the pwod. This raised the question as to how many of these perceived friends would exist if not for the paid roles. In other words, the people with disabilities were not necessarily part of a social network, but were more the focus of a work-related network.

A total of four pwd mentioned other people with disabilities as part of their social circle but these

relationships were typically quite isolated. For example, one person mentioned several people but none of them knew each other.

Satisfaction with Size

Participants were asked if they were happy with the overall size of their social networks and a difference emerged in the responses to this question. Only two females from the group with disabilities reported that they were happy with the size as compared to seven of the participants without disabilities. Seven of the people with disabilities stated that they would like more friends in their social circles, whereas only two people without disabilities reported a desire for more friends (both females). One person with a disability was unable to respond to the question and one person without a disability reported wanting less people in his life. Given the high quality scores for females with disabilities, it was interesting that four of them expressed some dissatisfaction with the size of their network.

Intimacy and Distance

There appeared to be similar patterns with respect to participants responses regarding people they would like to be either more intimate with, or conversely, from whom they would like more distance. Each group had eight people who

named someone they would like to be closer to, and there
were four participants from each group who named people from
whom they would like more distance. For pwod, only males
(four out of five) mentioned people that they would like
more distance from and for pwd there was no gender
differentiation. It seemed apparent from the responses to
this section that the people with disabilities were aware of
the concept of intimacy and being close to someone.

Is There One Person Above all Others to Confide in?

When asked if there was one person above all others in
the network to confide in, seven of the pwod mentioned the
same person that they had previously listed as a best friend
on the SSIDP and two of the participants mentioned a person
previously listed in the friend/family category of the
SSIDP. One female pwod said that there was no one person
above all others in whom she would confide. The
relationship types for pwod included six significant others
and three typical friends.

Six of the pwd said that there was no one person above
all others that they confided in and two pwd mentioned a
paid support person. One pwd mentioned a family member and
one person mentioned a professional. Of the four pwd who
named one person above all others, three had been previously
mentioned on the SSIDP (two from the friends/family category
and one from the professional category) and one person had

never been mentioned before. Not one pwd mentioned the person that they had previously mentioned as a best friend on the SSIDP and none of the people who were mentioned would typically be considered as "chosen" friends.

The indication here was that the pwd did not typically have one person above all others that they could confide in and there was evidence to suggest that pwod appeared to experience best friend relationships that were more consistent over time.

Comparing Support from Family to Support from Friends

There were a wide variety of perceptions regarding the differences in support between friends and family. Eleven people perceived differences in this area and the reasons given for the perceived differences included being able to "speak more easily to family" (2) and "speak more easily to friends about some topics" (6). Other responses were that "family is always there to help" and "you can't relax with family". Of these 11 responses, 4 were from pwd (three males) and 7 were from pwod (four males). Four pwd were unable to answer and three people perceived no difference (two pwod and one pwd).

Comparing Perceptions of Support Differences
Between Men and Women

With respect to differences in supportive relationships

between men and women, 13 participants felt that a difference existed. Of these 13 people, 6 were pwd (4 males) and 7 were pwod (3 males). Most of these responses made reference to how men and women "talk" differently. Examples included "a difference in how they discuss and experience things" (female pwod), "they talk different" (male pwd), "men don't speak the same language" (female pwod), "I like to talk to women, men don't understand" (female pwd), "conversations are different" (male pwod), "some things you can't discuss with men" (female pwod), "certain things I'd say to a man and not a woman and vice versa" (male pwd), and "females talk" (male pwod).

Other responses included "I treat them differently" (male pwd), "there's a difference in how men relate to men and how women relate to women" (female pwod), "men don't respond, they would rather have attention than give it" (male pwod), "women see me the way I am and treat me the way I am" (male pwd), and "men place more value on companionship and less on intimacy" (male pwod).

Three people felt that there was no gender difference (two males and one female without disabilities) and three female pwd were unable to answer due to the researcher's inability to present the question in an understandable manner.

Early Memories of Friendship

This section of the data was analyzed from the perspective of; a) whether there were any memories of early childhood friendships, b) the ages of the participants when the relationships took place, and c) the overall emotional tone.

All of the pwod had memories of childhood friendships and the average age of the participants when these friendships occurred was 4.6 years old (ages ranged from 3 - 9 years). For pwd, only four recalled early memories of childhood friends and all were males. The average age was 7.75 years (age range from 5 - 12 years). One female with disabilities mentioned an uncle but as he was significantly older (at least 10 years) this was not considered an early childhood peer friendship. Four of the female pwd said that their first friend was a paid support person and three of these mentioned the very first paid support person they had upon moving to an individualized community setting. One woman commented that she "never had no friends when I met [the paid support person]". The remaining female in this group did not have any early memories and did not mention a later "first" friendship.

In the responses that were given, the emotional tone is very different between pwd and pwod. Comments from the pwod included "we grew up [together]", "he's [been] my friend all my life", "we did lots of stuff together", "we did

everything", "we just did everything together", "we were together all the time", "we did everything together", "we were always together", and "were inseparable for years", all of which reflected a very positive emotional tone. These comments reflected the memories of 8 different participants. Other comments from this group included "she had the cutest little ringlets", "she pulled me out of the river when I fell", "playing in the sand, at the farm, playing by the creek", "going up to the door and yelling through the screen window 'cause I wanted to play", "used to climb along the fences, and jump into each others' gardens", "she used to protect me", "she was like a sister", "played the piano", "used to go down to the radio station", "she was a gorgeous child", " we were so close", and "a lot of giggles".

Comments from the people with disabilities included "yeah, I can remember being a little kid, a little bad kid", "you name it, we did it, things you wouldn't want to know", "I been to a lot of schools, yeah, oh God, and I cannot really remember", "I was very hurt and upset when it happened", "see, he had a crisis in his family, a very very bad crisis", "I never really was, wasn't, very popular way back there", "I never did see him again", "never phoned me back", and "clean forgot about me or decided he didn't like me for something". The closest comments indicative of a positive emotional tone included "went bike riding together", "we went to school together", "used to go to

school together", "I used to go to school with him", and, "I had good times with [person's name] and had bad times".

Initially it seemed very surprising that all of the male pwd and none of the female pwd reported memories of early childhood friendships, but on further consideration it seemed likely that this may have been related to the circumstances of their early lives. Three of the male pwd lived in family settings until at least the age of 8 years and none of these men had spent considerable years of their lives in segregated institutional settings (although all had experienced this type of "care"). On the other hand, four of the female pwd had experienced a minimum of 20 years in these settings. It seemed plausible that this could account for lack of memories regarding early friendships.

The most disturbing finding was the emotional tone that surrounded the responses of the pwd. All of the pwod appeared to enjoy the reminiscing, and references were made to old pictures and home movies. Often the participants commented that they were not sure if they really remembered or if they had just heard the stories from their parents. When the pwod were describing these early events, they would often smile and gave every indication that it was pleasurable just to remember. The pwd appeared to struggle with the memories when they had them. All of the pwd appeared to experience a degree of pain in attempting to recall their early friendships and gave very little

indication that this was a pleasurable experience.

The fact that the pwod all remembered early friendships and that all of these memories were positive reflections on their connection to another human being represents a very different life experience from the memories (where they exist) of pwd. It was also interesting that four of the female pwd referred to their first friend as a paid support person and that for three of these women, the person mentioned was the first support person they had upon moving to the community. These findings suggested quite strongly that the pwd have experienced early friendships in a different way than have the pwod.

SUMMARY

While it was anticipated that trends or patterns would emerge from the data, it was not known whether these trends would be across the entire group of participants or whether trends would emerge that were unique to a particular subgroup.

These results appeared to show that similarities existed in the social worlds of people with and without disabilities. Similar patterns were found for all of the participants across some of the domains that were examined. However, most of these domains tended to relate to the "surface" elements such as community presence or the number

of people mentioned on social networks. Patterns of difference between the groups emerged when examining the perceptions of the participants towards friends and friendships. This was particularly evident in the areas of network compositions and connections, early memories, and reciprocity. There also appeared to be some indications of gender differences among the participants.

These trends will be further explored in the following chapter.

CHAPTER IV

DISCUSSION

Introduction

Normalization provides a framework for envisioning the lives of people with disabilities as valued, contributing members of society. Part of the implementation of this ideology involves physically moving people out of segregated, institutional environments into "normal" community settings. While in many cases this has improved the overall life quality for people with disabilities, it is apparent that physical presence in the community has not necessarily resulted in community participation, nor has the community at large readily embraced these individuals as neighbours and friends.

The assets of people with disabilities are generally overlooked and there remains a focus on the deficits. In order for these assets to be visible and recognized by others, Wolfensberger (1988) states that life conditions must include integration that is implemented in a positive manner and includes loving, friendship relationships with typical people.

The concept of integration involves not only the presence and participation of people with disabilities, but also depends upon the receptiveness of the communities where

these people live their lives. The skill and understanding of paid caregivers can be vital determinants in assisting communities to be more accepting and in allowing the voice of the people they care for to be heard. These people can be effective bridges or barriers into community life. Therefore, when attempting to understand the social lives of people with disabilities, it is important to also consider the impact of paid caregivers and the broader community.

Community, Beliefs, and Values

Neufeldt (1991) identifies three levels of definition for "community" which include firstly, any place other than an institutional setting and, secondly, the neighbourhood wherein a person establishes a role, identity, and reputation. It is within these first two domains that the paid support people can have major impact. Ensuring that people have choice and opportunity in the places that they frequent, and assisting the community to perceive the value of the individuals that they serve can, over time, enable communities to become more open and accepting. Although the results of this study indicate that people with disabilities do enjoy presence in the community, for those individuals who are always in the company of paid caregivers, the question is raised as to the degree of personal choice involved.

The third level of definition refers to "inclusive

community" where people share a common set of experiences and beliefs (Neufeldt, 1991). Examples of the latter concept can be found in faith communities, self-help groups, voluntary organizations pursuing a social cause, or residential co-operatives (Neufeldt, 1991).

Given the terms by which this kind of community is defined (a common set of experiences and shared beliefs), it seems that social networks could also, at least in some instances, be included as examples of this type of community. Many of the friendships that we experience have their beginnings in a recognized connection of shared beliefs and values. The degree to which beliefs and values are shared will influence the development of the friendship, and if a high degree of connection exists, the friends will likely, over time, develop a common set of experiences. If more than two people are involved in this process, the beginnings of an inclusive community may well be in place. While the people may not go on to form a voluntary organization, they may well experience the benefits of inclusive community. This topic seems to hold major implications for the people with disabilities who were a part of this study.

Our beliefs and values develop out of life experiences and are greatly influenced by the society in which we live. Within western culture, a high degree of value is placed on both intelligence and independence, and for those

individuals who can achieve independence and who have average intelligence, acceptance into the community is often a matter of course. This is not to suggest that these are the only criteria for acceptance, but rather are illustrative of two areas that may preclude entry for individuals with disabilities. Further, the way in which people come to discover their shared beliefs and values is typically through communication and often people with disabilities may be limited in their ability to communicate verbally.

Within the context of this study, life experiences are reflected throughout the data. It is apparent from the analysis of the data that although the people with disabilities share some surface commonalities with the people without disabilities, closer examination, particularly from a qualitative perspective, reveals differences.

Similarities

Both groups indicate similar degrees of overall satisfaction with the quantity of time spent with people in their social lives and all participants are able to report the existence of social support. All participants indicate community presence and the majority of the individuals report regular contact with their families. Both groups report similarly on the numbers of people present in their

social networks. These findings are similar to those reported by Rosen and Burchard (1990) who compared the community activities and social support networks of adults with and without mild cognitive disabilities. Although the sizes of the networks in their study are found to be twice as large for people without disability, satisfaction with the frequency of contact with network members was similar.

Both groups engage in similar types of community activities and these community outings occur equally often. Everyone in the study has some criteria by which they determine what a friend or a friendship is as evidenced by their attempts at defining the words.

In comparing the compositions of the networks over time, all participants are more likely to retain their connections to persons they consider as friends and are more likely to lose connections with persons who could be considered acquaintances (i.e. from the community source category). Equal numbers of participants from both groups report the existence of persons in their lives that they would like either more intimacy with or from whom they would like more distance.

This creates an overall image of twenty people who have friends within their social worlds, some of whom are closer than others, and who all have personal views as to the meaning of friendship. These are people who spend a part of their lives in ordinary settings that are shared by the

community at large and most of the people name places that they would like to go to but can't or don't. Most of these people enjoy regular contact with their families.

Differences

Connections

In spite of these commonalities the other findings paint a very different picture. One indicative trend relates to the sense of connection (or inclusion) experienced by the participants. All of the persons without disabilities show evidence of being part of a unique social network comprised mainly of family and chosen typical friends and while the degree of connections between the network members varies, the person is central to that particular network. Each person mentioned as a network member is a chosen, valued friend and the relationships described involve a mutual, voluntary commitment to one another.

Social networks for people with disabilities consist primarily of paid support persons, followed by other persons with disabilities, and family members. These results are similar to those of Kennedy, Horner, and Newton (1990) who found the average network size for people with disabilities in their study to be 15 people, with family and paid support comprising two-thirds of the network. Although the person

with the disability is a factor in the lives of all the people mentioned in the network, there is a qualitative difference when we face the reality that many of these people were paid to be there. While the people with disabilities in this study had varying degrees of choice as to who their caregivers would be, the reality was that these people were not just choosing a paid support person, but also appeared to be inadvertently choosing members for their own personal social networks.

This is not necessarily a negative factor, especially for people who have been institutionalized and segregated. The relationship that develops between a paid caregiver and a person with a disability may act as a bridge into the community. Further, many relationships between typical people and people with disabilities begin as paid relationships. However, it is important to recognize the false security that exists in paid relationships. Paid "staff" come and go and the time commitment is to the "job" not to the person. Although paid caregivers meet many of the social and personal needs of the people they serve, usually they move on to other employment situations, leaving the person (and usually the relationship) behind. Kanfer and Goldstein (1991) state that certain "features are found in all...helping relationships: They are unilateral, systematic, formal, and time limited." (p. 2). Nevertheless, within the context of this study, the

importance that the people with disabilities place on their relationships with paid caregivers is evident in the comments relating to these people as "first" friends, and in the numbers of paid people mentioned on networks. On the other hand, people without disabilities give few indications that their paired partners (people with disabilities) are valued members of their own social circles. Without both parties mutually defining themselves as friends, and given the aspects of "paid relationships", it appears that people with and without disabilities experience and perceive friends and friendships differently from one another.

Family members are also mentioned as network members by the participants. As people have limited choice over who will be a family member, their presence on the network may be more indicative of duty and responsibility than friendship. This is not to demean the value of family relationships, nor to suggest that family members cannot also be valuable friends. Regardless, the fact remains that the majority of people reported as network members for people with disabilities involve relationships where the person with disabilities often has little or no choice as to their presence (or absence) in their lives.

People with disabilities report other people with disabilities as members of their social networks, and while choice is much more likely to be present in these cases, these relationships often exist in isolation. The people

with disabilities in this study often mention people that they work with as friends, but there is no evidence to suggest that these people see each other socially outside of "programs". While other research (Koller, Richardson, & Katz, 1988) indicates that "most of those who attended the day centres (70%) saw their day-centre friends outside of supervised settings" (p. 328), the people in their study were considered to be mildly disabled and almost all of the individuals were able to arrange all of the aspects of their social engagements independently. Perhaps these factors influence the degree of socializing outside of the structured settings.

Overall, the sense of connection that exists in the networks of the paid caregivers does not seem to exist in the networks of people with disabilities. It is worthy of note that people without disabilities very rarely mention a person with a disability if no paid role is involved.

Where people without disabilities vary in the numbers of people that they list as friends, the friends who are mentioned often know each other and voluntarily spend time together. For people with disabilities there appears to be very little interconnection between their chosen friends with disabilities and most of their time is spent in the company of people who are paid to be with them. There is no indication from this study that these paid caregivers voluntarily socialize or spend time with the individual

outside of the paid role.

Friendship and Disability

Although friendship is a universal phenomenon, people with disabilities have not been viewed as capable or worthy of experiencing or participating in this basic human relationship. It is only recently that friendship and disability have become a topic for consideration.

If values develop from our life experiences and from the impact of societal values and attitudes, what implication does this hold for people who may have lived most of their lives apart from society and whose life experiences are so drastically different from the norm? Further to this, what are the implications for researchers and practitioners whose work impacts directly on the lives of people with disabilities.

It is critical that better approaches and understandings be developed based on the stated needs and desires of people with disabilities. The evidence from this study demonstrates that people with disabilities can be willing participants who are quite capable of expressing their opinions and whose responses are both meaningful and reflect consistency over time.

The people with disabilities in this study indicate that they want more friends in their lives and it seems apparent that their friendship experiences are qualitatively

different from their paired caregivers.

This raises several questions. When people with disabilities say that they want more friends, do they mean that they want more people with whom they can socialize? Given that people with disabilities indicate that socializing and companionship are perceived as the most important aspects of friendship, does this mean that they are indeed happy with friendship as they are experiencing it and really just want more friends that are available for this purpose? It seems that the desire for more friends may also be a reflection of the desire to experience supports in their friendships that they usually receive only from paid support people.

Reid et al. (1989) found that children perceive friends as the best source of companionship support, and discovered that the perception of friends providing emotional support increases with age. The suggestion is made that developmental changes account for this shift in perception. Perhaps the life experiences of people with disabilities have restricted the social development of the individuals and perhaps the current life circumstances have not encouraged development in this regard.

It appears that many of the qualities that the people without disabilities associate with friendship are not experienced similarly by the people with disabilities. Often caregivers are paid to provide emotional support, to

be available when needed (milieu reliability), and to give feedback (esteem support), qualities that people without disabilities attribute to chosen friendships. If the current lifeworlds of people with disabilities are such that many of the qualities of friendship are connected to and performed by paid support people, it is not surprising that "friendship" is experienced in a different way.

There are hints from this research that people with disabilities may be very much aware of the difference between a voluntary "friend" and a paid "friend" as evidenced by the people chosen as best friends on the SSIDP. In spite of the fact that networks are largely comprised of paid support people, only three respondents with disabilities chose paid caregivers as best friends. Also, only two respondents with disabilities indicate a paid support person when asked if there is one person above all others in whom they confide.

One of the most disturbing results emerging from this data relates to the responses of the people with disabilities on the topic of early friendships. The limited scope of this research makes it difficult to know the degree of impact that these early experiences may have on the development of later friendships. Nevertheless, for the participants in this study, indications are that the two groups present very different experiences in this realm. It seems possible that these early experiences may have impact

on social development. If adult friendships are even partially determined by the experience of childhood friendships, a better understanding of these dynamics is critical to the understanding of adult friendships for people with disabilities. Further research could help to determine the impact of early friendships on the development and content of later friendships, and may lead to an awareness on the part of paid caregivers in terms of being better able to support and encourage friendships in later life.

It is the people with disabilities that have the answers to questions concerning their own lives and it is their voice that must be incorporated in directing research and guiding practice.

Reciprocity

Reciprocity is a characteristic of friendship that is mentioned by all of the paid caregivers, yet people with disabilities in this study do not tend to report reciprocity as a factor in friendships. In coming to an understanding of the life experiences of the individuals with disabilities, reciprocity is likely an area with which they have had little experience. These individuals have been receivers of service throughout their lives and are rarely in positions that encourage the dignity of giving.

It is suggested that reciprocity is not merely a

characteristic of friendship, but is a necessary precondition for the possibility of friendship to develop (Lutfiyya, 1990). Studies that examine friendships between people with disabilities and typical people illustrate how the people without disabilities define their friend with a disability as a reciprocating individual (Bogdan & Taylor, 1989; Lutfiyya, in press). The ability to view the person with a disability as a reciprocating individual applied even to those individuals who were unable to move or speak. The implication may be that the perception of reciprocity is critical to the friendship relationship, but how reciprocity is interpreted may be as varied and unique as are the friendships themselves.

It is worthy of note that Gottlieb's (1989) support typologies do not include the concepts of mutuality or reciprocity. Further to this, Gottlieb's (1989) method for assessing social networks provides information only on the receiving of support, not the giving. In fact, all of the support typologies that are used, with the possible exception of socializing/companionship, could be provided by a person living in another city!

One of the assumptions that accompanies the concept of reciprocity relates to the perceived equality of the friends and this has led many to believe that people with disabilities can only be friends with others with disabilities. It is not possible within the scope of this

study to know if it is the people with disabilities who do not understand or perceive the importance of a reciprocal relationship due to their life experiences, or if it is the paid caregivers who may be inadvertently restricting people with disabilities from behaving in reciprocal ways.

Recent findings (Lutfiyya, in press; Strully & Strully, 1985) demonstrate that typical people can have meaningful, reciprocal relationships with their friends who have disabilities, yet the indications from this study are that the people with disabilities do not perceive reciprocity as an important part of friendship.

While there is definitely evidence to suggest that relationships between persons with disabilities can be very meaningful (Siperstein & Bak, 1989; MacAndrew & Edgerton, 1966), there is little evidence to suggest that this was the case for these participants. Although 35 friends (with disabilities) were mentioned by the people with disabilities in the second interviews, only five participants mentioned a person with a disability when constructing their friendship circles and these five people mentioned a total of nine persons. Further, of the five people with disabilities who were mentioned as best friends on the SSIDP, only one of these individuals was mentioned in the later context of the friendship circles.

When the best friends are other persons with disabilities they tend not to be perceived as people who

know the participant well, as only one person with a disability indicated this aspect existing between them and their friend. It would be interesting to explore this topic further by asking whom the participants felt that they knew well.

Aside from the apparent difference between the networks based on a sense of connection, people with disabilities do not seem to experience friendship in the same way as do the people without disabilities. Although people with disabilities are quite able to name a best friend, the person categorized in this manner is not necessarily perceived as someone who knows them very well and the friends do not spend as much time together as do the best friends from the group without disabilities.

Socio-Cultural Factors

The findings from this study indicate an awareness of possible differences between men and women in friendship relationships and there are some indications that gender differences exist in how the men and women experience friendship.

Feminist literature and research provides further insight into the influence of societal values and attitudes. The high value which is placed on independence and autonomy is associated with the life experiences of men and can account for some of the gender differences reported between

male and female relationships. Women tend to experience the world in terms of interdependence and relationships.

A better understanding as to how gender influences friendships for people with disabilities is a necessary consideration for future work in this area. Women with disabilities may well be in a position of double jeopardy as a result of disability and their gender. Dossa (1990) points out that the underlying rationale for the delivery of services to these individuals is often based on helping the women to become autonomous individuals and she argues that there is a need to develop a model of interdependence that will lead to sharing and reciprocal relationships.

It is difficult at this point to know how these differences may impact on the lives of people with disabilities and difficult to know which differences may be a result of gender and which may relate to disability. Further research will help to unravel the mystery and will allow for better understanding.

Implications for Research

The combining of qualitative and quantitative methodologies is a useful approach for gaining a broad understanding of the social lives of people with and without cognitive disabilities. Quantitative methods, particularly for group comparisons, are helpful in exploring the similarities and differences between the groups. It is

important to understand how the lives of people with disabilities reflect similarities and differences to the typical members of society. Without this understanding, services to these individuals may either unwittingly help or hinder the development of friendships for the people served.

It is also critical that this understanding be based on the perceptions of the individuals concerned. Each individual is surrounded by a unique social network and while there are usually common properties of networks, such as the provision of support, the way in which that support is provided and experienced is also unique to each person. Qualitative methods provide a means of discovering the perceptions and experiences of the individuals involved. The focus is not to determine what is "wrong" with the networks of people with disabilities, but is on allowing the voice of these people to be heard in describing their social worlds. This voice must be allowed to speak on the quality of the relationships that are experienced.

Overall, the people with disabilities involved in this study report limited satisfaction with the size of their networks, and report varying degrees of quality, but this may be more a reflection of their satisfaction with the quality of paid support rather than the quality of friendship relationships. This seems like a plausible explanation given the expression of a desire to have more friends and the implication from the people with

disabilities that they know they are adequately supported because they have plenty of "people". The role of research may be to find ways to allow the voice of the people to be heard in both methodology and interpretation of findings.

A major benefit of an approach such as this may be to close the gap between research and practice. If the participants in research are actively involved in the process of guiding research and interpreting findings, then this partnership can only result in meaningful connections that benefit both parties. Research and theory have often been separated from practice which can result in the development of practices that are either not tied to the research, and therefore may not be as useful to the receivers of service as they might be, or the recommendations and theory that emerge from research may not be easily applied in the "real" world. Bridging this gap should allow for the development of practices that are tied to theory and can be implemented to the benefit of the people concerned.

People with cognitive disabilities have, until recently, been excluded from participation in the mainstream of society. Many of these individuals are now, for the first time, experiencing varying degrees of membership in their communities. As an understanding is developed as to how people perceive the supportive relationships in their lives, the areas of similarity and difference may provide

insights as to how the quality of people's lives may be enhanced. While this research would not presume to "tell" people what they may or may not need in their social lives, it is well accepted that people benefit from the presence of friends in their lives and that the quality of these friendships impact on overall life quality. It is also well documented that people with cognitive disabilities are often isolated in their communities and have few friends (Brown et al., 1989; Lutfiyya, 1988).

Given the accepted importance of friendships and the value of the information that people with disabilities can provide with regard to their own lives, research can begin to determine what, if anything, could be happening to assist people to experience meaningful social connections in their lives. This research only begins to look at this matter. The dual methodologies permit a glimpse into the social lives of people from their perspective and allow for comparing common and dissimilar aspects of the reported social networks. The Social Support Inventory for Disabled Persons provides a useful way of gaining information regarding the perceived social supports that exist in the lives of people. It does not attempt to access information with respect to the types of support received but does provide useful information on the perceived satisfaction of the quality of the relationship and information about the amount of time spent together. This form may limit

responses as spaces are provided to fill in the names of
social network members for most of the source categories.
As only five spaces are provided, people may list only five
individuals even though their networks may be considerably
larger. Given the increase in numbers of people mentioned
in the second interviews, this may have occurred in this
study. Nevertheless, this inventory did provide a broad
base of surface information and was found to be useful for
the purpose of this investigation.

Implications for Practice

The results of this study carry implications for the
individuals whose work will be to provide support to persons
with disabilities. People who are interested in providing
support must be aware of the impact of their role on the
lives of the people whom they support. An increased
awareness as to how paid support roles often mimic certain
aspects of voluntary friendships is essential. Paid support
persons need to be able to differentiate between the variety
of roles they may play while in the support role (i.e.
teacher, counsellor, friend, advocate, enabler, etc.) and it
would be helpful for practitioners to have a means whereby
they could evaluate the role expectations in terms of time
and quality.

For example, many people with disabilities who move
from institutional settings to a community home require

initial supports in every aspect of daily living. Most of these people are moving into a new and alien culture for which they have had little preparation. In situations such as these, support people must know which roles will ideally be of a temporary nature and which will be longstanding. Longstanding roles may be reflected by the practical support required by the individual whereas temporary roles may be more related to areas such as friendship. While it is important that a comfortable and trusting relationship exist between the person with disabilities and their paid support person, the relationship should be characterized by growth rather than dependency or overprotection.

Although the provision of emotional support may always be a part of the paid support role, the indication from this study is that people with disabilities do not perceive emotional support to be a significant aspect of friendship and yet the people without disabilities found this to be a very significant aspect of their friendship relations. It seems likely that people with disabilities may not have had the opportunity to experience emotional support in the context of their chosen friendships, and this may be further complicated by the reality that these needs are almost exclusively met by paid support people. Further to this, people with disabilities do not appear to enjoy many voluntary non-paid friendships and when they do, these relationships are characterized differently than are the

friendships of the paid support persons.

A helpful approach to this situation may be to teach prospective caregivers that their role is not so much to be a friend as it is to actively encourage and enable the people they support to develop and maintain outside friendships. A clear understanding as to the differing aspects of freely chosen friendships as opposed to paid "friendships" would enable the caregivers to better meet the social needs of the people they serve.

Limitations of the Study

The weaknesses that arise from the combination of the two methodologies must be taken into consideration as they limit the scope of the study. Qualitative research is not easily replicated and therefore the findings cannot be generalized to all people, but apply only to the people in the study.

The goal has not been to seek causes and effects but rather to understand people's perceptions. Nevertheless, explanations arise from this study that address cause and effect in the sense that how people report their experiences are "caused" by their previous life experiences and their current life circumstances, as well as by personality factors. In combining the two methodologies, the depth of the data and the reporting of people's perceptions were considerably less than would be expected from a qualitative

approach. While more descriptive detail is given than is usually presented within a quantitative method, the reader cannot come to "know" the participants in the same way as a qualitative study permits. Further, the participants have not been involved to the degree typically required by qualitative methodology. Although the data is subjective, the participants did not collaborate in the analysis and interpretation of the results and this places limitations on these domains, as the views of the people are not considered in the final outcome. This is an area worthy of further investigation as methods need to be developed that can better include people with cognitive disabilities.

The study is also limited by the small numbers of people; too small to generalize (aside from the problems arising from qualitative methods) and, for the scope of this study, too large to have provided detailed stories on each of the participants.

Conclusion

The results from this study prompt numerous questions regarding a variety of aspects concerning the friendship experiences of people with disabilities. The limited research available on friendship and disability is not surprising given the history of these people who have, until recently, been excluded from the mainstream of society. With the impact of normalization ideology and the increased

focus on quality of life issues, friendship relationships in the lives of people with disabilities must be considered for they contribute greatly to overall life quality and are experienced universally by typical people.

In examining the topic of friendship, it is important to come to understand these relationships from the perspective of the individuals concerned. This study only begins to look at the friendship experiences and perceptions of persons with cognitive disabilities. Further work in this area must be based on the expressed needs and desires of the people involved, and researchers must develop methods that incorporate (and ideally are directed by) the views of the participants. The lives of people with disabilities have been directed and determined by everyone except the person involved for too long and the time is overdue for these individuals to represent themselves. This research clearly demonstrates that people with disabilities can provide reliable and consistent information.

It appears that many of the social needs for people with cognitive disabilities are met through paid caregiving roles. A more thorough understanding of the advantages, disadvantages, and consequences of paid "friendships", as well as a deeper appreciation as to how to encourage and support adult friendships, could provide valuable information for caregivers, better enabling them to meet the needs of the people they serve.

It is very important that the opportunity to develop friendships does not become yet another service to be accessed. Friendship development appears to be a natural and voluntary phenomena for the majority of people. Each friendship is a unique experience between two people who have freely chosen to enjoy each other.

To date, mere presence in the community has not resulted in a sense of membership or belonging. Perhaps not enough time has elapsed for true acceptance on the part of the communities and the majority of people in the community may not yet see the value of the person with a disability living in their midst. Perhaps the paid support people are not well enough equipped to adequately support growth and development in the domain of social support. Perhaps the early experiences of people with disabilities have restricted these individuals such that friendships are inhibited from the perspective of a lack of experience with such relationships.

The results from this exploration of the perceptions of people with and without disabilities on friends and friendships suggest a variety of topics worthy of further consideration. Increased understanding of these areas will hopefully lead to a time when all members of society can experience the types of friendships that most of us take for granted.

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APPENDIX A

SOCIAL SUPPORT INVENTORY FOR DISABLED PERSONS
(SSIDP)

1. <u>PERSONAL</u> (Section 1)

Is there someone in your life that you feel particularly close to, perhaps someone you live with or a member of your immediate family? Please answer the following questions with that person in mind.

What is your relationship with _____?

( ) mother
( ) father
( ) sister
( ) brother
( ) daughter
( ) son
( ) other relative
( ) friend
( ) other, specify _____

How long have you known this person? _____

Do you live with _____?

( ) yes
( ) no

Is _____ disabled?

( ) yes
( ) no

a) About how often do you see _____?

4 ( ) every day
3 ( ) couple of times a week
2 ( ) once a week
1 ( ) less than once a week

b) About how much of your time do you spend with _____ on the average?

4 ( ) every day
3 ( ) half day
2 ( ) a couple of hours
1 ( ) less than two hours

c) How happy are you with the amount of time you spend
with _____?

4 ( ) very happy
3 ( ) quite happy
2 ( ) not that happy
1 ( ) not happy at all

d) Are you able to do things for _____ that
might be considered supportive; does he/she only do
things for you or do you do things for one another?

5 ( ) He/she only does things for me
4 ( ) He/she does things mostly for me
3 ( ) We do things mostly for him/her
2 ( ) I do things mostly for him/her
1 ( ) I do things only for him/her

e) How happy are you with the way you and _____
get along together at present?

4 ( ) very happy
3 ( ) quite happy
2 ( ) not that happy
1 ( ) not happy at all

f) How much can you count on _____ to be there
when you need him/her?

4 ( ) can count on him/her completely
3 ( ) can count on him/her quite a bit
2 ( ) can't count on him/her very much
1 ( ) can't count on him/her at all

g) How close do you feel to _____?

4 ( ) very close
3 ( ) quite close
2 ( ) not very close
1 ( ) not close at all

2. <u>FRIENDS AND FAMILY</u> (Section 2)

Other than the person just named in Section 1, are there any other people that you feel very close to (for example, members of your immediate family, relatives or friends)?

Please list their first names and their relationship to you.

Name	Relationship
( ) _____	( ) _____
( ) _____	( ) _____
( ) _____	( ) _____
( ) _____	( ) _____
( ) _____	( ) _____

The following questions pertain to one of these people. Please choose the one that means the most to you, and place a mark beside his or her name.

How long have you known this person? _____

Is this person disabled?

2 ( ) yes
1 ( ) no

a) About how often do you have contact with _____
    (either on the phone or in person)?

4 ( ) every day
3 ( ) couple of times a week
2 ( ) once a week
1 ( ) less than once a week

b) When you do see or talk to him/her, how much time do you
    usually spend?

5 ( ) half day or more
4 ( ) 2 or 3 hours
3 ( ) about an hour
2 ( ) about one half hour
1 ( ) a few minutes

c) How happy are you with the amount of time you spend with
    _____?

4 ( ) very happy
3 ( ) quite happy
2 ( ) not that happy
1 ( ) not happy at all

d) Are you able to do things for _____ that
    might be considered supportive; does he/she only do
    things for you. or do you do things for one another?

5 ( ) He/she does things only for me
4 ( ) He/she does things mostly for me
3 ( ) We do things equally for one another
2 ( ) I do things mostly for him/her
1 ( ) I do things only for him/her

e) How happy are you with the way you and _____
    get along together at present?

4 ( ) very happy
3 ( ) quite happy
2 ( ) not that happy
1 ( ) not happy at all

f) How much can you count on _____ to be there
    when you need him/her?

4 ( ) can count on him/her completely
3 ( ) can count on him/her quite a bit
2 ( ) can't count on him/her very much
1 ( ) can't count on him/her at all

g) How close do you feel to _____?

4 ( ) very close
3 ( ) quite close
2 ( ) not that close
1 ( ) not close at all

3. COMMUNITY - INDIVIDUALS (Section 3)

Now please think about other people who give you support,
but who you feel slightly less close to. They might be
people that you see regularly, but that you do not feel
particularly close to. THey could be friends, neighbours,
acquaintances, work or schoolmates, people you see in your
neighbourhood, people who help out in your home, local
business people, shopkeepers, etc.

Do you know any people like that? Please list their first
names, and their relationship to you.

        Name   Relationship

( ) _____   ( ) _____
( ) _____   ( ) _____
( ) _____   ( ) _____
( ) _____   ( ) _____
( ) _____   ( ) _____

The following questions pertain to one of these people.
Please choose the one that means the most to you, and place
a mark beside his/her name.

How long have you known this person? _____

Is _____ disabled?

2 ( ) yes
1 ( ) no

a) About how often do you have contact with _____,
   either on the phone or in person?

4 ( ) every day
3 ( ) once or twice a week
2 ( ) two or three times a month
1 ( ) once a month or less

b) When you see or speak with him/her, about how much time
   do you usually spend?

5 ( ) half a day or more
4 ( ) 2 or 3 hours
3 ( ) about an hour
2 ( ) about one half hour
1 ( ) a few minutes

c) How happy are you with the amount of time that you spend
   with _____?

4 ( ) very happy
3 ( ) quite happy
2 ( ) not that happy
1 ( ) not happy at all

d) Do you do anything for _____ that could be
    considered supportive; does he/she only do things for
    you or do you both do things for one another?

5 ( ) He/she does things only for me
4 ( ) He/she does things mainly for me
3 ( ) We do things about equally for one another
2 ( ) I do mostly for him/her
1 ( ) I do only for him/her

e) How happy are you with the relationship you have with
    _____ at present?

4 ( ) very happy
3 ( ) quite happy
2 ( ) not that happy
1 ( ) not happy at all

f) How dependable do you feel _____ would be if
    you needed something?

4 ( ) very dependable
3 ( ) quite dependable
2 ( ) not that dependable
1 ( ) not dependable at all

g) How close do you feel to _____?

4 ( ) very close
3 ( ) quite close
2 ( ) not that close
1 ( ) not close at all

4. COMMUNITY GROUPS (Section 4)

Do you belong to any organizations or groups in your community?

2 ( ) yes   (Continue with this Section)
1 ( ) no   (If no, go to Section 5)

If yes, please say what they are:

( ) social or recreational group _____
( ) labour union, professional or
     commercial group, work-related
     group _____
( ) church or church group _____
( ) group concerned with children _____
     (eg. Boy Scouts, P.T.A.)
( ) community, charity or service group _____
( ) disability or spinal cord related group _____
( ) other, specify _____

The following series of questions are related to one of these groups or organizations. Please choose the one that means the most to you, and place a mark beside the one chosen.

How long have you belonged to this group? _____

Are the people in the group mostly disabled?

2 ( ) yes
1 ( ) no

a) About how often do you meet with this group?

4 ( ) more than once a week
3 ( ) once a week
2 ( ) once or twice a month
1 ( ) every few months or less

b) About how long do you spend with the group on each occasion?

4 ( ) half a day or more
3 ( ) 2 or 3 hours
2 ( ) about an hour
1 ( ) less than one hour

c) How satisfied are you with the amount of time you spend participating in this group?

4 ( ) very satisfied

3 ( ) quite satisfied
2 ( ) not that satisfied
1 ( ) not satisfied at all

d)   Do you feel the group benefits from your being there,
     or do you primarily benefit from attending the group?

5 ( ) I benefit more than the group does
4 ( ) the group benefits more from my attendance than I do
3 ( ) we benefit about equally from my attendance
2 ( ) I mostly give to this group
1 ( ) I only give to this group

e)   How satisfied do you feel with your involvement or your
     participation in this group?

4 ( ) very satisfied
3 ( ) quite satisfied
2 ( ) not that satisfied
1 ( ) not satisfied at all

f)   In general, how comfortable would you feel asking
     someone in this group for help if you needed something?

4 ( ) very comfortable
3 ( ) quite comfortable
2 ( ) not that comfortable
1 ( ) not comfortable at all

g)   In general, how close do you feel to people in this
     group?

4 ( ) very close
3 ( ) quite close
2 ( ) not that close
1 ( ) not close at all

5. <u>PROFESSIONALS</u> (Section 5)

Are there any health care workers, social service people or clergy that visit you or that you visit NOW?

2 ( ) yes   (Continue with this Section)
1 ( ) no   (If no, STOP)

If yes, please say who they are:

( ) doctor _____
( ) nurse _____
( ) OT/PT/Speech _____
( ) social worker _____
( ) clergy _____
( ) other _____

The following questions relate to one of these people. Please choose the one that means the most to you, and place a mark beside the one chosen.

How long have you known this person? _____

a) About how often do you see _____?

4 ( ) once a week or more
3 ( ) once or twice a month
2 ( ) every couple of months
1 ( ) less than every couple of months

b) About how much time does he/she spend with you on each occasion?

4 ( ) a couple of hours or more
3 ( ) about an hour
2 ( ) about one half hour
1 ( ) a few minutes

c) How satisfied are you with the amount of time he/she spends with you?

4 ( ) very satisfied
3 ( ) quite satisfied
2 ( ) not that satisfied
1 ( ) not satisfied at all

d) Do you feel this person benefits from your visits, or do you primarily benefit from visits with him/her?

4 ( ) only I benefit
3 ( ) I mainly benefit
2 ( ) he/she benefits from our visits as well

1 ( ) we benefit about equally from our visits

e) In general, how satisfied are you with your relationship
with _____?

4 ( ) very satisfied
3 ( ) quite satisfied
2 ( ) not that satisfied
1 ( ) not satisfied at all

f) How dependable do you think _____ would be
in an emergency?

4 ( ) very dependable
3 ( ) quite dependable
2 ( ) not that dependable
1 ( ) not dependable at all

g) In general, how close do you feel to _____?

4 ( ) very close
3 ( ) quite close
2 ( ) not that close
1 ( ) not close at all

This form has been used and modified with written permission
from the author, Ms. M. A. McColl. Further information
regarding the Social Support Inventory for Disabled Persons
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APPENDIX B

Informed Consent

I understand that Ruth Lehman is conducting a study of
friendship as part of the requirement for completing a
Master of Science degree at THe University of Calgary. I
understand that I will be asked questions about friendship
in general and about my life in particular. It has been
explained that the initial interview will be approximately
two hours in length and that a second interview will also be
required, likely taking the same amount of time. It has
also been explained to me that the researcher may wish to be
involved with me in a natural social setting and that I may
have my paired partner present or not, as I wish, during any
part of this process. I have been told that either party
(i.e. myself or the researcher) may discontinue involvement
at any time without penalty and I understand that I will not
be identified by name in the thesis. It has been explained
that all of the individual information will be destroyed
after the completion of the thesis. I have also been told
that I may read the thesis if I am interested. I agree to
participate:

PARTICIPANT _____

WITNESS _____

GUARDIAN _____
(if required)

DATE _____

APPENDIX C

Community Presence

What community settings do you use?

How often?

Do you go alone?

Have you ever encountered problems in using these places?

Are there places you would like to use but can't or don't?

Why?

Community Participation

With whom do you spend most of your time on a daily or
weekly basis?

How does this person fit into your life?

Who else do you spend time with?

Who are your friends?

Who knows you really well?

Does anyone advocate for you?

Do you feel adequately supported? Why?

How could improvements be made?

APPENDIX D

INTERVIEW TWO

Part One

1. Could you tell me about the people who are most
important in your life these days and whom you see at least
once a week? I'm thinking of people who are important to
you because they can make you feel good or bad about
yourself and about how things are going, they can talk you
into or out of things, help you to make a decision or just
listen when you want to talk out a problem, and people who
are important to you just because you know they're there.

2. Could you tell me what category of relationship each
person falls into? Beginning with the first person you
mentioned, is that person a member of your immediate family;
a relative; a co-worker; a neighbor; a professional such as
a family doctor, a member of the clergy, or a counsellor?

3. Could you tell me which of the people in your social
circle know each other? Which of them have a relationship
(more than a nodding, casual hello) that is independent of
their relationship with you?

4. I'd like to know whether any of the people in your
social circle give you any of the following types of help
and support.

ESTEEM SUPPORT (ES): Someone who gives you feedback about
your performance or yourself.

MATERIAL/TANGIBLE SUPPORT (MTS): Someone who gives or lends
you goods, services, money.

COGNITIVE GUIDANCE (CG): Someone who gives you advice and
guidance, especially about decisions.

EMOTIONAL SUPPORT (EmS): Someone who can listen when you
need to talk about your feelings.

BELONGING SUPPORT (BS): Someone (or a group) who makes you
feel included - reliable alliance.

SOCIALIZING AND COMPANIONSHIP (SC): Someone you can go out
and have fun with.

MILIEU RELIABILITY (MR): Someone you can turn to or count on

when needed.

Let's start with the first person that you mentioned. Does
_____ give you feedback about yourself? Can you
tell me about something that you have done together in the
past month or so.

Part Two

1. Please tell me the names of up to 10 people who are
important in your life these days. Think of people who are
important because they affect the way you feel about
yourself, about how things are going for you, and because
they have the ability to boost or lower your spirits. Also,
the people in your network may be people you see on a
regular basis, or people who you don't see very often but
speak to on the telephone or correspond with. You certainly
do not have to list 10 people. There may be just one person
who you feel is important in your life these days, two
people, or any number up to 10.

2. Which of these people are friends and which are family
or relatives? If the person is both a relative and a friend
then we will place that person in both categories.

3. Mapping: Starting with the friendship section of your
network, try to show how close you feel to each friend
(intimacy of the relationship) by placing him or her closer
or further away from you. A small circle will be used to
designate each friend. Place the initials of the friend in
the circle, and let the distance of that circle from you
reflect how intimate or close that relationship is. Repeat
this process for the family/relative section.

The last steps will help us to see how tight-knit or loose-
knit the networks are. That is, we will be able to see
whether our friends tend to know one another or not and how
close their relationships are to one another. Beginning with
the friendship part of the network, we will draw lines
between friends that know each other and who have a
relationship with each other that is more than just a
nodding hello.

Repeat this process for the family/relatives section.

Repeat this process combining the two groups (ie. friends
who have a relationship with your family/relatives).

Part Three

1. How satisfied are you with the overall size of your personal network? Is it smaller than you would like it to be? Is it too large to the point where you feel it makes too many demands on you or involves too much effort to keep up with relationships?

2. Are there any relationships that you would like to make more intimate?

3. Are there any people from whom you'd like to get more distance because they insist on maintaining a closer relationship than you want?

4. Is there one person, above all others in your network, who you can confide in about private matters and feelings?

5. Does the support that you give and receive from family differ from the kinds of support you give and receive from friends? How does this differ?

6. Does the support you receive from the men in your life differ from the support you receive from the women? How does this differ?

7. I would like you to think back as far as you can and tell me about your first friendship? What did the person look like? What did you do together? Can you tell me about one special time or a special memory of that friend?

Circles of Friends/Family