A PHENOMENOLOGICAL STUDY OF THE WORK EXPERIENCES OF AGING ADULTS WITH INTELLECTUAL DISABILITIES AND THEIR PERCEPTIONS OF RETIREMENT

by

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Abstract

With the deinstitutionalization of people with intellectual disabilities, they are not only living and working in their communities, they are living longer and reaching retirement age. It is now understood and accepted that old age is a distinct stage of life experienced by people with intellectual disabilities. To understand the needs of this population as they retire, this study examined the work experiences of five older adults with intellectual disabilities and their perceptions of life without work (retirement). The purpose of the study was to gain an understanding of the role and meaning of work in their lives, and their vision of the future. Five participants over the age of fifty were interviewed using a phenomenological methodology. This research method allowed the participants to speak directly of their experience and made no a priori assumptions about those experiences. The findings of the study concluded that work played a very important role in the lives of the five participants and indicated they had no desire to give up work completely should they reach retirement age. It was anticipated the insight gained from this study would assist in providing valuable information needed to develop services and programs to meet the needs of this growing population.

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Chapter One

Introduction

The aging of people with intellectual disabilities is a growing issue in many countries, particularly in those countries that anticipate a significant increase in the numbers of older persons within their general population (Sutton, Factor, Hawkins, Heller, & Seltzer, 1993). People with intellectual disabilities are now living longer due to better overall health care, nutrition, and housing. With the closure of public institutions and the move to community living, people with intellectual disabilities are living and working in their communities. As this population reaches retirement age, it has become necessary to consider their needs in terms of services and programs. With service provision the responsibility of each province, "most provinces do not have any established policies or systems in support of aging persons with intellectual disabilities" (Janicki & Seltzer, 1991:27).

The focus of this research study is to explore the lived experiences of aging adults with intellectual disabilities in order to gain an understanding of the meaning of work in their lives and their perceptions of life without work (retirement). This study used a phenomenological methodology to specifically examine the various work experiences of older adults with intellectual disabilities in an effort to discover the various themes and patterns that arose from their experiences. The research was guided by the need to know more about the work experiences of older adults with intellectual disabilities and to include their personal accounts in the current body of literature.

While there is little research data specific to Canada regarding the exact numbers of persons with intellectual disabilities, it is estimated that 4 persons per 1000 of those 60 years and older are people with developmental disabilities. This is

estimated to be approximately 17,000 persons in Canada (B.C. Association for Community Living, 1996). In British Columbia, there are currently 7200 adults with intellectual disabilities receiving support services with 15 percent over the age of 50 (Community Support Services, 1997). These statistics do not include individuals who live at home with family members and do not receive support services. However, as the caregivers age, their adult intellectually disabled son or daughter will eventually require support services. Jacobson, Sutton, and Janicki (1985) suggest that "aging and elderly persons with mental retardation constitute about 10 percent of the known service system participants. Since these individuals are typically serviced in sheltered care settings and public institutions, increasing demands on the service system are bound to be experienced" (p.138). Therefore, it is important to recognize that aging intellectually disabled adults are a distinct group who will require services to meet their specific needs.

A review of the literature emphasized the importance of work in our society and its contribution to one's self-esteem. What one does, how well one does it, and the feedback one gets from others all contribute to a sense of who one is. Work provides stability and continuity to that sense once it has been established. Chestang (1982) suggests that work "is a central element in achieving and maintaining a sense of personal identity" (p.63). Work is no less important to people with intellectual disabilities. They also wish to be engaged in meaningful work that gives them a sense of purpose (DeBrine & Howell, 1989). For many people with intellectual disabilities, "work has frequently been considered as synonymous with attendance at sheltered workshops and low-level repetitive, production-line tasks for little financial reward" (Ashman, Suttie, & Bramley, 1995:107). In the last 2 decades, intensive efforts have been made by researchers and advocates to encourage the development of employment opportunities for people with disabilities that approximate conditions

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which apply to others in the community (Wehman, 1988 in Ashman et al., 1995).

It has been recognized that most persons with intellectual disabilities can be employed in meaningful, remunerative work. Noble, Conley, and Elder (1986) are among a growing number of researchers who believe one of the goals for most persons with mental retardation and other developmental disabilities should include placement in substantial gainful employment. However, the authors also suggest that people with intellectual disabilities should be allowed to work past the customary retirement age if they choose to work and are able to do so.

For many older intellectually disabled adults, especially those born prior to the Second World War, "a job has never been a reality. For these individuals, the term 'work' has not meant an occupation or productive enterprise, but more often, activities undertaken in day programmes which have been oriented toward craft, hobbies, or basic communication and self-help skills" (Ashman et al., 1995:108). This may have been due to the fact that many people with intellectual disabilities were institutionalized, or of those living in the community, work was not seen as an activity they were capable of undertaking.

A review of the literature on work and people with intellectual disabilities focused on two areas. One area discussed the lack of employment opportunities for people with intellectual disabilities as stemming from their disability and devalued role in society (Picard, 1990; Oliver, 1990; Farber, 1968; Rioux & Crawford, 1990). The second area discussed the different employment options for people with intellectual disabilities (Rusch & Hughes, 1989; Sylvestre & Gottlieb, 1992; Mank, Rhodes, & Bellamy, 1986). As this study is concerned with work and retirement, the literature reviewed in chapter two presents the definitions of work; the personal and social meanings of work; work opportunities for people with intellectual disabilities; definitions, history, and theories of retirement, as well as a review of the literature on

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retirement for people with intellectual disabilities.

Researchers Janicki (1986) and Wolfensberger (1985) have argued that since the work histories of the current cohort of older people with intellectual disabilities are quite different from those of the general population, retirement may not be appropriate. For many people with intellectual disabilities, employment and retirement have not been clearly differentiated and many may not make the transition between the two states (Ashman et al., 1995). However, Glade (1995) suggests that the current cohort of intellectually disabled older adults is the first group to reach retirement age in significant numbers. The result of this increased longevity is a group of people without a plan for their retirement years.

Some researchers have stressed the need for retirement planning and programs for older people with intellectual disabilities (Sutton, Sterns, and Schwartz Park, 1993). "While the non-disabled worker may have planned out and thought about retirement, the typical retiree from a sheltered workshop may return to the workplace on a daily basis, but participate in alternative-to-work or retirement programming developed by staff teams" (p.99). The fact remains that the preferences and opinions of people with intellectual disabilities are rarely included in the planning process (Roeher Institute, 1995).

To gain an understanding of the work experiences of aging adults with intellectual disabilities and their opinions about retirement, a phenomenological methodology was chosen because it provides a deeper understanding of the nature and meaning of the everyday experience. Phenomenology is the study of the lifeworld -- the world as we immediately experience it pre-reflectively, rather than as it is conceptualized, categorized or reflected upon (Husserl, 1970b in Van Manen, 1990). Phenomenology aims at gaining a deeper understanding of the nature or meaning of our everyday experiences. From a phenomenological perspective, this study asks,

"What is the nature of the experience so that I can now better understand what this particular experience is like for these people" (Van Manen, 1984:38).

Phenomenology is a systematic attempt to uncover and describe the structures, the internal meanings of structures, of life experience. It attempts to describe and interpret these meanings to a certain degree of depth and richness. Phenomenology attempts to "explicate the meanings as we live them in our everyday existence, our lifeworld" (Van Manen, 1990:11). The experiences of people with intellectual disabilities has not been included in the literature. A phenomenological study of their work experiences and how they feel about retirement will help to fill that omission.

The findings of the study are presented in three phases. The first phase describes the actual work experiences of the participants. The first part of the work experience, "The Worksite, Tasks and Responsibilities" depicted their work environment, the tasks they were responsible for, and their hours of employment. The second part of the work experience, "Interpersonal Relations" described their experiences with their peers and supervisors at the worksite. The participants described both their negative and positive experiences with those they worked. The third part of the work experience, "When The Job Ended", described the experiences of two of the participants. Their experience was similar to members of the non-handicapped population who had also lost a job. They suffered a loss of income, a loss of routine and structure, and a loss of purpose and meaning to their day.

The second phase of the findings represented the meaning of work in the lives of five people with intellectual disabilities. The first theme, "Work as an Opportunity to Use Their Special Abilities" described the special talents and abilities the participants recognized in themselves and were able to bring to the workplace. Each person had something unique and special about themselves and work gave them an opportunity to use those special abilities and talents.

The second theme, "Work as Structuring the Day" described the importance of work in organizing and structuring one's day. By having a job and going to work, the participants felt there was a sense of order, stability, and continuity to their day. The routine and ritual of getting ready for work, catching the bus in the morning and taking the bus home, provided a structure to each person's day. Not having a job to go do contributes to an individual's vulnerability of having little routine and structure in their life and no purposeful activity known as work.

The third theme was identified as "Work as an Opportunity to Socialize and Meet Others". This theme presented the social aspect of the workplace and the opportunities to develop friendships that continued outside the workplace. Not all work environments offered the same opportunities to socialize. The participants who worked in a sheltered workshop environment appeared to have more opportunities for social interaction than the participants who worked in competitive employment.

The fourth theme presented was "Work as Service to Others". Often people with intellectual disabilities are the recipients of the service delivery system. Through their opportunities to work, the participants were able to give and be of service to others. Helping others allowed them to see themselves as contributing members of society.

The fifth theme, "Work as a Source of Income" demonstrated the importance of being paid for their work, however, it had varying degrees of importance. For those who supported themselves and lived independently, earning money was necessary for their survival. For one individual who received a disability pension, the money she earned supplemented her pension cheque and helped to pay for extras. For those individuals whose basic needs were provided for by government funding through service providers, the opportunity to earn money gave them a chance to pay for extras such as recreation and leisure activities and holidays.

The third phase of the findings presented the participant's vision of their future.

While their ages ranged from 53 to 69 years, most preferred to continue to work in some capacity. They discussed reducing the number of days worked each week, seeking out new work opportunities, and exploring other avenues and interests. It was evident that as the participants continued to age, they had a desire to continue growing and developing.

The rich description of the participant's work experiences showed that work was as important people with intellectual disabilities as it is to people who are not intellectually disabled. Their experiences can provide valuable information when planning and developing services to meet the needs of older adults with intellectual disabilities. Given the fact that increasing numbers of adults with intellectual disabilities will reach retirement age, the experiences of this aging population could have significant implications for social policy, service agencies, programming, government budgets, and their families and friends. Social workers need to understand that people with intellectual disabilities have varying degrees of abilities and functioning and cannot be broadly categorized. Their individual abilities, strengths, interests, needs, dreams and aspirations are as varied and diverse as the rest of society. "People with a mental handicap should have an opportunity to state their own preferences and assumptions should not be made about their inability to communicate their needs and expectations" (Hogg, Moss, & Cooke, 1988:152). Planning must be undertaken with the individual as the central focus, with consideration given to their experiences, preferences, and opinions. This requires creativity on the part of all those who wish to improve the quality of life for people with intellectual disabilities.

The personal experiences of aging adults with intellectual disabilities are missing from the literature and has been suggested by numerous researchers as a void that needs to be filled (Seltzer & Krauss, 1987; Sutton, Sterns & Schwartz Park,

1993; B.C. Association for Community Living, 1996; Janicki & Seltzer, 1991). There appeared to be a gap in the literature on the work experiences of people with intellectual disabilities, how they feel about their work, and how they would feel should work be taken away (retirement). This study is necessary because older people with intellectual disabilities have something important to say about their work and how they envision their future.

Chapter two presents a description and review of the literature relevant to work and retirement. Chapter three presents the methodology used in this study, the data analysis, and an examination of the trustworthiness of this study. Chapter four describes the work experience of the participants and the five themes to emerge from their experience. Chapter 5 presents a discussion of the findings and the implications for social workers.

My Position as Researcher

This research study came about because of my interest and curiosity in an area about which I knew little.e. Often, people conduct research in areas they have a personal interest in. They may have a brother, sister, cousin, relative, or neighbour that is intellectually disabled. I have not had this personal experience. Instead, like many who chose social work as a profession, I have always been a champion for the rights of marginalized people in our society. Recently, I had an opportunity to work as a service broker on behalf of adults with intellectual disabilities. Through my work, I met many individuals who went to work each day. Some went to the same work location every day, while others had several different jobs at various locations. I wondered what they thought about their work. What meaning did work have for them? Did work have the same meaning for individuals with intellectual disabilities as it does for the non-disabled population? What do they want to do when they reach retirement age? Will they be forced to continue working because funding is not available should

they choose to stay home or prefer to do something else? Do they want to retire from their work or do they want to continue working? What would take the place of work? For many intellectually disabled people under the care and support of community agencies, what plans do agencies have should work no longer be an option? I felt this population had something important to say and I wanted to hear from them.

I suppose what really prompted me to pursue and explore this issue was the comments I heard, not only members of the public, but from support staff who work with people with intellectual disabilities. Many times I had heard people state quite emphatically that "mentally handicapped people don't work", "you can't call what they do as real work", "they are permanently retired", or "what would they retire from?" While it is recognized that work is not a goal for all people with intellectual disabilities, there are those who go to work each day and find satisfaction and meaning in their work. According to Hall, (1989) work is a socially constructed phenomenon and requires a consideration that work is what we define it to be. In order to help me understand their experiences and to answer some of these questions, a phenomenological methodology was chosen as a way to gain a deeper in-depth understanding. It was hoped this study would clarify some of the myths about work and retirement for aging people with intellectual disabilities.

Chapter Two

Literature Review

The literature on work and retirement represents an enormous body of literature and could not be completely reviewed for this study. Instead, I have focused on specific areas that I felt were relevant to this study. This review presents some of the definitions of work, considering there are numerous definitions of 'work' as a noun and as a verb. The work and employment patterns of people with intellectual disabilities focused on the barriers to employment and the different types of employment programs. As this study is also concerned with the participant's views of retirement, I have reviewed the definitions of retirement, the history of retirement in Western society, selected theories of aging and retirement, and a review of the literature on retirement for people with intellectual disabilities.

Definitions of Work

Work is a difficult term to define given the profusion of available definitions and meanings. Shostak (1982) states that the *Webster's International Dictionary* offers over twenty different definitions of "*work* " as a noun and over thirty definitions as a verb. Given the complex nature of defining the concept, I have presented a review of the work of a selected number of authors.

Braude (1975) provides both a narrow and a broad definition of work. His narrow definition conceives of work as the way in which a person earns a living in order to survive. From his broad perspective, Braude (1975) suggests "a person works in order to maintain or enhance any of the statuses that are his by virtue of his membership in a multiplicity of groups" (p. 12). He suggests "a person may be happy doing the necessary survival tasks or he may be woefully miserable. An individual may work to receive a weekly paycheck, or work for no other reason than the sheer joy

in the task" P.12). Braude (1975) concludes his definition of work by stating that "as long as the person defines, or has defined for him, the activities in which he is engaged as in some manner related to his survival, either physical or social, then we can say that person is working" (p.12).

A report of the Special Task Force to the Secretary of Health, Education and Welfare (*Work in America*) was published in 1973. This report was a response to perceived problems regarding work, workers, and retirement (Hall, 1986). The authors of the report noted that work was all too frequently defined in terms of common measures used to count workers:

> We measure that which we can measure, and this often means that a
> rich and complex phenomenon is reduced to one dimension, which then
> becomes prominent and eclipses the other dimensions. This is
> particularly true of "work", which is often defined as "paid employment".
> This definition conforms with one readily measurable aspect of work,
> but utterly ignores its profound personal and social aspects and often
> leads to a distorted view of society ... Using housework as an example,
> we can see the absurdity of defining work as "paid employment". A
> housewife, according to this definition, does not work. But if a husband
> must replace her services -- with a housekeeper, cook, babysitter --
> these replacements become workers, and the husband has added
> to the Gross National Product the many thousands of dollars the
> replacements are paid. It is, therefore, an inconsistency of our
> definition of work that leads us to say that a woman who cares for
> her own children is not working, but if she takes a job looking after
> the children of others, she is working (Special Task Force,1973:2-3
> in Hall, 1986:11).

The authors of the Special Task Force assert that equating work with pay has the unfortunate consequence of implying something about the work of an individual based on the amount of pay received for work. They concluded that work is "an activity that produces something of value for other people" (In Hall, 1986:11). This definition also encompasses volunteer work, because it too produces something of value.

Parker and Smith (1976 in Hall, 1986:12) define work in modern society as a means of earning a living.

To the individual in a modern industrial society, work is usually defined with the means of earning a living. In simpler societies, the relationship between work and such basic necessities as food, clothing, and shelter is a direct one for the individual and a comparatively small group; they consume only what they are able to produce. The evolution of society through various forms of social production and ownership of property progressively breaks down the link between individual productive effort and consumption of goods and services. Hard physical labour is less and less required as machines take over more of the tasks of production. Fewer people are needed to produce the necessities of life, and the goods and services of what are sometimes called the 'leisure industries' account for an increasing proportion of total production and employment.

This definition of work by Parker and Smith (1976 in Hall, 1986) not only uses the term 'work', but also four of its synonyms: production, effort, labour, and employment. Of the terms 'work, labour, and employment', only 'employment' implies a social relationship (Hall, 1986). The most common form of employment consists of an employer hiring the working abilities of an employee for a period of time. Parker and Smith (1976 in Hall, 1986) continue with their definition of work:

Two other concepts of work and labour ... have to do with activity rather

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than time. Both are equated with employment, but while it is true that
all employment implies work of some kind, the reverse is not necessarily
so. Employment is work in the narrow sense of income-producing
activity, but work has a wider biological and physiological meaning of
purposeful and sustained action. Whereas employment may be
contrasted with idleness or with work that is economically unremunerative
or disinterested, work in its broadest meaning is the opposite of rest
(Parker & Smith, 1976:41 in Hall, 1986:12-13).

Hall (1986) suggests that "it matters not where the source of the purpose lies - within
the individual in some form of intrinsic or extrinsic motivation, or outside the individual
in some form of job description or other prescription for action. The key factor here is
that work is an activity; it is not rest" (p.13).

Fox and Hesse-Biber (1984 in Hall, 1986) provide a broader definition of work
as "any activity or expenditure of energy that produces services and products of value
to other people" (p.12). Hall (1986) proposes that this definition "has the advantage of
introducing the concept of services into the nature of work" (p.12), but that other factors
should be included in a comprehensive definition of work. Hall (1986) suggests a
complete definition of work requires a consideration that work is what we define it to
be. Work is a socially constructed phenomenon as well as an objective reality. Miller
(1981) stresses the fact that what people define as reality is based on continuing
personal negotiation (social interaction) as they continually define and redefine their
own realities. Based on these considerations, Hall's (1986) admittedly cumbersome
definition of work is described as "the effort or activity of an individual performed for the
purpose of providing goods and services of value to others, it is also considered to be
work by the individual so involved" (p.13).

The Social and Personal Meanings of Work

Work is so overarching in our daily lives that we tend not to see or contemplate it. Gamst (1995) suggests that the way in which we humans organize our work guide individual fortunes, interactions with others, interconnections among groups, and structuring of the wider society. He argues that work has one of the broadest ranges of meanings of any word in the English language. Given the fact that there are many meanings and definitions of the word 'work', this literature review will focus on the social and personal meanings of work.

Chestang (1982) suggests that "[w]ork has come to be accepted as an integral aspect of personal identity, with the potential of fostering a person's sense of social contribution and validating the meaningfulness of one's life" (p.63). Work is a way of finding meaning in one's life and brings together the personal and social dimensions of the subject. When an individual's work is valued and has significance within some group or society context, an important aspect of the meaningfulness of life is experienced first hand (Chestang, 1982).

Chestang (1982) examined the meaning of work and argues that it relates to human development in at least four ways: as an internal organizer, as social learning, as a source of social recognition and status, and as a way of finding meaning in life.

Work as an Internal Organizer

Work as an internal organizer begins in the earliest infancy, when the human organism engages in activity which gives pleasure in itself, but also promotes the evolution of ego potentials and personality organization. According to Robert White (in Chestang, 1982), as the infant accumulates experience and gratification through activities, the sense of competence is enhanced.

A child's early activities are precursors to work and are fundamental to the later ability to work. These early activities and the internal organization they foster is a

stage-appropriate step in a continuing process, to be taken over by other steps as the child progresses through the subsequent stages of life (Chestang, 1982). As a child matures, more specific and structured tasks are assigned. It is during adolescence that work becomes a time for experimenting and testing, contemplating the future, and revising plans many times (Chestang, 1982).

The function of work as a regular activity comes into the foreground in young adulthood and beyond. Chestang's (1982) review suggests that the human need for order is well established and work offers order and consistency to one's day. He suggests that most individuals accustomed to going to work each day become frustrated and anxious if the opportunity to work is removed for an extended period of time.

The organizing function of work does not end with advancing years. Older workers who contribute as volunteers or continue work on a part-time basis help to keep a sense of identity and self-esteem through the work itself. A job, merely as "a place to go", or something a person "needs to do" takes on a deeper meaning. Workers have stated that without this "place to go" or this "something to do", their lives would be "threatened by the absence of a way to use one's time, rendering the individual vulnerable to a lack of purpose and order, increasing the potential for the upsurge and expression of personally and socially injurious actions" (Chestang, 1982:69).

Work as Social Learning

The second perspective related to human development suggests we learn about work through social learning. Four principles of social learning were drawn from experiments by Bandura (cited in Mussen, Conger, & Kagan, 1979 in Chestang, 1982). The first principle states that repeating behaviours modelled by parents is a part of every child's repertoire. Through repetition, children acquire attitudes,

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orientations, and skills related to work. As the child observes parents performing tasks, certain attitudinal orientations toward work are conveyed. These orientations suggest how parents feel about work (Chestang, 1982).

Bandura's second principle concerns the relationship between investment in work and obtaining a certain goal. This idea is applicable to early childhood as well as other stages of life. For example, the young child picks up his toys at the end of a play session in order to please the parents; teacher reinforcement and parental rewards motivate the child to invest in school work. These and other goals that have meaning for an individual heighten the interest in working (Chestang, 1982:70). The third principle stated by Bandura suggests that status and relationships are important motivators because a person is more likely to emulate prestige models. The social and personal value placed on prestige makes such models desirable to the individual and suggests that he or she can hope to attain a similar position (Chestang, 1982). The fourth principle set forth by Bandura suggests that a model who is similar to the learners themselves has a greater effect on behavior than a dissimilar model. Chestang (1982) cites the advertising industry as capitalizing on this principle by using children to promote products designed for children.

Chestang (1982) comments that in addition to the broad social implications of Bandura's concept, the ramifications for smaller units such as the family are more important. The critical position of parents and other relatives to serve as models for children with regard to work is extremely important.

> Parents who are employed and invested in their work, convey messages
> to their children about the importance of work. Likewise, if parents are
> uninvested in what they do, or work habits convey indifference, lack of
> responsibility or low esteem for working, these attitudes are also modelled"
> (Chestang, 1982:70).

Social Recognition and Status

Perlman (1968 in Chestang, 1982) made the point that people work for social recognition. Approval and social recognition assures a link with other people and elevates one's self-esteem. Social recognition and status is the relationship of an individual to production and society and work becomes the way to fulfil these needs for the adult. Work is about status, one's place in the hierarchy, one's value, and the importance of being a member of a group or organization. Status, then, is socially ascribed and relates to the positive estimate of one's competence by valued others (Chestang, 1982).

However, social recognition and status are not available to all workers, particularly members of minority groups and for many women in Western society, and denied to people because of their race, gender (Chestang, 1982) and their disability. Jean Miller Baker (1986) suggests there are two types of inequality. The first type of inequality is temporary and includes relationships such as those between a parent and a child. The second type of inequality is permanent and moulds the way we perceive and conceptualize ourselves and defines who we are. Dominant people in our society label decide who is ascribed and given the label of inferior, defective, or substandard. For people who are ascribed to these inferior or defective roles, it becomes difficult to achieve recognition and status in our society.

Work as Meaning in Life

Chestang (1982) suggests that satisfaction of a job well done is the end result of competence, but competence has both personal and social aspects. The sense of satisfaction merges with one's sense of competence to produce self-esteem.

Work is not only related to a personal fulfilment, but is also related to what Maslow (1971 in Chestang, 1982) referred to as self-actualization. Through work, an individual can realize his/her potential by utilizing physical, intellectual, social and

creative abilities. Chestang (1982) suggests that personal fulfilment may be a function of attaining personal goals associated with personally meaningful values. Human and environmental barriers to self-fulfilment limit but do not prevent the attainment of personal fulfilment. Chestang (1982) also suggests that what is important "is that the individual derives through work a sense of satisfaction based on the exercise of the best of his or her abilities in a task that is personally meaningful and socially useful" (p.74).

Social confirmation is essential because it gives meaning to one's work beyond the self. "The acknowledgement of others links the individual and her work to a social context, which in the analysis defines both its value and its meaning "(Chestang, 1982:.74). He argues that this is why all workers await with anticipation and anxiety the judgments of their superiors, peers, and critics. Chestang (1982) concludes that it is not only judgment that binds workers to their society, but also "the sense of social contribution growing out of the usefulness of one's products to others gives the sense of being purposeful and needed -- both vital to a person's self-esteem" (p.74).

Studies have examined the meanings of work and found that one of the rewards of work was economic, but it was not the single most important meaning of work. Rothman (1987) states that numerous studies beginning in the 1950s and replicated since, found that "over 70 percent of workers at every occupational level admit that they would stay on the job even without the economic imperative" (Morse & Weiss, 1955; Renwick and Lawler, 1978; in Rothman, 1987:201). Work also offered other benefits and had some meaning beyond the simple material rewards. Renwick and Lawler's study (1978 in Rothman, 1987) provided insight into the meaning of work if money was not a motivating factor. Participants' replies were organized into several major groups and themes: performance, self-identity, activity, social value, and social contacts and concluded that work had many meanings and met many needs, money

being merely one.

Braude (1975) suggests that the meaning of work for an individual can be as varied as the gamut of human emotional responses. He states that "factors that appear to structure work meanings, particularly as they are expressed in attitudes of satisfaction or dissatisfaction with the work include: absenteeism, achievement, advancement and promotion, a sense of alienation, job and career aspirations, degree of autonomy in work, automation, a sense of challenge, clarity of goals, education, job involvement, intellectual stimulation, social and occupational mobility opportunities provided by the job, personal and social motivations of the job, morale, needs, interpersonal relationships, organizational structure, salary, race, sex, ethnicity, job skills, status and prestige of the work ... " (p.137).

A study of the meaning of work and retirement by Friedman and Havighurst in 1954 (cited in Braude, 1975) indicates that all work provides common threads of meaning even though a particular occupation may stress one or more strands at the expense of others. They suggest that all work seems to provide income, to regulate life activity, to provide a source of identity, association, and meaningful experiences. Friedman and Havighurst's study of five occupations varied in skill, prestige, and commitment -- steel workers, coal miners, skilled craftsmen, retail salespeople, and physicians, attest to these commonalities. According to Braude (1975), "the centrality of the meaning of work in an occupation should not obscure the fact that all work does possess meaning" (p.140).

Mannell and Reid (in Reid, 1995) conducted a survey of people from all walks of life and engaged in all kinds of work. The personal meaning of work was assessed by having the respondents rank the importance of the outcomes or meanings work had for them personally. An individual sense of accomplishment appeared to be the major incentive for the respondent's work, rather than remuneration, or the commitment or

loyalty to the company or organization for which they work.

Auster's (1996) work examined how worker's feel about their work. Although workers' feelings about their work may be attributed in part to psychological differences among individuals, attitudes toward work both shape and can be shaped by the occupational environment in which the work is performed as well as the management practices and formal structure of the employing organization. Auster (1996) also suggests that larger societal forces have an impact on a variety of aspects of workers' jobs that may then affect their feelings about their work.

Individual, Organizational, and Societal Influences

Individual influences can impact on the feelings an individual has regarding work. Maslow's (in Auster, 1996) hierarchy of human needs acknowledges that the hierarchy of needs may vary from one individual to another. "A sociologist taking the life-span development approach might argue that this hierarchy of needs differs depending on one's stage in life. On the other hand, this hierarchy of needs may explain why some workers are motivated to do their work well" (Auster, 1996:201).

The occupational environment can also affect how an individual feels about work. Hackman and Oldham (1976 in Auster, 1996) argue that a set of core job dimensions affect critical psychological states, which in turn affect work motivation satisfaction, and performance. "The five core dimensions of work are: skill variety, task identity, task significance, autonomy, and feedback affect critical psychological states such as the experienced meaningfulness of the work, the experienced outcomes of the work, and the knowledge of the results of the work activities" (Auster, 1996:203).

Blauner (1964 in Auster, 1996) argues there are alienating forces in modern industry that alienate workers in a variety of ways. Workers feel powerless over their immediate working conditions. They often cannot control noise, temperature, or

lighting at their work environment. A second dimension of alienation is that of meaningless. As the division of labour increases and workers become more specialized, their tasks become so small that workers lose sight of how their task contributes to the final product. Workers feel an increasing sense of isolation and disconnectedness to their community. The last dimension of alienation is that of workers feeling self-estranged. Work activities that many employees engage in are not self-expressive or creative (Auster, 1996).

The influence of organizational structures and management practices also impact on workers' feelings about their work. Max Weber's analysis of bureaucracy defines work in this field (Gerth & Mills, 1946 in Auster, 1996). Weber's model characterizes bureaucracies as having a distinct division of labour, a hierarchy of authority, written rules that define the way in which the bureaucracy will be governed, rational and objective decision-making, and technical competency. Weber thought that many organizations were already bureaucratic or headed in that direction. Auster (1996) states that "while Weber thought the bureaucratic model was the most efficient way to run an organization, he feared it could also be dehumanizing for its members. Increasing specialization of tasks and fragmentation of work could reduce individuality and creativity, and the impersonal and formal relationships between co-workers could reduce friendships, thereby leading to a reduction in work satisfaction" (Auster, 1996:208-209).

The scientific management model proposed by Frederick Taylor (in Auster, 1996) relished the idea of efficiency. Taylor's scientific model of management emphasized human beings as economic beings and presumed the most basic motivator was economic. Under this model, management and labour would recognize that high productivity would be in the best interest of both. Fundamental to Taylor's model is that individual opinions and judgments must be replaced by scientific

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investigation and knowledge. Auster (1996) suggests that while scientific management and efficiency made sense on paper, workers became demotivated by the boring and tedious nature of their work. "This is not surprising, since scientific management encouraged managers to treat workers as robots, programming each for an efficient, repetitive task" (p.210).

The human relations approach understood that there was more to worker motivation than money. While the scientific management approach focused on the worker as an economic being, the human relations model emphasized people as social beings. Human relations theorists recognized that "informal norms that emerge as a result of personal relationships within groups, have an impact on workers' perceptions of their work, including their feelings of motivation, satisfaction, and alienation" (Auster, 1996:211).

Societal influences also affect an individual's feelings about their work. Auster (1996) cites Marx and his classic statement on the relationship between work and workers' feelings about their work. Marx argued that "workers' feelings of alienation are caused by society's economic structures and that when the bourgeoisie own the means of production and reap all the benefits of the work of the proletariat or labourers, alienation is inevitable" (Auster, 1996:212).

The state of the economy can also impact workers' feelings about their work and themselves. Unemployment, societal stereotypes and biases at the organizational level, and gender stereotypes affecting occupational socialization can all impact on how one feels about their work. "Discrimination and bias against women, members of racial and ethnic groups, homosexuals and lesbian, and people with physical and intellectual disabilities have all contributed to unequal treatment in the work force" (Auster, 1996:214).

This literature review of the meaning of work and the factors and forces that

contribute to those meanings is by no means exhaustive. Rather, it provides a selection of the various personal and social meanings of work as well as the individual, environmental, and societal factors that contribute to the meaning of work in an individual's life. For a more in-depth and thorough understanding of the meanings of work, the reader is directed to the works of Shostak (1982) and Gamst (1995). Shostak traced work meanings through 2500 years of Western history. He found that four issues were particularly influential in shaping the history of work meanings: power distribution, needs satisfaction, participant roles, and value emphasis. Gramst's (1995) work presents a collection of essays which contribute to the ongoing considerations of the meaning of work in sociocultural anthropology. Each essay views work as the central human concern and as something that makes us human. Most of the contributing authors in Gamst's (1995) book view work in market economies as radically changing with profound consequences for each of us personally, our families, our communities, and our countries.

Work and People with Intellectual Disabilities

It is important to recognize that people with intellectual disabilities are a heterogeneous population and vary widely in their levels of abilities. The population of aging adults with intellectual disabilities is comprised of persons who experience differing levels of intellectual disabilities, and who display different functional and social skills (Kaufman, DeWeaver, & Glicken, 1989). A review of the literature on work and people with intellectual disabilities focused on two areas: their exclusion from the mainstream of society and the different employment opportunities and programs available to individuals with intellectual disabilities.

People with intellectual disabilities have a devalued role in our society. Picard (1990) argues that their disadvantages arising from their disability does not originate in the person, but rather, in the rejection of the person by society. Oliver (1990)

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argues there are economic reasons for the exclusion of disabled people and it is the embodiment of social and economic relations under capitalism which has led directly to the exclusion of disabled people in a capitalist society. As capitalism developed, disabled people were excluded from the work place and the mode of production. "Changes in the organization of work from a rural based, cooperative system where individuals contributed what they could to the production process, to an urban, factory-based one organized around individual waged labour had profound consequences for disabled people" (Oliver, 1990:28). "The operation of the labour market in the 19th century effectively depressed handicapped people of all kinds to the bottom of the market" (Morris, 1969). As a result, "disabled people came to be regarded as a social and educational problem and more and more were segregated in institutions of all kinds including workhouses, asylums, colonies and special schools, and out of the mainstream of social life" (Oliver, 1990:28). The rise in capitalism excluded disabled people from the process of work and its consequent social relations. It also changed the way disabled people were viewed, for "capitalism, whether free market or welfare, encourages us to view people ... as a commodity for sale in the labour market" (Burton, 1983 in Oliver, 1990:28).

Farber (1968) developed the concept of surplus population to explain the social status of mentally handicapped people historically, cross-culturally, and contemporaneously. Farber acknowledged the view of disability as a social imposition rather than a personal limitation. "[T]he vicissitudes in the life of the mentally retarded individual result primarily from the status and role assigned him" (p.15). He concluded the life-chances of mentally handicapped people are determined "both by being labelled as deviants and by their incompetence" (p.19).

The exclusion of people with intellectual disabilities from the mainstream of society and economic life has kept them dependent on society. Jenkins (1991) views

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their total exclusion from the labour market "as an expression of global social marginality with the crux of the problem as the nature of their membership in society to the degree to which they are citizens" (p.571). Hogg, Moss, and Cooke (1988) came to the same conclusions as Jenkins (1991) when they stated that the problem people with intellectual disabilities experience in their everyday life (including opportunities to work), is compounded by enforced social exclusion from their wider society. Based on the work of Oliver, Faber, Jenkins, and Hogg, Moss, and Cooke, people with intellectual disabilities are excluded from society because of economic reasons, the label of "mentally handicapped" and their incompetence to do the work.

It has been suggested that close to 24 percent of Canadians with disabilities live on incomes below the poverty line (Ross & Shillington, 1990 in Roeher Institute, 1995). Estimates suggest there are over 196,000 individuals in Ontario who live in poverty "and who have some form of disabling condition including psychiatric, learning, developmental, or physical disability" (Roeher Institute, 1992:80 in Roeher Institute, 1995:12). Poverty goes beyond not having enough money for sustenance. It has been linked to a variety of determinants affecting health and well-being, including fewer occupational rewards, and has been found to foster low self-esteem. The link between poverty and disability exists for two important reasons: there have been few systematic and proactive attempts to enable individuals with disabilities to participate fully in the labour force; and the structure of social assistance programs does not take into account the cost associated with disability (Roeher Institute, 1995).

Rioux and Crawford (1990) suggest that most barriers to employment fall under physical inaccessibility of workplaces and social inaccessibility due to negative and ignorant attitudes among workers and employers. This is an adjunct to the social stigmas attached to disability that is pervasive in the rest of society. Rioux and Crawford (1990) argue that very little has been done in the realm of employment

related programming at the federal, provincial, and municipal levels of government to enable the active participation of individuals with disabilities in the workplace. They claim that of those who are employed, most are in low-paying and/or temporary jobs, or in sheltered workshops getting close to pennies for wages.

Employment Opportunities for People with Intellectual Disabilities

As the previous review demonstrated, people with intellectual disabilities are devalued, stigmatized, and excluded from participation in the labour force. A review of the literature suggests this may be slowly changing with the implementation of supported employment programs. I will expand on the literature on these programs later in the review. Work is no less significant for the person with intellectual disabilities than for the person without intellectual disabilities (Beirne-Smith, Patton, & Ittenbach, 1994) and the opportunity to work is valued by many people with intellectual disabilities. According to DeBrine and Howell (1989), their clients with intellectual disabilities have told them they value work because it makes them feel productive and important, because "it's what everyone does" (p.225). Work provides social contact, a respectable occupation five days a week, and the money earned allows a degree of independence, choice, and pleasure.

May and Hughes (1988) suggest that "[j]obs are valued not so much for the financial rewards they bring, nor for the social contacts they promise, but for what they say about identity" ... Entry to the job market, or placement at a vocation training program, especially one simulating a work environment or offering a degree of integration with non-handicapped people, encourages the belief that one is more or less normal" (p.75).

Castles (1996) suggests that it may surprise many people to learn that the majority of adults with mild mental retardation do in fact work. Studies indicate that over 50 percent of adults with mild mental retardation are in the competitive work force,

usually in unskilled or semi-skilled jobs (Stroman, 1989). However, the employment history of these individuals is often characterized by instability and change (Kernan & Koegel, 1984 in Castles, 1996). People who are moderate or severely intellectually disabled are much less likely to be employed in the competitive labour force. "It is estimated that only 5 percent of these individuals hold competitive jobs. Some of the rest attend sheltered workshops, vocational training programs, or day activities" (Castles, 1996:112). However, this situation is slowly changing with the implementation of supported employment initiatives which "enable individuals with moderate and severe retardation to obtain and keep competitive jobs" (Salzberg, Likins, McConaughy, & Lignaugaris/Kraft, 1986 in Castles, 1996:112).

At one time it was thought that people with intellectual disabilities possessed little potential for gainful employment, but even individuals with the most pervasive support needs are quite capable of performing complex vocational tasks when provided with appropriate and systematic training (Bellamy, Sowers, & Bourbeau, 1983 in Beirne-Smith, Patton, & Ittenbach, 1994).

The range of paid employment opportunities for people with intellectual disabilities varies from highly protected to highly competitive settings. The following is a brief description of the types of employment opportunities:

Sheltered employment. Sheltered workshops consist of programs that provide daytime activities for persons who require continuous supervision. These workshops provide both long-term and short-term placements, they stress self-sufficiency over employability, and service persons with intermittent to pervasive support needs. Most workshops provide basic rehabilitation services, including screening, evaluation, training, placement, and follow-up services.

Supported employment. For persons for whom competitive employment is not an option, supported employment is often used. Supported employment exemplifies

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the movement away from sheltered settings toward integrative ones. These programs allow for decreased supervision and segregation and increased autonomy and integration through structured support (job coaches), paid employment, and the opportunity to work in competitive settings.

Competitive employment. This category represents employment in the labour force, usually alongside persons without intellectual disabilities. More adults with intellectual disabilities are obtaining placements in independent, competitive settings than ever before. Adults seeking this form of employment are as likely to obtain jobs through family, friends, or their own efforts as through organized vocational programs (Beirne-Smith, Patton, and Ittenbach,1994).

In the last two decades, intensive efforts have been made in many countries to encourage the development of employment opportunities for people with disabilities that approximate conditions which apply to others in the community (Wehman, 1988). However, it has only been in the past 10 years that supported and competitive models of employment have become widespread (Ashman, Suttie, & Bramley, 1995). These programs offer the greatest potential for handicapped individuals to attain non-sheltered work and achieve status as working, contributing members of society (Ross & Cameto, 1988).

A qualitative study conducted by Ford, Ninnes, and Parmenter (1995) examined the attitudes toward supported employment of parents and primary caregivers of individuals with severe intellectual disabilities. The respondents of the study felt that supported employment programs offered more normalized and beneficial work experiences than those typically provided for persons with severe disabilities. They also expressed relatively low expectations for improving wages, opportunities for career advancement and social integration. The respondents also expressed "apprehension about future moves to less restrictive settings and a desire for the status

quo" (p.257), regardless of their current level of satisfaction with the employment experiences.

Much of the literature regarding work and people with intellectual disabilities has focused on supported employment programs and initiatives. Supported employment, with its focus on facilitating successful participation in integrated work settings, provides an alternative to the sheltered workshop model (Rusch & Hughes, 1989). It offers occupational choices to persons who traditionally have been considered unemployable in the competitive labour market. Supported employment represents a major shift away from programs that segregate disabled workers in sheltered workshops to programs that promote integration. Like all community-based programs for people with intellectual disabilities, the paramount goals of this policy are to improve the quality of life, minimize their marginalization, and drive the entry of people with intellectual disabilities into the mainstream of community life (Emerson, 1985).

Until the early 1980s, adults with intellectual disabilities living in British Columbia had few options when deciding what to do with their day. The majority of people requiring supports attended segregated centres funded by the provincial government, where activities ranged from social or recreational pursuits through to contracted work activities. People who did not attend centres had little in the way of services to assist them in integrated activities, including work (BCACL, 1991).

The first employment agency for people with intellectual disabilities was created in 1977 to serve people from a number of municipalities within the greater Vancouver area. POLARIS was funded by Employment and Immigration Canada's Outreach program. The program worked closely with community colleges to establish post training options to prepare people with intellectual disabilities for employment. Other agencies throughout the province initiated supported employment programs, but most

were short term federally funded programs that faced problems of financial insecurity. Continuity of support to people with intellectual disabilities and their employers was a major issue affecting the future growth of this new program (BCACL, 1991).

In 1987, the provincial government of British Columbia introduced a funding program to develop supported employment services. This program was introduced to enable the development of innovative options to support adults with intellectual disabilities within an integrated setting and productive work activity. In 1989, the Ministry of Social Services and Housing funded four types of day programs for people with intellectual disabilities. The training and support services included achievement centres, self-help skills programs, employment initiatives for handicapped, and supported work. Of a total of 5,762 available spaces, 641 or 11 percent were for supported work. The achievement centres and self-help skills programs provided 77 percent of the spaces, while the employment initiatives program provided 12 percent of the spaces (BCACL, 1991). Of the total placements 23 percent were for work or employment. These figures did not account for people on wait lists to get into work related programs.

In June of 1991, the Ministry of Social Services began a review of its training and support services for adults with intellectual disabilities which culminated in the report Common Themes and Future Directions, 1992. The report identified that individuals wanted real goals, real choices, and real futures. There were not enough program choices that provided for employment choices. Individuals with intellectual disabilities stated they did not want trivial program objectives or goals set for them. They did not want to be placed in programs solely because a space was available. Instead, they wanted training and support services to assist them with a transition from life-skills to work-related work experiences and to paid employment. They wanted a variety of models of service delivery to support people in work and work experiences.

They wanted individual placements, work stations, enclaves, mobile work crews, and entrepreneurial options. They wanted more options than just facility-based programs (Province of British Columbia, 1992).

The supported employment initiative in British Columbia is guided by the recommendations from the 1992 report *Common Themes and Future Directions*. The recommendations adopted by the provincial government provided for a time-limited self-help skills program and the supported employment initiative where individuals are paid a wage for their work. People with intellectual disabilities have said they not only want to work, but they also want a decent wage for their work.

To achieve this objective, changes to the Employment Standards Act and Employment Standards Regulations were required. This Act and its regulations set out the rules and regulations governing employment in the Province of British Columbia. People with intellectual disabilities have been excluded from coverage under this Act because they were seen as not being able to participate in paid employment. The Act was repealed on September 30, 1996 to read, "Effective September 30, 1996, the Employment Standards Act does not apply to an individual receiving income assistance under the Guaranteed Available Income For Need Act while participating in a time limited government incentive program that provides on site training or work experience and is operated under the latter Act. The Act applies to most intellectually disabled individuals in self-help skills programs and supported work programs.

Employees are excluded from the Act where the intention of their day program is primarily therapeutic, rehabilitative or basic support. The following is a definition of the classifications to determine whether or not an individual is employed or receiving support: support, where an individual attends a site and is provided with general support and safety; preparation, where an individual attends a site to learn work

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related behavior; training, where an individual is provided with employment skill development; and employment, where an individual is expected to have skill and related behavior performance with work activity (Ministry of Labour, 1996). If the intention is to provide employment to people with intellectual disabilities, then they must be treated as employees under the Act.

Rationale for Supported Employment

The emergence of supported employment reflects three related historical developments. First, sufficient empirical evidence was accumulated in the 1970s to challenge the prevailing theory that mental retardation is a long-term debilitating condition with poor prognosis for remediation. Rusch and Hughes (1989) cite numerous studies conducted in segregated sheltered workshop and educational settings which demonstrated that individuals with mental retardation could acquire specific job skills.

Second, toward the end of the 1970s, studies of individuals with mental retardation placed in non-sheltered, competitive employment began to appear in the applied literature. These reports reflected the development of alternative employment patterns for persons with mental retardation and were important because they set the stage for researchers to identify new goals and to test behavioural procedures in the context of integrated work environments (Rush & Hughes, 1989).

Third, at the time when illustrations of competence were being conducted in sheltered workshops and segregated educational settings, there was growing recognition that the human service delivery system was "broken" (Rusch & Hughes, 1989). In a U.S. study conducted by Whitehead (1979), it was reported that more than 200,000 adults with severe disabilities were being serviced in sheltered workshops. However, more than 6,000,000 others were not receiving appropriate services, even though the number of work activity centres grew by over 600% during the period

between 1968 and 1977. Whitehead (1979) also pointed out that the only individuals who attained competitive employment after entering sheltered workshops were those who did not require skill training. While this was a U.S. study, the trend was likely similar in Canada.

Gold (1975, in Rusch & Hughes, 1989)) suggests that the transition to competitive employment among persons with severe handicaps was "unusual". He also maintained that "the typical sheltered workshop staff lacked knowledge of skills to be trained, how best to train these skills, and how best to structure programs to facilitate progress toward nonsheltered competitive employment. These allegations came as no surprise because sheltered workshops traditionally rely on staff who have little knowledge about instructional technology or industrial design necessary to develop an individual's potential for employment" (Pomerantz & Marholin, 1977 in Rusch & Hughes, 1989:353).

Whitehead (1979) proposed that the emergence of supported employment was fuelled by a dissatisfaction with a mental retardation service system that prepared people for jobs that never materialized. Although purportedly transitional, existing vocational options (eg., sheltered workshops, day activity centres, and adult day-care centres) resulted in limited movement of clients toward community employment (Bellamy, et al., 1988 in Rusch & Hughes, 1989). Also, "there was a growing dissatisfaction with service options that resulted in institutionalization as the predominant treatment in the 1960s and early 1970s for persons with severe disabilities" (Rusch & Hughes, 1989:353).

The concept of supported employment was unique by reflecting a reversal in thinking about mental retardation in two ways. First, supported employment was based on the belief that the issue was not whether or not people with disabilities could perform real work, but what support systems were needed to achieve that goal (Roads

& Valenta, 1985 in Rusch & Hughes, 1989). Second, the concept of supported employment proposed that "warehousing" of persons with handicaps be replaced by the more pragmatic approach of finding a job for the person and then providing the support necessary for successful employment integration (Revell, Wehman & Arnold, 1984 in Rusch & Hughes, 1989).

Factors and Forces Influencing Supported Employment

By the 1960s, governments began to consider the issues and problems of intellectual disabilities. In 1963, the late President Kennedy's "Panel on Mental Retardation" began the process of thinking about the needs of people with intellectual disabilities. In Canada, in 1964, "the Federal-Provincial Conference on "Mental Retardation in Canada" had a similar thrust. At this time, legislation began appearing throughout North America dealing with services for people with intellectual disabilities" (MacPherson, 1978:9). It was during this time when the deinstitution of people with intellectual disabilities was taking place, that more community- based services and options were needed. People leaving institutions were placed in community residences, but they needed more that just a place to live. They needed opportunities to work or to attend a vocational or day activity program. People with intellectual disabilities dispelled the myth that they were incapable of employment. Programs in sheltered workshops were set up to provide work opportunities, but now it has been shown that people with intellectual disabilities need more options and opportunities for employment, hence the move toward supported and competitive models of employment. Several factors have influenced this future direction. Sylvestre and Gottlieb (1992) provide an analysis of the factors and forces that have influenced the interest in supported employment programs.

Disability Rights Movement

Supported employment has been welcomed as the leaders of a "national civil

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rights movement on the part of people with severe disabilities who have been excluded, devalued, and disenfranchised on the basis of their perceived lack of vocational competence" (Wehman, 1988:357). Its origins as a service strategy has been credited to a grass roots, consumer movement composed of persons with severe disabilities, their families, their advocates and friends (Wehman, 1988).

It was during the late 1960s and early 1970s that the "consumer movement" had become a "viable part of the social fabric of North America. Consumers and advocates were demanding more accountability and better quality of services from service providers. Eventually, such groups even demanded input into government policy-making" (MacPherson, 1978:8). In British Columbia, parents' organizations such as the Woodland's Parents Group, the People's First movement, and the B.C. Association for Community Living, among many other individuals, groups, and organizations, were instrumental in lobbying the government for change in services to people with intellectual disabilities.

The disability rights movement is based on the premise that disabled people themselves are capable of deciding where they will work and live (Asch, 1986). Ideologically, the movement views the economic and social barriers facing people with disabilities as created and reinforced by the dominant institutions of the larger society. The point of change must shift from the individual with a disability to the social, political, and economic structures that bar disabled citizens from full and equal participation in society (Ferguson, 1987 & Hahn, 1985 in Sylvestre & Gottlieb, 1992). Sylvestre and Gottlieb (1992) suggest that "[w]ith greater influence over where they work, and a larger measure of economic security, people with disabilities can gain control over their individual lives. Supported employment is therefore considered a strategy that eschews the encapsulation of handicapped persons in a devalued labour ghetto in favour of their integration in settings where they can pridefully and publicly

demonstrate their productivity" (p.2).

<u>Disillusionment with Sheltered Workshops</u>

There has been widespread endorsement of supported employment programs because of a concern that sheltered workshops and vocational rehabilitation programs isolate people with disabilities from the larger labour force and from the broader labour market (Sylvestre & Gottlieb, 1992). The sheltered workshop made competitive employment an unachievable goal for many people with severe and complex disabilities. The work and social skills acquired in these protected environments do not easily generalize to the nature and conditions of the work performed in competitive workplaces (Enns, 1981).

Some advocates argue that any arrangement that congregates individuals, especially without their free and informed consent and without their access to alternative arrangements, is a de facto institution. Similarly, some would argue that simply because a service happens to be "in" the community does not mean it is "of" the community. For example, "some sheltered work environments can segregate people with intellectual disabilities from the socio-economic mainstream as effectively as do large, congregate care facilities. In this regard, community programs can be institutional in effect, if not by design" (Crawford, 1996:15).

Lunt and Thornton (1994) explored the nature of disability employment policy from 15 countries and suggested that a discussion of the sheltered workshop versus supported employment debate is vital to any understanding of disability employment policy. They state that in North America and Australia there has been a shift from sheltered to supported provision. Their research has shown that:

> [B]y sheltered provision, what is meant is separate provision within
> units for disabled people where there is little integration with non-disabled
> people. It is suggested that at best the emphasis is on learning skills and

transition to open employment, while at worst they are just containment

measures ... This type of provision has been called factory provisions (p.233).

Low wages, reliance on social security benefits and underemployment are all

associated with sheltered provision or workshops.

Sylvestre and Gottlieb (1992) state supported employment has adopted the

principle of "unconditional inclusion" which means that programs should service all

interested people with severe disabilities rather than screen and exclude people

based on evaluations of their employment readiness. Therefore, the task facing

program staff has shifted. Instead of determining who is employable, the vocational

specialist must determine the quantity and kinds of support a particular individual

requires in order to maintain competitive employment in an integrated setting.

Normalizaton and Social Integration

Supported employment also receives support from proponents of the principle

of normalization that calls for the "utilization of means which are as culturally normative

as possible" (Wolfensberger, 1972:28). Services which approximate normal models of

independent living and normal competitive work score highest on measures of quality

of life (Keith, 1990). Sylvestre and Gottlieb (1992) suggest that improvements in the

quality of life of people with intellectual disabilities depend upon their wider

participation in typical activities and settings. Competitive employment presents an

important avenue for promoting normalization. Supported employees are not only

occupied by the same work as their non disabled co-workers, but also participate in

the same social environment. It is proposed that they have an equal opportunity to

form social ties on the basis of natural affinities and as a byproduct of the manner in

which their work is socially structured (Sylvestre & Gottlieb, 1992).

Reduced Social Costs

A final reason for the popularity of supported employment is based on an

economic argument. When people with disabilities receive competitive wages rather than the modest compensation provided by sheltered workshops, they will become less dependent on government and charitable organizations, and achieve a significant measure of economic independence (Sylvestre & Gottlieb, 1992). In fact, a number of studies have demonstrated that supported employment programs do result in significant increases in the incomes of persons with disabilities (See Sylvestre & Gottlieb, 1992) and corresponding decreases in their dependence on social assistance (Annable, 1989; Conley, Rusch, McCaughrin, & Tines, 1989). Based on a review by Conley and his colleagues, they concluded that "although costs of supported employment are greater than benefits during the first years of implementation, costs decrease and benefits increase over time because employees increase both their hours and average hourly wages, while the amount of support needed on the job decreases" (p.441).

A closer examination of the supported employment programs which have been subjected to cost-benefit analyses reveals relatively low participation on the part of more severely disabled persons, and therefore lower costs associated with the staff support functions (Sylvestre & Gottlieb, 1992). One study reported that 48% of the employees had IQ scores in the borderline to mild range, and approximately half worked in clustered groups, receiving collective rather than individualized support (Conley et al., 1989). According to Sylvestre and Gottlieb (1992), the true costs of maintaining people with severe disabilities in competitive work settings over a prolonged period of time, with labour intensive support from a job coach, have yet to be determined.

Sylvestre and Gottlieb (1992) also suggest that in this era of fiscal restraint, it is inevitable that economic considerations will come into play in determining policy and programming in the human services. They state that if economic considerations are

assigned more weight than considerations of distributive justice, civil liberties, and the full integration of persons with disabilities, then promises of supported employment will not be realized. Sylvestre and Gottlieb (1992) also suggest that focusing primarily on an economic justification, administrators of supported employment programs will attempt to optimize program efficiency by only serving the most able of disabled persons who require the least investment of support.

Supported Employment Alternatives

Four supported employment alternatives are offered by Mank, Rhodes, and Bellamy (1986): the supported jobs model, the enclave model, the mobile crew model, and the benchwork model. In the supported jobs model, the individual is placed in regular community jobs and provided with support at the worksite as needed for the person to learn and perform the work. In this model, a non-profit community agency is funded to provide on the job support and training, as well as provision for job development. The work opportunities usually come from the service sector such as restaurants, offices, and hotels.

The enclave model is another option for providing supported employment. An enclave is a group of individuals with disabilities who are trained and supervised among non-handicapped workers in an industry or business. Mank, Rhodes, and Bellamy (1986) have developed the enclave model in a small number of electronics companies. In one model, people with severe disabilities perform work tasks within a host electronics company while the not for profit organization is government funded to provide support to the individuals and the host company.

The mobile crew model provides a combination of service and business. Working from a van rather than a building, a crew of individuals with disabilities spends its working day performing service jobs in community settings. Usually groundskeeping and janitorial work are the mainstay of the contracts. A mobile crew is

set up as a small, single purpose business with one supervisor and approximately five employees.

The benchwork model is designed to provide employment in electronics assembly work in a service agency that also functions as a business enterprise. According to Mank, Rhodes, and Bellamy (1986), this model was developed in the early 1970s as an alternative to traditional day activity programs to provide long-term employment to individuals previously denied access to any vocational services. This model operates as a small, single-purpose, not for profit corporation usually providing employment and related services to approximately 15 individuals with severe and profound mental retardation and related disabilities. "This model shares many features and constraints with traditional sheltered workshops. Work is performed in the program's own workspace, reducing the opportunities for social integration during the weekday. Successful employment depends entirely on the program's ability to secure an adequate supply of contract work" (Mank, Rhodes, & Bellamy, 1986:147).

These models are only four of a large variety of options for the supported employment of persons with severe disabilities. All the models are small, specialized, single-purpose organizations that have the sole mission of employment of people with severe disabilities. No supported employment alternative can meet the needs of every person with intellectual disabilities. Each program must fit into a community's service need and business opportunity. As suggested by Mank, Rhodes, & Bellamy (1986), "in order for citizens with severe disabilities to realize meaningful and integrated employment, it is incumbent on service professionals to design and make available vocational options that combine employment outcomes with community integration and ongoing employment support" (p.150).

Future Directions in Employment of Adults with Intellectual Disabilities

Kiernan and Stark (1986) analyzed the future direction of employment of adults

with intellectual disabilities. The 1960s was a time of concern over civil rights with the implementation of a body of laws directed at giving minorities access to the mainstream of society. In the 1970s, the emphasis was on human rights. In the 1980s, the emphasis was on societal rights. Kiernan and Stark (1986) see the 1990s as an era marked by an emphasis on individual rights. With an improvement in social and economic conditions on an international scale, a focus on the needs of individuals may be at hand. They suggest that "members of minorities, among them developmentally disabled individuals, will organize into more effective and aggressive grassroots coalitions that will attempt to hasten improvements in living standards and employment opportunities for themselves" (Kiernan & Stark, 1986:305).

As suggested by the literature, people with intellectual disabilities want an opportunity to work. While some people with intellectual disabilities are working in the competitive labour force, others are working in sheltered workshops or training centres. Rather than excluding people with intellectual disabilities from work opportunities, society needs to look at each individual's abilities, strengths, and capabilities to do the job and provide the necessary supports.

Retirement

The study of retirement and aging has produced an enormous amount of scholarly research on the non-handicapped population. Much of the literature has focused on the sociology of retirement (Atchley, 1976); the history of retirement (Graebner, 1980); theories of aging and retirement (MacDonald & Wanner, 1990; Roadburg, 1985: Carp, 1972); causes and consequences (Palmore, Burchett, Fillenbaum, George & Wallman, 1985); adjustments, attitudes and well-being (Atkinson & Rein, 1993) and social policies (McClusky & Borgotta, 1981).

Research on aging people with intellectual disabilities is now coming to the forefront due to their longer lifespan and membership in community living (Hogg,

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Moss, & Cooke, 1988). However, much of the literature on aging intellectually disabled individuals tends to focus on the aging process, behavioural problems, and health decline rather than the social aspects (Roeher Institute, 1996). A review of the literature on retirement and aging people with intellectual disabilities indicates that some agencies are developing retirement programs in an effort to meet the needs of this aging population (Seltzer & Krauss, 1987; Sutton, Sterns, & Schwartz Park, 1993). As this study is not only concerned with the work experiences of intellectually disabled aging adults, but also their views on retirement, I have chosen to review the literature defining retirement, the history of retirement in Western society, as well as the literature on retirement and people with intellectual disabilities.

Definitions of Retirement

Retirement is a creation of industrial society whose concept is less than 100 years old. For some, it is a time to pursue leisure activities, a time for travel, and a time to do the things one did not have time to do when working. For others, retirement may be a time of stress due to a decrease in income, a loss of status, or a decline in health (MacDonald & Wanner, 1990). Society has been 'sold' the benefits of retirement by business, government, and the media (Graebner, 1980) and has come to be seen as a new stage of life with its own name, organizations, magazines, economic and legal infrastructure, and full-blown planned communities (Savishinsky, 1995:243). Despite the common use of the word, it is neither simple nor straight forward in its definition. Atchley (1976) has defined retirement as a social institution, an event, a social role, a process, or a phase of life.

Retirement as an institution is primarily concerned with the problem of moving the older worker out of the labour force in an orderly fashion without causing undue financial hardship (Atchley, 1980:264). The institutionalized form of retirement that Canadian society has adopted is a function of numerous factors such as population

aging, the economy, technology, and historical events. Part of the institutionalization of retirement has been the growing acceptance of the belief that older workers have a right to retire by virtue of their years of service to a job (MacDonald & Wanner, 1990:4).

As an event, retirement involves the formal end of employment and the beginning of life without a job. The event could be "marked by a ceremony, a party, a commemorative gift, paper work for receiving the retirement pension and social security benefits, the cleaning out of desk or locker, the turning in of keys, and the retirement trip" (Palmore, Burchett, Fillenbaum, George, & Wallman, 1985:2).

Retirement as a social role means "focusing on the rights, duties, and relationships associated with the position of retired person" (Atchley, 1976:9). The rights of the retired person usually include the right to economic support without holding a job and without the stigma attached to being unemployed, and the right to use one's time as one sees fit. "The duties of the retired person include assuming responsibility for oneself and avoiding physical and financial dependence on family or the state, and to avoid full-time employment" (MacDonald & Wanner, 1990:4).

As a process, retirement consists of preparation for retirement, the decision to retire, the event itself, and the states the individual might experience (Atchley, 1980; Palmore, et al., 1985). "For those who study retirement as a process, it has to do with how the retirement role is approached, taken, and relinquished by each individual" (MacDonald & Wanner, 1990:4).

Finally, retirement as a phase or transition in life generally occurs later in the life cycle, usually at or near the end of the occupational life cycle. Golan (1981) views retirement as a transitional process made up of three phases: leaving the work world, the act of formal separation, and adjustment to retirement. Whether retirement is an institution, event, social role, process, phase, or all of these, "it is seen as a withdrawal from the paid labour force and therefore, qualitatively distinguishes those individuals

who are members of the labour force from those who are not" (MacDonald & Wanner, 1990:3).

History of Retirement in Canada

This section provides a brief overview of the major social, political, and economic processes that have shaped retirement since the Industrial Revolution era.

Following Confederation in 1867, Canada witnessed completion of a transcontinental railway, large waves of immigration, expansion to the West and an escalation in the development of industry. "Canada was rapidly changing into an industrial society and the participation of older workers in the labour force most likely remained high during this period due to the expansion of the country" (Myles, 1984:8).

Several trends began during this time that contributed to the explosive growth of retirement later. "The first was the emergence of industrial work organization and labour unions, the second was the emergence of mandatory retirement rules, and the third was the development of a new ideology of retirement" (Atchley, 1982:267). Unlike an agrarian society where people tended to work at home, workers in factories and offices could be organized and managed more readily. (This would later set the stage to make mandatory retirement seem possible).

It was hoped that the older workers would voluntarily leave their jobs (Graebner, 1980), and when they did not, new ways were devised to remove them from the work force. Some corporations began to impose mandatory retirement sporadically through the provision of pensions. Meanwhile, a new social ideology of retirement was being developed in the industrial world with Germany in the lead. Germany had experienced the most rapid industrialization in Europe during the last half of the 19th century. In the late 1880s, Germany spelled out a new role for government in securing welfare of wage earners in a highly industrialized society. The worker unfit to continue in the labour force because of old age had a right to be cared for by the State (Atchley,

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1982). However, it would take many years before a system was implemented in Canada.

Under Sir John A. MacDonald, a Royal Commission on the Relations of Labour and Capital detailed the grim exploitation of men, women, and children in urban industrial society. The commission recommended the creation of a government annuity system "under which working people and others might make provision for old age by periodical or occasional payments of small sums" in the hopes that this would "remove from many the fear of dependence upon relatives or charity in their declining years" (MacDonald & Wanner, 1990:24). Politicians saw old age as a time of decline and dependency. Those who did not own property or have a job, and who had no family support were faced with institutionalization in a poor house. "In 1891, an Ontario Royal Commission on the Prison and Reformatory System decried the numbers of homeless old people who were lodged in local jails on charges of vagrancy because they had no place to go" (Guest, 1985:35).

The seeds were sown for the relations between old age and incapacitation, the notion of mandatory retirement, and the idea of the "deserving" old, but it was not until 1951 that the role of government as advocated by Bismarck in Germany in the 1880s, was fully embraced by Canada (MacDonald & Wanner, 1990). With urbanization and industrialization well under way and changes in demography and technology, "labour became a commodity to be bought and sold in the market place. Productivity meant profit and corporations were developed to efficiency and effectiveness" (Myles, 1984:12). "This found expression in the impersonal forms of bureaucratic organization that emphasized a specialized division of labour, a hierarchical chain of command, formal rules, and centralized authority" (Atchley, 1982:269). At the same time, the "wear and tear" theory of aging had gained popularity (Achenbaum, 1978).

Changes in the organization of work, the new technology, the prevailing

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ideologies of scientific management, and the "wear and tear" theory of aging created conditions right for retirement. "The impersonal procedures of the organization provided a means to move the worker out of the labour force easily, while scientific management and the "wear and tear" theory provided the rationale" (MacDonald & Wanner, 1990:27).

The idea of old age pensions was first raised in the House of Commons in 1906, but it took until 1927 before the Old Age Pension Act was passed under MacKenzie King (Guest, 1985). The purpose of the Act was to supplement, not replace the income of older workers and was subject to strict eligibility rules and a means test. Due to the difficulties in divided jurisdictions between federal and provincial governments, the old age pension scheme took nine years to become national (MacDonald & Wanner, 1990).

During the Depression of the 1930s there was mass unemployment and attitudes reminiscent of the Elizabethan Poor Laws tended to prevail. The Old Age Pension Act was inadequate and could not accommodate the needs of the elderly poor. Several trade unions and Members of Parliament lobbied for a reduction in age eligibility because there was little security for workers being forced to retire before age seventy, and also to encourage older workers to retire earlier to create jobs for the unemployed (MacDonald & Wanner, 1990).

Pensions grew in numbers, benefits were increased and retirement ages were lowered. The leading advocates and beneficiaries of retirement, mainly corporations, labour unions, and insurance companies began marketing retirement as a consumable commodity, and ignored its origins as a device for corporate and bureaucratic efficiency and control (Graebner, 1980). Universal pension plans were eventually instituted in Canada via the Old Age Security and Old Age Assistance Acts of 1951.

The Keynesian revolution in economics pointed the way to avert the disasters of the 1930s through emphasis on government responsibility for economic growth and social security. The broadly read Marsh Report (1943) highlighted the notions of "universal risks" (old age being one) and of a "social minimum" (Guest, 1985:112-115). "In light of the flaws in the 1927 pension plan and the dominant ideology of comprehensive social security, debates continued about the means test component of the pension plan" (MacDonald & Wanner, 1990:31).

The concept of universal retirement benefits was pitted against the concept of retirement as a deserved reward for long service. A universal pension plan was still viewed as a defense against destitution resulting from retirement, while business and industry promoted retirement as a reward for service. The tension between the two was resolved in the 1960s in favour of business and industry, and implemented by the Canadian Government in the form of the Canada Pension Plan (MacDonald & Wanner, 1990; Guest, 1985).

Views began to shift in the direction of providing the retiree with a reasonable standard of living, consistent with the standard of living achieved during the work years. The restructuring of the public pension program in Canada during the 1960s and 1970s had a number of consequences. The government took over primary responsibility for retirement income, the "concept of retirement was separated from the concept of poverty, public pension benefits became a deferred "wage" to which people were entitled because of their contributions, and withdrawal from economic activity took place in advance of physical decline. Under these conditions, retirement became an accepted social institution to most Canadians" (MacDonald & Wanner, 1990:33).

Theoretical Perspectives on Retirement

There is a profusion of research on retirement at the individual (micro) level, but few studies at the societal (macro) level. "This bias toward individualistic

conceptualizations of retirement can be traced to the perspectives on aging that have served as a backdrop to the study of retirement" (MacDonald & Wanner, 1990:8). The micro-level theories like disengagement and activity theory prescribe a different model for good old age: disengaging from activity, and staying active in new pursuits. The micro-theories assume retirement will bring a decrease in social activity, focuses on individual responses to retirement, and assumes that retirement will cause problems and that people need to adjust to live a happy life. According to MacDonald and Wanner (1990) these theories view retirement "as a problem caused and solved by individual behavior" (p.9).

Macro-level theories like modernization theory (Cowgill, 1974) and structural theory of retirement (MacDonald & Wanner, 1990) take social structures into account. Modernization theory explains that retirement arises when society industrializes and technology puts older people out of work. Older people then have lower incomes and lower status. The structural perspective identifies the social, economic, and political forces external to the individual that shape and constrain the decision to retire and the circumstances after retirement.

Disengagement Theory

Disengagement theory states that "aging involves an inevitable withdrawal or disengagement resulting in decreased interaction with those in the aging persons's social milieu. It is a way in which society and the individual gradually prepare for the ultimate withdrawal of the individual through an incurable, incapacitating disease and death" (Cox, 1996:33).

The disengagement theorist would argue that retirement is part of the normal, mutual, and beneficial withdrawal of the individual and society from each other. Both society and the individual are gratified by disengagement. The individual is relieved from societal pressures to continue a high level of productivity, and for society,

the withdrawal of older members makes room for younger, energetic, competent people to assume the roles to be filled. Disengagement is necessary for the survival of the social system and is an example of *sociological functionalism,* which views the elements of society as functionally interdependent. Many would argue that disengagement is functional as it allows a smooth transfer of power to younger people (Cox, 1996).

Role losses are accompanied by diminished interaction between aging persons and others in their social system. According to Cox (1996), "disengagement theory, if followed to its logical conclusion, would predict withdrawal from previous activities, followed by preoccupation with self and ultimately death" (p.33).

Disengagement theory involves the removal of people, either forced or voluntarily from the labour market. Translated in social policy, disengagement theory would legitimize mandatory retirement (MacDonald & Wanner, 1990). Streib and Schneider (1972) suggest that disengagement can occur at different rates for different roles, and that an individual could disengage from the world of work, but could become more active in other spheres of life.

<u>Activity Theory</u>

The activity theorist would view retirement as a withdrawal from an occupation that must be replaced with other forms of social involvement. Activity theory focusses primarily on optimizing the well-being of people as they age. It begins with the premise that people will lose primary roles (e.g. suffer forced retirement from work, fewer social involvements, etc.) and that these losses should be compensated for by other activities. "Successful adjustment to old age involves maintaining the activities of middle age as long as possible, finding substitutes for work when forced to retire, and substitutes for friends lost through death" (Havighurst, 1968:21). By compensating for lost roles, "people will remain socially and psychologically fit" (Roadburg, 1985:47).

There are commonalities underlying activity theory and disengagement theory. "Both assume that social interaction will be reduced; they direct attention to the individual by emphasizing the quality and amount of activity; they ignore the autonomy of the individual; and they assume that the transition to retirement is potentially traumatic, since they offer prescriptions for the best way to adjust to retirement" (MacDonald & Wanner, 1990:9). The emphasis is on the individual and not on the political, economic, and social structures of society.

<u>Modernization Theory</u>

This theory focuses on the decline in the status of the aged (Cowgill, 1974). Retirement is viewed as an intervening variable in the process. Increased longevity and declining birth rates create an aging population, which in turn produces intergenerational competition for jobs, while modern technology creates new jobs suitable to younger workers and fewer jobs to which older workers are suited. The conjunction of these two developments creates retirement; retirement inevitably leads to lower incomes, and lower incomes produce lower social status for the aged (MacDonald & Wanner, 1990). Retirement is seen as an inevitable result of the unidirectional and evolutionary march of society on its journey to full modernization (Marshall, 1980). "Retirement is assumed to be a normal part of the evolutionary process, precluding any consideration of social class, public policy, ethnicity, and gender as possible mediating factors" (MacDonald & Wanner, 1990:10).

Unfortunately, modernization theory was developed at a time when little historical research had been done. Cowgill (1974) assumed that the status of the aged was high in the past and that "modernization" caused it to decline. But the works of Achenbaum (1978) and Graebner (1980) indicate that the decline in the status of the aged was mainly an ideological shift brought on by the change from a hierarchical, traditional philosophy of social organization to a more egalitarian, achievement

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oriented philosophy. This shift occurred well before the population aging and industrialization occurred (Atchley, 1982).

Although modernization theory attends to social structure via the notions of technology, population composition, age cohort and social change over time, the individual is still scripted to play out the inevitable role of retirement, a normative part of the life cycle (MacDonald& Wanner, 1990). This theory did not incorporate the recent rise in social status of the elderly that came about with the improvement of retirement benefits. Also, modernization theory, like the previous two theories assumes the individual is part of the labour force, and therefore, subject to the benefits and potential disadvantages of retirement.

Structural Theory of Retirement

The structuralist perspective assumes that the social, economic, and political forces external to the individual shape and constrain both the retirement decision and circumstances after retirement. MacDonald and Wanner (1990) suggest the main "institutional structure is the welfare state, which has been largely responsible for the establishment of the modern institution of retirement in industrialized societies. However, other social and economic formations condition the individual experience of retirement, often mediated by government policies. These include the structure of the labour market, particularly industry structure, occupational structure, and the distribution of unemployment" (MacDonald & Wanner, 1990:97).

An individual's place in the labour market establishes the most direct context within which retirement takes place. Advocates of the dual economy theory argue that the trend toward concentration and centralization of wealth and resources has caused the development of advanced capitalism increasingly to polarize the economy into two main sectors. The core industrial sector is dominated by large corporate businesses, recognized for high productivity, high profits, intensive utilization of capital, and a

tendency to have a high degree of unionization. "The general result is high wages, better working conditions and fringe benefits. A large percentage of both men and women who work in core industries receive benefits beyond the basic Old Age benefits" (MacDonald & Wanner, 1990:100).

In contrast, at the perimeter of the economy are the smaller firms which tend to be concentrated in agricultural production, and in portions of nondurable manufacturing, retail trade, and subprofessional services. "Firms in this sector are noted for labour intensity, low productivity and profits, intensive market competition and lack of unionization. These factors are then translated into lower wages and fringe benefits" (MacDonald & Wanner, 1990:100).

An individual's position in the paid labour force has a direct impact on the timing and conditions of retirement. MacDonald & Wanner (1990) argue that "occupying any position in society that has status implications will influence the manner in which the individual encounters the institution of retirement " (p.111). Two such positional systems are ethnicity and gender. Ethnic and gender groups have differential access to social and economic resources, membership in these groups influences both treatment under government programs and labour market influences and outcomes. It is this sense that these authors argue that ethnicity and gender are treated as structural features of Canadian society that affect both timing of retirement and life circumstances after retirement.

Conceptualizing gender as representing a set of structural positions in society rests to a large extent on the nature of the sexual division of labour, both in the labour force and in the household (Stone & Minkler, 1984). Being a woman represents a distinct status position that restricts access to scarce resources as well as other desirable positions. Gender represents a set of "distinct cultural positions in society, both in the division of labour and in the stratification hierarchy, that has important

consequences throughout the life cycle" (MacDonald & Wanner, 190:115).

MacDonald and Wanner (1990) argue that retirement is influenced not only by individual level characteristics, but by the social structure in which an individual is enmeshed. Characteristics of the labour market, the occupation and economic sector in which an individual works, employment status and the employment rate encountered in the local labour market, ascribed characteristics of the individual, particularly ethnicity and gender, contribute to the retirement decision. However, "given the powerful influence of supra individual forces on the probability of retirement, can one voluntarily make a decision to retire?" (MacDonald & Wanner, 1990:125).

Retirement and People with Intellectual Disabilities

With increased longevity now evident in the population of people with intellectual disabilities, considerable interest is focused on providing for the needs of those over the age of 55 (Stroud & Sutton, 1988). The literature suggests that the retirement age for people with intellectual disabilities can be considered to be in the 50 - 55 year range (Sutton, Factor, Hawkins, Heller, & Seltzer, 1993). Other research suggests the onset of old age can start as early as 40, depending on the health of the individual (Seltzer & Krauss, 1987). A review of the literature revealed two different views of retirement for aging people with intellectual disabilities. One group suggests that since the work histories of people with intellectual disabilities are quite different from those of the general population, retirement is not appropriate (Janicki, 1986; Wolfensberger, 1985; DeBrine & Howell, 1989). Other research suggests that retirement needs to be planned for with appropriate options for older people with intellectual disabilities (Stroud & Sutton, 1988; Sutton, Sterns, & Schwartz Park, 1993).

Researchers argue that "whether or not an individual is perceived as retired will depend upon which definition of retirement is adopted" (Sutton, Sterns, & Schwartz

Park, 1993:98). Fields and Mitchell (1984) describe six common definitions of retirement: 1) absence of participation in the labour market; 2) acceptance of social security benefits; 3) receipt of a private pension; 4) reduction in hours of work or pay per hour; 5) subjective evaluation of the individual as being hired; and 6) permanent withdrawal from a long-term job or career.

In our society, it is culturally normative for people to retire sometime in their mid 60s. Wolfensberger (1985) suggests that while retirement may be statistically normative, to a significant degree it has been forced upon an often reluctant elderly population by legislation that was designed as an economic measure for young and middle-age workers. "Retirement, rather than protecting the elderly forces people out of the labour market and often into poverty and poor health" (p.74).

Advocates for people with intellectual disabilities such as Blaney (1990) and Wolfensberger (1985) object to the idea of retirement for this population. Wolfensberger (1985) writes:

> ... to talk about retirement is ludicrous for the vast majority of mentally
> retarded people whose adult lives may have been spent in utter inactivity,
> or at best in poorly challenging programs that make low demands and
> operate short hours. In fact, in a 'retirement program' for elderly retarded
> persons, the clients may experience the same or worse life-wasting
> activities as they did earlier ... only now under a new title that gives such
> disgraceful practices legitimacy. Instead, such persons are desperately
> in need of activity, enhancement of their skills, and a positive image,
> both in their own eyes and in the view of others that comes with being
> a contributing worker (p.74-75).

DeBrine and Howell (1989) suggest that giving up work (retiring) is regarded by many people with intellectual disabilities with some puzzlement. On the one hand,

retirement (like work) is seen as something everyone does, while on the other hand, work is so highly valued that the idea of giving it up can be worrisome, threatening, and even frightening. DeBrine and Howell (1989) suggest that although retirement is now often considered to be a normal process of the life cycle, "we need to reevaluate our assumptions about retirement as a process, program, and policy for people who are old and mentally retarded" (p.228) The authors suggest that retirement forces the retiree to take on an "oldness" role which encourages dependence on others because the adult who is old is often seen as being non-productive, incompetent, and expendable. DeBrine and Howell (1989) suggest:

> The great majority of people who are both old and mentally retarded
> have never been allowed to become adults. They have moved from
> adolescence to old age, missing opportunities for competitive
> employment, stable relationships with unpaid friends, marriage and
> parenthood, and other signal experiences of adulthood ... Retirement
> as a policy usually removes them from low-paying, highly repetitive,
> structured work, and places them in non-paying, age segregated
> activity-centre day programs. The result of these programs is even
> more isolation from the community than was previously experienced (p.228).

Sutton, Sterns and Schwartz Park (1993) suggest that programs for aging adults with intellectual disabilities run counter to the concept of retirement because goals, objectives, and outcomes (which are set for individuals through agency plans) are "just more manipulation of their lives when a more relaxed and less structured approach should be applied" (p.98). Others, such as Wolfensberger (1985) caution against the double jeopardy that may result when aging adults with intellectual disabilities are included in activities for older adults where some older adults may already feel the effects of ageism. "Programs such as senior citizen centres, 'day-care'

centres for the elderly ... do poorly in terms of protecting and enhancing the competencies and image of their elderly clients. The adoption of such programs as analogues for service delivery to elderly persons who are mentally handicapped can only harm their social image and competencies in the same ways this happens to ordinary elderly persons" (p.75).

Not all six definitions of retirement provided by Fields and Mitchell (1984) are applicable to people with intellectual disabilities. While practices have varied from area to area, most people who have been included in the social service delivery system for people with intellectual disabilities have experienced structured work only since deinstitutionalization began in the 1970s (Sutton, Sterns, & Schwartz Park, 1993). Prior to that time, many people with intellectual disabilities worked in institutions. For those who never left home, employment was not common. Placement in sheltered workshops or for a limited number, in supported employment, was one consequence of deinstitutionalization (Sutton, Sterns, & Schwartz Park, 1993). Janicki (1986) argues the work histories leading to a possible retirement for the current cohort of older adults with intellectual disabilities are quite different from the work experiences of the general population. He also suggests that older persons with intellectual disabilities may even be viewed as part of the class of underemployed persons for whom retirement is inappropriate.

Other researchers take a different approach to the idea of retirement for aging adults with intellectual disabilities. Hogg, Moss, and Cooke (1988) provide a definition of retirement and suggest it could equally apply to the mentally handicapped. Retirement indicates "the cessation of any activity which has engaged the individual as a primary occupation for several years" (p.148). While this may entail paid employment, it could also equally apply to any day service such as an adult training centre "where the person has been involved in some form of structured physical or

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social activity, to an alternative day program for retired people " (p.148).

According to Hogg, Moss, & Cooke (1988):

Society's view of retirement is conditioned by our experience of, and the

value we place on, the activity of work itself. Work has not, historically,

necessarily been viewed as anything more than a brutalizing necessity;

and there is ample evidence of alienation and job dissatisfaction at all

occupational levels. Nor is the transition of retirement a universal one

either with respect to age or factors that lead to the event. Consequences

differ markedly between and within societies from ensuing reduction in

self-esteem and withdrawal from social interaction, to an ambiguous

'roleless role', to retirement as a highly positive experience (p.150).

Cotton (1994) suggests that retirement is graduation to another stage in the

development of the individual. He states that retirement is not and cannot be

synonymous with the term quitting. Going home, regardless of how lovely the home is,

rocking is not retirement. That is quitting. Instead, retirement is a time, after the

necessities are accomplished, to do what one wants to do; to explore new interests

and friendships; and to have leisure time to engage in activities of the person's own

informed choosing.

Several research studies discussed retirement with participants with intellectual

disabilities. In a study by Stroud and Murphy (1984 in Stroud & Sutton, 1988)

participants were asked if they liked what they were doing and whether they wished

they could retire. Several replied that it would not be a good idea to retire from a

workshop because "a person ought not just sit at home and watch television".

"Instead," they commented, "people need to be around other people, keeping active".

Others noted their main interest in the day program they attended was in the social

activities which offered opportunities for making friends and being with those of the

opposite sex.

A survey conducted by Elizabeth DeBrine of the Kennedy Aging Project in April, 1987 asked eighteen adults from two group homes and a group residence at a state institution what retirement meant to them. The following is a sample of their responses:

1. *What is retirement?* We're not retired yet! I don't want to be retired!
Sitting in a rocking chair. Go out and see the world before I go. Relax
doing things you want to do.

2. *When do people retire?* When you retire is when you retire. I'm
not ready. When I get old. No particular age. Don't want to work
anymore. Damn sick of it. When I get to be 65.

3. *What would you like to do in your free time after retirement?* Dancing.
Live with my sister. Anything is possible. Travel. Help my family, someone
has to take over after they are gone.

4. *Describe a typical day after you retire?* Beautiful day. Don't know.
I could participate at the Activity Centre. Go for a walk. Go to town. Feed
pigeons. Watch the ducks. Nothing. Smoke a pipe cigar, watch T.V.
Sleep till 9. Have breakfast. Plan my day, not rushing. Have a good day
as each day comes along (in DeBrine & Howell, 1989:229-230).

Ashman, Suttie, and Bramley (1995) conducted a national Australian study of intellectually disabled adults over the age of 55 and investigated their attitudes to work and retirement. Two cohorts were recruited: one included all known members of the target group from the states of Queensland and Western Australia; the second was a proportional, random sample drawn from a national database on a state population. A large number of the participants had never been involved in full or part-time employment, in a competitive or supportive work environment. The majority of those who had worked expressed strong positive attitudes toward employment and concern about retirement.

Fifty-three percent of 69 participants from the two-state sample and 57 percent of the 21 participants from the national sample who were currently working, expressed attitudes which were predominantly negative or mixed toward the prospect of leaving

work. Comments commonly made by participants who were negatively disposed to retirement included, 'I never want to leave work', 'What would I do if I didn't go to work', 'wouldn't dream of retiring yet', and 'I'd get bored staying at home'. In contrast, 40 percent of the 121 participants in the two-state sample and 34 percent of the 32 participants from the national sample who were not currently working or retired, had positive attitudes toward retirement (Ashman et al., 1995).

To put the topic of retirement for intellectually disabled adults in perspective, Glade (1995) conducted a number of interviews with vocational and residential providers in Minnesota, along with professionals who work in the delivery system. Through their insight, they suggested that the issue of retirement needs to be addressed now. Programming for this group of people cannot suddenly stop. Work is more than a job; it is their social life and support system. "The participants identified the significance of work in relation to a person's self-image. They felt that clients needed to be encouraged to become involved in providing service to others in order to remove the stigma of always 'being served' (Glade, 1995:65).

Other comments from Glade's (1995) study suggests the industry has been taken up by rules, regulations, and funding issues and has failed programmatically to prepare intellectually disabled people for their retirement years. There has been little emphasis on development of leisure, interests, and hobbies. However, Glade acknowledged there are programs for aging adults with intellectual disabilities in some areas of the United States whose focus is on leisure and maintenance of skill. Seltzer and Krauss (1987) identified 30 supplemental retirement programs for intellectually disabled people in their U.S. survey. "These leisure-oriented centre-based programs showed the highest level of social and community integration (including access to the generic aging network) of all day service provision for older people with intellectual disabilities" (Janicki & Seltzer, 1991:44).

Janicki and Seltzer (1991) suggest much progress has been made during the 1980s in accomplishing three goals with respect to older persons:

1) It is now accepted that old age is a distinct stage of life experienced by persons with intellectual disabilities. As recently as a decade ago (now 16 years ago), most policy analysts, researchers, and service providers viewed the period past childhood as an undifferentiated stage of life, with a flat curve of development characterizing psychological and functional abilities. It is now understood that development occurs throughout the life course and that old age brings to persons with intellectual disabilities, new opportunities for development.

2) The second accomplishment is the creation of the beginnings of an infrastructure of programs and services for older persons with intellectual disabilities. This infrastructure is based on the services to persons with intellectual disabilities and the aging service network.

3) The third accomplishment is the development of a professional training initiative on aging and development of a critical mass of expertise in this area, although there is a great deal to be done (Janicki & Seltzer, 1991:100).

Janicki and Seltzer (1991) state that in Canada, "the nature and extent of service provision is the responsibility of each province, yet most provinces do not have any established policies or systems in support of aging persons with intellectual disabilities" (p.27). It is now recognized that the area of aging and intellectual disability needs to be addressed now. Community forums, with representation by older adults with intellectual disabilities, families, service providers, government, and advocacy agencies are beginning to work together to share information and develop recommendations to address the needs of older people with intellectual disabilities (B.C. Association for Community Living, 1996).

Sutton, Sterns, and Schwartz Park (1993) suggest that good health and a

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positive attitude should enhance later life activities of people with intellectual disabilities, but that "loss of discretionary income, lack of preparation and information about options for leisure, and the relative unavailability of new experiences are limiting factors. Opportunities for phase-down, part-time, or continuation of full-time work are, however, more available to this population than to others, at least at present"(p.104). Sutton, Sterns, and Schwartz Park (1993) also suggest that planners and service providers "must recognize the later years and retirement as a new stage in the lives of individual they serve. Above all, it is most important that older adults with intellectual disabilities participate in the decision to modify work schedules or give up active work roles entirely" (p.104).

Summary of Current Knowledge

A review of the literature provided information about people with intellectual disabilities from the perspective of researchers, academics, and service providers. The literature demonstrated the heterogeneity and diversity of this population and showed that people with intellectual disabilities, even those with severe disabilities, are quite capable of working if given the opportunity to work and provided with the necessary supports. Most of the literature associated work with paid employment, yet the definitions of work suggested that volunteer work was also considered as work.

According to the literature, the meaning of work is determined by many factors and influences including one's earlier experiences, education, role modelling, individual factors such as personality and temperament, and organizational factors and the type of society we live in. While the literature focused on the meaning of work in the general population, it has yet to examine the meaning of work for the population of people with intellectual disabilities. This may be due to the perception that people with intellectual disabilities do not 'work' in the same sense as the non-disabled population .

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With an increase in longevity of people with intellectual disabilities and the need to provide meaningful daytime activities for this population, the literature has focused on the need for and development of leisure-oriented retirement programs. The literature suggests that retirement programs for people with intellectual disabilities should include a number of options and programs, and a recognition of the heterogeneity of this population. Much of the research literature was American, British and Australian, although I was able to locate some Canadian research. I was able to locate two studies which focused on work and retirement for older adults with intellectual disabilities. One study was conducted by DeBrine (1989) in the United States and the other by Ashman, Suttie, and Bramley (1995) in Australia. These studies did not provide the in-depth experiences I hoped to achieve through this study. An in-depth description of the work experiences of aging adults with intellectual disabilities is missing from the literature.

Many researchers concerned with aging and retirement suggested the need to include people with intellectual disabilities in the planning process. The need to understand the working experiences of intellectually disabled people and to bring their views and opinions to the forefront is the purpose of this study. How people with intellectual disabilities feel about their working experiences and their views on retirement need to be included in the current body of literature. To understand their experiences and perceptions is essential as professionals, families, and service providers attempt to meet the needs of this aging population.

Primary Research Question

This qualitative phenomenological research study hoped to capture the essence of the meaning of work through the everyday lived experience of the participants and to gain an understanding of how the participants would feel should work be removed (retirement) from their lives. Placing the individual with an

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intellectual disability at the centre of research and obtaining their views firsthand was the primary purpose of this study. There is little qualitative research that seeks to discover the experiences of aging adults with intellectual disabilities. It was important the participants of this research study shared their own experiences of work and their expectations for the future. This study hoped to capture those views through the lens of their experiences of everyday living.

The main research question I hoped to learn more about was the role of work in the lives of older adults with intellectual disabilities in order to understand their needs as they get older. This study was important because this population, like all aging populations, is growing and there needs to be adequate plans in place to address their needs and concerns as they get older. This study hoped to fill the gap in the literature by including the experiences, views and opinions of aging adults with intellectual disabilities. As people with intellectual disabilities are consumers of the service delivery system, they need to be part of the planning process and have their voices not only heard, but given the attention it deserves. The information gained from this study can directly assist social workers, family members, policy makers, service providers by informing them as to the factors that are important when planning for future services.

Chapter Three

Methodology

Research Design

The research method of phenomenology was used to explore the working experiences of aging adults with intellectual disabilities. "Phenomenology is the study of experiences and the ways in which we put them together to develop a world view" (Marshall & Rossman, 1995:82). "It attempts to describe and interpret the meanings (of the phenomenon) to a certain degree of depth and richness" (Van Manen, 1990:11). A basic philosophical assumption of phenomenology is that "one can know what one experiences only by attending to perceptions and meanings that awaken conscious awareness (Husserl, 1962 In Tatano Beck, 1992). In essence, phenomenology is the systematic study of phenomena.

The discovery of the meaning of human experiences is the goal of the phenomenological method. To achieve this goal, the researcher must reawaken his/her own presuppositions and make them appear by abstaining from them for the moment (Merleau-Ponty, 1956 in Tatano Beck,1992). This process, called bracketing, involves peeling away the layers of interpretation so that the phenomenon can be seen as it really is. "As the layers of meaning that give persons interpreted experiences are laid aside, what is left is the perceived world prior to interpretation and explanation" (Oiler, 1986 in Tatano Beck, 1992). For these reasons, it is an appropriate method of investigation into a true understanding of the phenomenon from the experiencing individual's perspective (Pallikkathayil & Morgan, 1991). The personal experiences of aging adults with intellectual disabilities is an area that is missing from the literature.

Sample Criteria

A purposive sample was chosen for this qualitative study because I was familiar with the setting and the individuals. A purposive sample could provide a comprehensive understanding of the phenomenon under examination. Morse (1994 in Sandelowski, 1995) proposes that "phenomenology directed toward discerning the essence of experiences should include about six participants" (p.182). Sandelowski (1986) suggests that "sample sizes in qualitative research are typically small because of the large volume of verbal data that must be analyzed and because qualitative research tends to emphasize intensive prolonged contact with subjects" (p.31). The purposive sample may have to be expanded only if the data obtained from the participants is deemed informationally insufficient (Sandelowski, 1995).

Given the amount of information elicited using a phenomenological method, the time constraints of the researcher, and the challenges of recruiting and interviewing people with intellectual disabilities, five participants who met the criteria of the study were selected. Subjects were initially selected because of their potential to illuminate the phenomenon under examination, and my access to locating suitable participants. After interviewing the five participants, it was determined that the information obtained provided a rich description of their work experiences and their views of life without work.

As this study was concerned with the work experiences of aging people with an intellectual disability, certain criteria were established. The participants were over the age of 50, intellectually disabled, currently working or had previous work experience, and able to share their experiences. The next section provides a definition of the terms used in this study and the rationale for those decisions.

Definition of Terms

Individuals with an intellectual disability were selected as the subjects for this study because their views are missing from the literature. Intellectual disability is defined as a "significantly sub-average general intellectual functioning resulting in or associated with concurrent impairment in adaptive behavior and manifested during the developmental period" (Jenkins, Hildreth, & Hildreth, 1993:70). The participants were previously identified as intellectually disabled by the Ministry For Children and Families (formerly the Ministry of Social Services; and Ministry of Human Resources), and eligible to receive service and support.

Beirne-Smith, Patton, & Ittenbach (1994) suggest there are four classifications of mental retardation: mild, moderate, severe, and profound. Individuals with mild mental retardation have a good potential for competitive employment, while those with moderate or severe levels may work in supported employment settings. "People with profound intellectual disabilities, are for the most part, totally dependent on others and employment or training is not likely" (Jenkins, et al., 1993:71). The participants were not screened for this study according to their intellectual disability, but rather, were selected because of their ability to illuminate the phenomenon I wished to study.

As this study was not only concerned with the work experiences of aging intellectually disabled adults, but also their perceptions of life without work (retirement), participants selected were over the age of 50. Fifty was selected as a minimum age because the literature on aging and people with intellectual disabilities suggests that the retirement age for this population is considered to be 50 - 55 years (Sutton, Factor, Hawkins, Heller, & Seltzer, 1993). However, other research suggested that the onset of old age can start as early as 40, particularly with individuals with Downs Syndrome, and depending on the health of the individual (Seltzer & Krauss, 1987). There were no participants with Downs Syndrome.

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A definition of work was left to the individual participants to determine its meaning. Hall (1986) suggests that work is a socially constructed phenomenon and therefore, requires a consideration that work is what we define it to be. All participants described work as a job they went to outside their home and were paid an income.

<u>Description of the Participants</u>

A purposive sample of five adults with intellectual disabilities participated in this study. The three men and two women ranged in age from 53 to 69 years. Three participants worked under the guidance and support of a large agency. Two worked full-time, five days a week, while another worked four days a week, but considered herself "semi-retired". A fourth participant had worked on and off for many years in the competitive labour force and is now "semi-retired" and does volunteer work. The fifth participant is currently unemployed, but worked part-time job in the competitive labour force for twelve years. She claimed that she was fired from her previous job, even though her former employer gave her a note saying she was "retired".

All participants were Caucasian and born in Canada. Four had spent a part of their lives in an institution. Two participants lived independently (one is married) in an apartment, two lived in a proprietary care arrangement with a family, and one lived in a group home.

<u>Participant Recruitment</u>

Two methods were used to contact potential participants. Two individuals who met the criteria of this study were contacted by a former colleague of mine who had a friendship with two of the participants. They gave permission to my former colleague to contact them by telephone to explain the nature of the study. Three candidates were recruited through the Burnaby Association for the Mentally Handicapped (Appendix A). A letter introducing the study, its purpose, and importance was sent to the Executive Director of the Burnaby Association (Appendix B). Approval to conduct

the study was granted by the Ethics Committee at the University of British Columbia. Agency approval was obtained prior to selection of participants (Appendix D).

I met with the Executive Director and the Vocational Coordinator of the Burnaby Association to discuss potential candidates. Three individuals were initially selected as meeting the criteria. The three names were given to the supervisor of the work area who asked each potential candidate if they were willing to participate in this study. Permission was granted by all three candidates. On separate occasions, each of the participants from the Burnaby Association for the Mentally Handicapped was introduced to me by the worksite supervisor. The purpose of the study, as well as its voluntary nature, and the method of interviews were explained to each participant. At times, I was not sure the candidates fully comprehended and understood the nature of the study and their role as a participant. To help clarify the situation or any misunderstandings, I used plain language and provided many opportunities to answer any questions. All five candidates agreed to participate in the study.

Prior to the interviews, a letter of consent (Appendix C) was discussed and signed by each participant and by myself. One individual preferred I contact the family he lived with to explain the study and obtain approval and permission prior to an interview. The interview took place at the participant's home. Another individual was interviewed in a private meeting room provided by the Burnaby Association. A third participant requested I speak to his residential support staff to explain the study and to set a time for an interview at his home. The remaining two candidates were contacted by telephone, explained the nature and purpose of the study, and the voluntary nature of their participation. A first interview meeting was scheduled to take place in each of their homes.

It was explained to all participants that the interviews would be tape recorded and transcribed by myself. I attempted to maintain their anonymity by removing all

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identifying information from the data and presented in the findings. Participants were advised that the transcripts would be read by myself and possibly by the thesis committee. Each participant was given a copy of their personal transcript. The results of the study were made available to all participants.

Data Collection Procedures

The phenomenological style selected for this study was Giorgi's (1975, in Omery, 1983) method which recognizes that "all phenomenological research starts with a naive description of the experience under study" (p.57). The researcher is the primary study instrument in allowing the experience to unfold as it exists for the subject in an unbiased way (Pallikkathayil & Morgan, 1991; Omery, 1983). The method of phenomenology was chosen to explore the work experiences of aging adults with intellectual disabilities because it was consistent with my values, it allowed the participants to speak directly about their experiences, and made no preconceived assumptions about what that experience meant to them (Van Manen, 1990).

Using plain language, the voluntary nature of the study was again explained to each participant prior to signing the consent form. Each participant was provided with an opportunity to ask questions and discuss whether they felt comfortable tape recording the session. Janesick (1994) suggests that it is important the researcher establish trust, rapport, and authentic communication patterns with the participants. All interviews were taped recorded at the individuals' homes with the exception of one participant who wished to do an interview immediately after the initial introduction meeting. A private room was arranged through the Burnaby Association and the interview proceeded as planned.

A semi-structured interview format (Appendix E) was used to serve as a guide only and to assist the researcher and participants to stay focused to the phenomenon under study. It was anticipated that once the participants felt comfortable, they would

set the pace and control the information. Open-ended questions were asked as a means of exploring and gathering experiential narrative material that could serve as a resource for developing a richer and deeper understanding of the phenomenon under study (Van Manen, 1990:60). Ludwig and Young (1996) found that the most difficult task of their participatory action research project involving intellectually disabled adults was trying to keep the respondents on topic. I had to constantly remind myself about the purpose of the study. It was easy to become distracted by important information the participants wanted to share and I wanted to learn, but was unrelated to the topic of interest. At times the participants became distracted. To keep the focus on the phenomenon under study,I asked the same question at different points during the interview. By using this technique, the participants were able to elaborate on their work experiences and to provide a rich description of their experiences.

However, there were times when the participants and myself seemed to be communicating on different wave lengths. An example of this was when one respondent spoke of his parents. Sometimes he referred to his parents as his "mother" or his "father", while on other occasions he referred to them as "Millie" and "Tommy"[1] . I found this confusing because I thought he was discussing four different people. He became frustrated when I had difficulty following his story. On another occasion, another respondent became anxious and frustrated when I did not understand some of the words he used. He suggested I contact his brother or his work supervisor if I wanted to know about his work. On these occasions, I changed the topic or turned the tape recorder off. The participant was assured that it was his experience I wished to learn more about, and that there were no right or wrong answers. I tried to present myself as the "learner", recognizing it was the participant who was the expert. It was their experience the research hoped to capture

The interviews were scheduled according to the wishes of each participant and

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[1] Pseudonyms were used to protect confidentiality and identity .

lasted between 45 minutes and 1 1/2 hours. The initial plan was to have the tape recordings transcribed professionally, however, after listening to the first tape, this was not possible. Due to difficulties in understanding the pronunciation of some words and the speech patterns of most of the participants, it was determined that accurate and verbatim transcription could only be completed by myself. I was at the interview, had first hand experience, and would be in a better position to understand the language and nuances used by each participant.

The taped interviews were transcribed verbatim, but in one instance, prior to giving the participant a copy, repetitive words and stuttering sounds were deleted. One transcript had data which could be potentially harmful to the participant if read by others. This situation was discussed with the participant who decided that certain segments of the data should be deleted from his copy of the transcript. I met with each participant separately to go over their transcript, to ensure the information was correct, and to give each participant a copy of their transcript. The meetings took place either at the participants' place of employment or their residence.

Two participants were interviewed and tape recorded a second time to probe further into their experiences, while two additional participants were interviewed informally and without the use of a tape recorder. One individual appeared more comfortable at the second meeting and helped clarify and further elaborate on his experiences. The second interviews were usually not more than one hour and took place at the participant's home and in one case, at a restaurant. The tapes were transcribed by the researcher in the same manner as the first tape recorded interviews. Individuals were sent a thank you card or small momento in appreciation of their participation.

Data Analysis

A phenomenological method was used to explore and uncover themes and

patterns that emerged from the experiences of aging adults with intellectual disabilities. As recommended by Maxwell (1996), analysis of the data began immediately after the first interview and continued throughout the process. The phenomenological method views the "generating of data as part of the research process and as the educational development of the researcher to find ways to develop deeper understandings of the nature of the phenomenon being studied" (Van Manen, 1984:50).

Giorgi's (1975 in Pallikkathayil & Morgan, 1991; Omery, 1983) five-step procedure of data analysis was used throughout the process. After transcribing each tape recorded interview, the entire transcript was read through to obtain a sense of the whole experience. The transcriptions were then read simultaneously along with the corresponding taped interview in order to seek out any discrepancies in the data. I circled particular words on the transcripts that were not understood, in order to clarify in a further interview.

Each transcript was read and reread in a purposeful manner, noting any transitions in the experience with the intention of discovering the essence of the phenomenon under study. Two approaches toward uncovering the thematic aspects of the phenomenon were used simultaneously. Using the highlighting approach, the text was read several times seeking key statements or phrases which seemed particularly essential or revealing about the experience described. The line-by-line approach examined each sentence or complete thought relating to the phenomenon (Van Manen, 1984). Ideas and thoughts I had were noted in the margins of the transcripts or in a notebook. Sandelowski (1995) suggests that "[t]hese thoughts, in combination with other ideas that come with simultaneous immersion in the literature of the field and other sources of inspiration, compromise the theoretical or reflective memos that also constitute data for analysis" (p.373).

Bracketing was used throughout the analysis to enhance the trustworthiness of the phenomenological method of analysis. This is a process "whereby the researcher shifts focal attention by reflective orientation and suspends theoretical assumptions, interpretations, labels, categories, and judgments thus eliminating a priori assumptions" (Pallikkathayil & Morgan, 1991:196). At this stage of the analysis, each line or complete thought linked with the phenomenon under study was coded in a simple, one or two word code. Examples included "tasks and duties", "helping others", "responsibilities", "special abilities", "retirement", "relationships", "job loss", and so forth. This resulted in a series of meaning units or themes.

The third step in Giorgi's data analysis examined the meaning units for redundancies, clarification or elaboration by relating the meaning units to each other and to a sense of the whole. This was an important part of the process as it allowed a more in-depth understanding of the work experiences of the participants in the context of their own lives. In the fourth step, I carefully scrutinized all data describing the phenomenon and assigned a formulated meaning to each line or complete thought. This was accomplished by reflecting upon the meaning units (still expressed essentially in the language of the participant) and by extrapolating the essence of the experience for each participant. "Each meaning unit was systematically examined for what it revealed about the phenomenon under study for each participant and was transformed into the language or concepts of psychological science when relevant" (Omery, 1983:58; Pallikkathayil & Morgan, 1991:197).

The fifth step in Giorgi's method formalized a description of the structure of the phenomenon under study across the participants of the study by integrating and synthesizing the insights achieved in the previous steps (Pallikkathayil & Morgan, 1991). Sandelowski (1995) suggests that among "the most common and serious violations of rule are premature analytic closure and a tenacious and (often

unrecognized) commitment to some a priori view of the phenomenon under investigation. Among the most serious violations of spirit are cookbook applications of techniques and a lack of imaginative play"(p.371). While I had some understanding of the work experiences of people with intellectual disabilities, I did not undertake a formal review of the literature on work definitions and the personal and social meanings of work until after the interviews were completed. I did not want to have any preconceived ideas about the structure or essence of work. I wanted the experiences of the participants to speak for itself.

The overarching theme of work as a meaningful and purposeful activity eventually emerged from the work experiences of aging adults with intellectual disabilities. The findings were presented in three phases. The first phase presented the work experience under the themes, "Worksite, Tasks and Responsibilities", "Interpersonal Relations", and "When The Job Ended". The second phase of the findings presented the five themes that represented the meaning of the work experience. The five themes were: "Work as Service to Others", "Work as Providing Opportunity to Socialize and Meet Others", "Work as Structuring the Day", "Work as an Opportunity to Use One's Special Abilities", and "Work as "Earning an Income". Original themes such as "Recognition from Others" and "Identity and Self-Worth" were collapsed into the theme "Interpersonal Relationships" under the subthemes of "Peers", "Supervisors", and "Others". The third phase presented their vision of the future if work was no longer a part of their day. The themes were not presented in a descending order of importance because each theme seemed to have varying degrees of importance to each of the participants.

Trustworthiness of the Research Methodology

In qualitative research, trustworthiness refers to whether the findings represent the experience of the participants, they are worth paying attention to, and worth taking

account of. Lincoln and Guba (1985) suggest it is useful to discuss four factors when determining the trustworthiness of a qualitative research study: a) truth value b) applicability c) consistency and d) confirmability.

Truth value (Credibility)

Truth value asks: "How can one establish confidence in the "truth" of the findings of a particular inquiry for the participants with which the context in which the inquiry was carried out?" (Lincoln & Guba, 1985:290).

The truth value of a qualitative investigation generally resides in the discovery of human phenomena or experiences as they are lived and perceived by subjects, rather than in the verification of a priori conceptions of those experiences (Sandelowski, 1986:30).

Guba and Lincoln (1981 in Sandelowski, 1986)) suggest that credibility be the criterion against which truth value of qualitative research be evaluated. They suggest a qualitative study is credible when "it presents such faithful descriptions or interpretations of human experience that the people having the experience would immediately recognize it from those descriptions or interpretations as their own" (p.30).

Lincoln and Guba (1985) suggest that credibility uses a number of techniques that make it more likely that credible findings and interpretations will be produced: prolonged engagement, persistent observation, and triangulation; peer debriefing; and member checking. Prolonged engagement insists that sufficient time is invested in learning and understanding the culture under study. The literature suggests that the "period of prolonged engagement is intended to provide the researcher an opportunity to build trust" (Lincoln & Guba, 1985:303). In order to understand the culture under study, I worked with this population for a year prior to undertaking this study. I also met with each participant in an attempt to establish trust and build a relationship prior to the first interview. A second interview was needed to go over the transcripts and to

clarify previous information, misunderstood words, and to further explore their experiences. This was particularly useful in one situation where the participant felt uncomfortable during the first interview, but at a second meeting appeared more comfortable and able to discuss his experiences in a relaxed manner. All interviews lasted as long as the individuals felt comfortable and were able to shed new light on their experiences.

The purpose of persistent observation is "to identify the characteristics and elements in the situation that are most relevant to the problem or issue being pursued and focusing on it in detail" (Lincoln & Guba, 1985:304). Three participants of the study were observed at their place of employment which allowed the researcher a chance to observe the tasks performed and the interaction with peers and supervisors.

Triangulation is the third mode of improving the credibility of the study by collecting information from a diverse range of individuals and settings, using a variety of methods. "This reduces the risk that your conclusions will reflect only the systematic biases or limitations of a specific methods" (Maxwell, 1996:75). The participants from this study varied in age, work experience and settings, and three participants were observed at their place of work.

Sandelowski (1986) suggests that a major threat to the truth value of a qualitative study lies in the closeness of the investigator-subject relationship.

> The threat of 'going native', or becoming so enmeshed with subjects
> that investigators have difficulty separating their own experiences from
> their subjects, can be offset by deliberately focusing on how the researcher
> influenced and was influenced by a subject ... The researcher in
> qualitative inquiry ... may also be unable to maintain the distance from
> those experiences and to describe or interpret them in a meaningful
> way (p.30).

Sandelowski (1986) notes a useful way to view the researcher in a qualitative study is as *subject* in their own study. As the researcher in this study, I became part of the study because I provided the questions, prompts, and probes in order to extrapolate information I thought would adequately reflect the experiences of the participants. I recognized the participants were the experts, while I was the student.

Peer debriefing is another technique useful in establishing credibility. Lincoln and Guba (1985) suggest it is "a process of exposing oneself to a disinterested peer in a manner paralleling an analytic session and for the purpose of exploring aspects of the inquiry that might otherwise remain only implicit within the inquirer's mind" (p.308). Maxwell (1996) suggests that feedback should come from a variety of people, from those who are familiar with the phenomenon under study and those who are strangers to the situation. Several discussions took place with two experienced professionals who had several years experience working adults with intellectual disabilities. As well as professionals, several individuals with little or no experience in this field were consulted. These sessions helped clarify and focus my thoughts, feelings, and assumptions regarding interpretation of the data.

Another method of establishing credibility or truth value is by member checking. Member checking is the "single most important way of ruling out the possibility of misinterpretation of the meaning of what they say and the perspective they have on what is going on" (Maxwell, 1996:94). The member check, "whereby data, analytic categories, interpretations, and conclusions are tested with members of those stakeholding groups from who the data were originally collected, is the most crucial technique for establishing credibility" (Lincoln & Guba, 1985:314). They suggest that, "if the investigator is to be able to purport that his or her reconstructions are recognizable to audience members as adequate representations of their own ... realities, it is essential that they be given the opportunity to react to them" (p.314).

I discussed the emerging themes with two participants who were chosen because of their ability to describe and understand the phenomenon of this study. They identified the themes as representative of their experiences, however, I was not completely satisfied one of the participants completely understood the categories and themes presented. Young (1996) suggests that the analysis and interpretation of data is probably one of the most difficult areas in which to involve people with intellectual disabilities. She states, "if researchers are looking to present the information to practitioners or academic audiences, both of which expect information to be presented in particular ways, they will find that some of the [information] is not accessible to all [participants of the study]" (p.6). I was respectful of the participants, used plain language when presenting the themes, and provided opportunities to respond.

Applicability (Fittingness)

Qualitative research emphasizes the study of phenomena in their natural setting and therefore, have few controlling conditions. Sandelowski (1986) suggests that "[g]eneralizability and representativeness, as in the quantitative sense, are not usually sought in qualitative research" (p.31). Sample sizes are generally small due to the large amounts of verbal data that must be analyzed, and are often not representative, but if the participants' experience is well described, it represents "a slice of the life world" (Denzin, 1983:134 in Sandelowski, 1986). It was important in this study that participants were from a range of ages and experiences so that the phenomenon under study presented a richness and depth to the information gathered.

Guba and Lincoln (1981 in Sandelowski, 1986) suggest that fittingness be the criterion against which the applicability of qualitative research be evaluated. As suggested by Sandelowski (1986):

A study meets the criterion of fittingness when its findings can 'fit' into contexts outside the study situation and when its audience views its

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findings as meaningful and applicable in terms of their own experiences.

In addition, the findings of the study ... 'fit' the data from which they

are derived. The findings are well-grounded in the life experiences

studied and reflect their typical and atypical elements (p.32).

In this study, I paid close attention to presenting the data as described

by each participant. Themes that emerged from the data represented varying

experiences and were supported by verbatim quotes taken from the transcripts.

Consistency

Guba and Lincoln (1981 in Sandelowski, 1986) propose that auditability be the

criterion of rigor or merit relating to the consistency of qualitative findings.

[A] study and its findings are audible when another researcher

can clearly follow the 'decision trail' used by the investigator in

the study. In addition, another researcher could arrive at the

same or comparable ... conclusions given the researcher's data,

perspective, and situation (p.33).

Auditability was achieved by the decision trail of this study. How I became

interested in the subject matter was documented, how the phenomenon was viewed

was presented in the literature review, the specific purpose of the study was clearly

stated, and the methodology of data collection and analysis were clearly outlined. Use

of a tape recorder to collect the data, verbatim transcription of the tapes employing the

same analysis procedure on each transcript, and journaling and memoing, all

contribute to the consistency of this study.

Confirmability

"Neutrality refers to the freedom from bias in the research process and product"

(Sandelowski, 1986:33), however, Marshall and Rossman (1995) suggest

confirmability captures the traditional concept of objectivity. By asking "whether the

findings of the study could be confirmed by another ... they remove evaluation from some inherent characteristic of the researcher (objectivity) and place it squarely on the data themselves" (p.145) Marshall and Rossman (1995) suggest the qualitative criteria is: "Do the data help confirm the general findings and lead to the implications" (p.145).

Qualitative research emphasizes the meaningfulness of findings achieved by reducing the distance between the researcher and the participants by eliminating artificial lines between subjective and objective reality (Van Manen, 1983 in Sandelowski, 1986). Subjectivity, rather than objectivity is valued in qualitative research.

> Engagement with rather than detachment from the things to be known
> is sought in the interests of truth. Qualitative researchers acknowledge
> the complexities of this kind of involvement with subjects, but view the
> benefits of it as far outweighing the liabilities. Confirmability, as the
> criterion of neutrality in qualitative research refers to the findings
> themselves, not to the subjective or objective stance of the researcher
> (Sandelowski, 1986:34).

Summary

The aim of this study was to explore the experiences of aging adults with intellectual disabilities in order to understand the meaning of work in their lives and their perceptions of life without work. Using Giorgi's five-step (1975 In Pallikkathayil & Morgan, 1991; Omery, 1983) phenomenological procedures for data analysis, themes and subthemes emerged from the transcribed data provided by the participants. By paying close attention and detail to the phenomenological methodology, the criterion of trustworthiness (truth value -credibility, applicability -fittingness, consistency, and confirmability) of the study was established.

Chapter Four

Presentation of the Findings

The goal of this study is to explore and describe the work experiences of aging adults with intellectual disabilities and their perceptions of life without work (retirement). The participants were a heterogeneous group of individuals with diverse histories, families, and experiences. Their personalities, early life experiences, abilities, role modelling, and opportunities to work have all contributed to the meaning of work in their lives. Although the sample size of this study was small, the participants provided a rich in-depth descriptive account of their experiences.

In the following vignettes, I have attempted to portray a picture of each of the participants. Their stories were based on their recollection of their early experiences and their memories of significant life events. At times, it was difficult to follow their stories and to understand what they were telling me, but I have tried to present their stories as accurately as possible. I felt it was important to learn about their work experiences so that I would have a better understanding of the role of work in their lives, and how the meaning of work may affect their plans for the future. It was also important to understand their experiences within the context of their lives.

The Participants

Kathlene

Kathlene is a 53 year old woman who lives alone with her cat in a new one-bedroom apartment in a suburb of a large metropolitan city. When I first met Kathlene two years ago, she was working two half-days a week at a veterinarian clinic. She provided care to abandoned cats and dogs who lived permanently at the clinic. She described her job as the most important aspect of her life and suggested the animals she cared for "were my kids ... I was always in the back talking to the cats or the dogs". Kathlene worked at the animal clinic for twelve years before she lost her job. "Then

one day I got laid off, two months after my first cat died". She is currently unemployed, "but if I get another job, it'll still be with animals".

Kathlene began our interview by telling me that when she was twelve years old she was sent to an institution because of seizures. "Well, when I was twelve, I got sent to [name of institution]²when they used to start". She suggested this was a difficult time because she remembered the conflict between her parents about placing her in an institution . Her perception of the situation was that of her father in agreement with the doctor, while her mother wanted her to stay at home. "As usual" she stated, "my father won".

At the age of twelve, Kathlene went to live in the first of several institutions. "I spent a year and a half at [institution for the mentally ill], went to [institution for the mentally handicapped] for another year and a half. That was a hell hole. Went to [institution for the mentally handicapped]. For a child who had spent the first twelve years of her life at home with the family, the move to an institution made her grow up fast. "I had to grow up in a matter overnight. That spunkiness had to come out of me, so I sorta had to grow up fast, which I didn't like." Kathleen related a story about being asked to move from one institution to another, with the understanding that if she did not like her new home, she could move back. "I was thinking of coming back in six months. They said 'yes', so when six months was up, I asked them, and it was 'NO' ... Well, to get back at them, I set fire to my room. That got me back in a hurry. And I laughed at them when they figured they could lie".

With the assistance of a social worker, Kathlene was released from institutional care when she was 37 years old. She lived in a series of foster homes where she claimed she was abused and mistreated.

> I went to three homes. I wish I never did. They were rotten apples.
> The first home I was in I got mistreated, the second home I got slapped

around. I got pulled up the steps to my room, thrown on the floor and slapped until I was seeing stars ... (????)[3] on my face, couldn't eat, then the guy asked me to stay. I said, 'NO WAY'. And I left in a social worker's car. Apparently, they had to shut down the home.

Throughout this period of institutional care and foster homes, Kathlene received several shock treatments. She related her perceptions of her experience.

I only had two shock treatments. I couldn't stand it and I took off ... They wouldn't let me do the talking, they did the talking. I sat there like a bump on a log, mouth shut. Then I went in the following Wednesday, didn't realize what was going on, they wouldn't tell me, but as soon as they gave me the medication, I was dead out to the world. They gave me shock treatments ... The third time they gave me shock treatments, I was gone. I just took off ... and then, many years later, I got out.

It seemed that during this period in her life, Kathlene had little or no contact with her family. "My mom died when I was nineteen", and I believe her father had also died during the time she was institutionalized. She has a younger brother, but rarely has contact with him. "I've got a brother, but I never see him. Last time I had to phone him. I'm not gonna give him my new address and phone number." Kathlene also stated that she has no contact with any relatives.

Kathlene lives alone with her cat. "I got [Misha] May 29th, the day after I moved in here. I would say the first five months with her, with [Misha] were hell. I couldn't shut the curtains, couldn't shut nothin'. She'd bang them with her head". Now that she is no longer working, Kathlene spends her day playing with her cat and visiting with her friends who live in the same apartment building. "Some mornings, or seven-thirty, no more than quarter to nine, she lets me know. Breakfast! Playing time! "

Her friends live upstairs and she usually spends most of her time with them and often is invited to stay for lunch and dinner. "I go upstairs, watch the T.V. with a friend of mine, then sometimes I go to [211], that's where another friend (is), and she can't talk, but I sure the hell know what she says, (of) course I learned in a matter of

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[3] (?????) = I did not understand the word.

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minutes." Kathlene often goes out with her friends for coffee or down to the neighbourhood pub. "I go to Beans, if we don't go to Beans, we go down to the pub down the street". However, she went to places she did not enjoy just to be with her friends. "I don't drink, so I don't look forward when we go there ... they got TV's going, and I don't know where these tapes come from, but they're on the wall and they're blaring".

Fred

Fred is a 69 year old married man who lives in a one bedroom apartment with his wife of thirteen years. He worked for many years at various jobs in the competitive labour market until his last job ended fourteen years ago. "I worked at two or three different jobs, then I was on welfare for a while ... then I got a job through some people ... I worked there for 14 years". Fred did not work again competitively, but lived on social assistance for ten years until he became eligible to collect the Old Age Pension. "I left that job when I was 55 years old ... Most of the people there didn't think it was right they fired me ... I only had about eleven years to go ... then I would have retired and I would have got a pension".

To fill his time, a friend introduced him to the idea of volunteer work, where he quickly became involved in advocacy work for people with intellectual disabilities. [Mike] introduced me to public speaking ... I worked for [name of agency] for sometime. I've been on their board for a long time". I met Fred several years ago when he was a guest speaker at a workshop for social workers. He shared his experiences with professionals so they could have a better understanding of what it was like to be a person with intellectual disabilities.

Fred was born in 1927 and grew up on the prairies during the Great Depression. He lived with a family and their two sons on a farm until he was 16 years old. "I was just looked after by other people, only one family. I was never allowed to

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be adopted". Fred has two foster bothers, but only has contact with one of them. "I have two brothers, one brother never writes to me or nothing, never see him, he's kind of an odd ball, some people are like that". He sees his other foster brother occasionally. "I think he's retired now, but he was a teacher. He knows me real good, he helps me out once in a while". Fred described a situation where his brother had given him money as a Christmas gift and he felt he should have reported it as income. "He gave me some money at Christmas time. I never told the welfare 'cause sometimes you have to do things behind their back. I HATE doing things behind their back, but what are we gonna do, I can't live on (my income)".

Fred attended school, but found that he was never "any good at that. "I tried that, but I was never able to do it. I never got much schooling at all". Instead of attending school, Fred learned the skills needed to work on a farm. "I learned how to feed the cows and the chickens and learned how to drive a tractor". As a child and early adolescent, Fred wanted to be independent. He quickly taught himself the skills he needed. "If I wanted to learn something, I had to learn it on my own ... because that was life in those days. You either learned or else you failed, so I learned about life ... the hard way".

Fred lived at home until he was sixteen years old, "then they chased me out of there". I was not sure if he meant his family "chased him out" or if his legal guardian, the Children's Aid Society, "chased him out". "They told me to leave. I was under the Children's Aid". He was sent to work on a farm, but after stating his preference to learn a trade, he was sent to an institution instead. "I didn't really want to go to farms. I really wanted to learn a trade, and that's when they put me in an institution ... for ten years ... that was no life at all". I never could figure out why they sent me there".

After leaving the institution, Fred moved to British Columbia where he connected with a friend who introduced him to others. He formed a close friendship

with his new friends, especially with one particular woman who became his good friend. "I met her when I first came out here. I met these people through a friend that was introduced to me ... they were my best friends I ever had and I really miss them ... especially this lady because I could talk to her about anything ..." Fred appeared sad when he described the loss of his friends. "When you get older, I lost all my friends, They all died, everyone of them died, except one is left". With the help of his new friends and a church-based organization, Fred was able to find work that paid him an income and allowed him to live an independent lifestyle.

Fred felt that others saw him as "handicapped" but he did not consider himself to be "handicapped". He was more concerned about "working and doing a good job, rather than worrying about what others thought about it".

> There's a difference between them and I, see, they didn't have to work, so there's a big difference. They never worked until they went to those workshops, otherwise they stayed at home. There's a big difference between what they do and what I did, you see, so you've got to consider it because most of those kids didn't know what to do or how to do it because they had never done work.

In spite of his efforts to support himself and live independently, Fred found that he was treated differently by people from the non-handicapped population.

> I've had lots of experiences ... they walk on the other side of the street, or they walk around you ... they don't want to talk to you to say 'hello' ... Fear is the biggest thing I find ... People are ascared of us.

Today, Fred's mission in life is to teach and educate professionals about people with intellectual disabilities by sharing his first hand experiences. "For the last few years, I started talking to different groups ... I want people to understand how we feel about things". He is concerned about the needs of older people with intellectual disabilities because he feels their needs will be ignored. "We need to be understood better ... when you get older people have a tendency not to listen to us very much".

Fred is "semi-retired" (his term), but has remained active with his volunteer work in public speaking, education, and advocacy. He takes life a little slower today than during his work years in the competitive workforce, but wants to remain active. "I can quit anytime I want, go out and walk around, do what I want, I have no clock to punch, I can go at my own speed ... same when I go out public speaking".

<u>Richard</u>

Richard is a 60 year old quiet man who lives in the basement suite of a home of a middle-aged woman and her young adult daughter. This is a proprietary care arrangement where the family is paid a fee to provide a home for a person with an intellectual disability. Richard seemed to live a fairly quiet, structured life. He took the bus to work each morning and returned home each afternoon. After dinner, he watched television so he could stay current with the newsworthy events of the day. "I don't go to the social clubs, you know, I just stay home from work, watch T.V." He rarely went out in the evening, but on weekends if the weather was nice, he took public transportation to explore the city and the surrounding suburbs. "On my day off, I like to go some places in the summertime, the spring". Richard tended to keep to himself, claimed he had no friends, and was not interested in socializing. "I don't know where the friends are. I got friends in [name of workplace]". I wondered if he had lost touch with his friends because of his move to the city. "I got no friends here". He claimed that he never shops for clothing as he receives new clothes through gifts at Christmas and birthdays. "I didn't buy clothes, I get clothes for Christmas presents, shirts and things".

Richard was born in 1936 in a large city where he lived with his parents and an older brother. When he was six years old, his parents bought a piece of property in the suburbs. They lived in a "shack" on the property until their new house was built. "My parents took me to [suburb] and bought a lot ... they owned a house, they had their old

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shack". He attended elementary school in his new neighbourhood and later during adolescence, attended high school in the city. "In '54 and '55, went to [name of high school]".

Richard's mother died when he was thirteen years old. "She passed away in '49, then my Dad got married three times. I think I was about thirteen". His father remarried twice, and both times Richard continued to live at home with his father and his two step-mothers. He helped out with the house and garden work when he could, and often went to movies in the evening. "I did things around the house, garden, went to movies at night". Richard did not work outside the home because "the doctor told my father Richard can't work, you know". "The doctor or somebody told my Dad I shouldn't work". Richard seemed to accept the doctor's suggestion that he "couldn't work". I asked him if that had bothered him. He replied, "Don't bother me, it's OK".

After the death of his father, Richard moved in with his older brother and his sister-in-law in the central part of the province. "Well, in '77, my brother took me to [name of city]. From what I could understand from our interview, Richard was about forty years old when he went to live with his brother. It was during this time that he had his first experience at work outside the home, and it was at a sheltered workshop in a new community. A few years later his brother retired, and Richard moved out to live in the first of a number of residential settings. He lived in group homes and "private homes" until he moved in with his present family. "In '86 I went to the group house, in '87 I went to private people in [name of city], then '91 out to [name of city], then I came to this place in February, '91. With the different changes in residence, Richard continued to work at sheltered workshops and moved to a new workshop each time he changed residence. Each move required he learn a new bus route and time schedule to get to his work.

Richard attended summer camp each year and showed me his attendance

certificates, his souvenirs, and a photo album of a recent trip to Los Vegas. "In '94 and '95, went to Los Vegas. Took Delta to Los Angeles, transferred to Los Vegas". He was met by his brother and sister-in-law who had arranged side trips for him. "Went to Riverside, on the Strip, one side is Nevada, the other is Arizona. Went to a chocolate factory and (to) where they make cranberry juice". It seemed that Richard had travelled before because he said his father had worked for the airlines and got him a pass to travel free. Richard told me that "if you got a son or daughter who's mental or handicapped, you get to travel free. So my Dad wrote a letter to Winnipeg to say he had a handicapped son. My step mom took me to Ontario to see her daughter in '76".

I saw Richard as a sixty year old man who preferred to spend quiet times alone. His worksite at a sheltered workshop/training centre provided an opportunity to socialize with others if he wanted, but he seemed to prefer to spend his evenings relaxing at home after a day at work. He enjoyed his leisure time travelling by bus and exploring the city. He maintained contact with his brother who took him on vacation and arranged site seeing tours.

Sarah

Sarah is a 65 year old independent active woman who worked four days a week. I was introduced to Sarah by her work supervisor and it was evident from our first meeting that she loved to be around people and share her experiences. She portrayed herself as a capable woman who loved her work, enjoyed keeping busy, and socializing with others.

Sarah stated that she was born blind, although she had sight in one eye. "I was born blind, and I lived in schools for the blind. I left school at the age of seventeen and I was working in a convent ..." When she was in her mid-20s, Sarah moved home for a period of time, then lived in several institutions for people with an intellectual disability.

> I left the convent at the age of twenty-six ... I was home for a while,
> then I went into [name of institution], then to [name of institution],

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> *... then to [name of city] to [name of city] ... then I moved in with*
> *[name of family] and two other ladies, that are in their thirties, and*
> *their now twenty year old daughter.*

I wondered why the transition to institutional care, especially since she seemed like a capable independent woman.

Sarah was proud of her abilities to care for herself and assumed responsibility for her own medication. "I can also get my own medication. They have never had to give me my medications themselves". Sarah was responsible for caring for her bedroom, her personal belongings, and helping out around the house.

> *Everybody has to do each of his own job. Each person gets a job*
> *to help look after the house ... I take care of my own part. I've got a*
> *brand new bathroom all remodelled ... and now I've got a new floor...*
> *and I help with the dishes ...*

For the past thirteen years, Sarah worked at various sheltered workshops and at a local community centre. She enjoyed her work and the friendships she made through her work. "I like it up there, I've got lots of friends". Sarah took the bus to and from work each day and to her social functions during the evening. "I take the bus. I have a big flashlight for Thursday nights, 'cause I'm walking down from the bus, home ... but when I go to use it ... it doesn't do me any good ... I told them my flashlight doesn't give me much light."

Sarah was proud of her accomplishments and her ability and interest in learning.

> *I've got a new desk and a new top shelf ...I try to do arithmetic, things*
> *like that. I've got a grade three's arithmetic book, so then I can try*
> *to get myself up to grade four.*

Besides an active social and home life, Sarah maintained a connection to her family members. "I've lots of brothers and sisters, and lots of nieces and nephews, and great nieces and nephews ... And I get to see my sisters sometimes, if they sometimes take me out on an outing". It seemed that Sarah's family, friends, and her work were

an important part of her life.

<div align="center">Jack</div>

Jack was born in a house on the Prairies in 1940. I had difficulty following parts of his story, but I have attempted to piece together some of the important highlights he shared with me. It appeared that after his birth Jack lived with his aunt while his mother was in hospital. "I was born in a house ... my mother was in the hospital in Saskatchewan and I grew up in my Aunty [Lynne's] house". Jack began his story about his childhood by explaining that his mother had a difficult time getting his birth certificate.

> *I didn't have no I.D., no birth certificate card where I was born, so she had to go to the judge, and she had a rigamorol getting my birth certificate .... My mother had to go thirty times down to a lawyer in Vancouver to say I was her son. They wouldn't believe her until she got my birth certificate.*

I was not clear about the significance of this story, but it seemed to be an important story to Jack.

Jack moved with his parents to British Columbia and attended school in the city. "I went to school in [name of city] ... I had to go out there everyday on the number nine bus, every day coming back on the number nine bus ... I was in a special class out there". When he was nineteen years old, he began to have seizures. "My mother and [name of father] found out, see I was having seizures". Jack's father wanted him placed in an institution, but his mother wanted to keep him at home. "My mother had a heck of a time telling him, NO, don't put him in [name of institution]. I want my son home".

Jack said he lived in an institution for five or six years. After he left the institution he returned home to live with his mother and continued to do so until her health began to fail. His father had died while he was living away from home. "My father had two heart attacks when he was forty-eight". With his mother in poor health, and Jack now

fifty years old, he decided it was time to move out. "I said I can't stay any longer with an old mother, with you mom ... so she says if you have to move, you have to move, what's the sense of staying with an old lady like me..."

Jack made several attempts to live away from home, but found the experience difficult. "I couldn't stand it out there, it was too noisy, so I moved back home. I moved back and forth five or six times, then I moved back home". It seemed the transition to group home living was a difficult experience for Jack, especially after spending most of his life at home with his mother. He commented on his current living situation and how the behavior of one of his roommates upset him. "He can't keep his voice down. I get so mad ... sometimes he gets me really mad at the supper table and I go and leave the supper table and go to my bedroom to eat".

Jack had a close relationship with his mother and visited her on weekends after her health declined and she could no longer drive. "I phoned her up and told her I'm coming up to visit her. That's when she couldn't walk, she had an oxygen tank to keep her alive ... every weekend I went up and saw her". Both his parents are deceased and he has no brothers or sisters. "I was the only one in the family".

These are the five participants of the study. The remainder of the chapter describes the work experiences of the five participants, the meaning of work in their lives, and their vision of the future. By the time I had interviewed all five participants, it was evident from their stories that work was an integral part of their lives. The findings of the interviews were organized into three parts. The first part is the actual work experience and includes the themes, "The Worksite, Tasks, and Responsibilities", "Interpersonal Relations", and When The Job Ended". The second part is the five themes that emerged from the work experience. The themes are: "Work as an Opportunity to Use One's Special Abilities", "Work as Structuring the Day", Work as an Opportunity to Socialize and Meet Others", "Work as Service to Others" and "Work as a

Source of Income". The third part is the participant's views and their opinions of their life without work (retirement).

The Work Experience

The participants worked in a variety of different work settings. Some worked full-time, others worked part-time. All workers had certain tasks and responsibilities when they assumed the role of worker. Some people enjoyed their work, while at least one individual found it repetitive or boring. All worksites offered social interaction with others, but the degree of interaction depended on the particular worksite. As with many people, the work experience included losing one's job. The following is a presentation of the work experiences of the five participants of this study.

The Worksite, The Tasks & Responsibilities

Kathlene began working when she was in her late 30s. She described where she worked, her hours of work and how she got the job.

> I've had janitor work, and I hated that. Some mornings I dreaded to go
> to work, 'cause I only had an hour to do it. I had to be there at eight ...
> I was working at a second-hand store ... I knew a guy from [name of agency] ,
> and he opened it ... I was hired to work one hour from eight to nine in the
> morning. I worked there Wednesdays and Fridays.

Kathlene also stated that she had previous work experience at a thrift store, but found the work boring. Before it closed down, an employee helped her find another job. It seemed that janitorial work and the job at the store did not interest Kathlene or meet her needs as she found the work "boring".

> Before that I worked at a thrift store on [name of street] - BORING - for one
> year after I left [name of institution] in 1981 ... I was working at a second-hand
> store, and it was closing down ... and a girl who was working there knew the
> vets and talked to him, and I took over from there.

Kathlene's last job was part-time work at a veterinarian clinic where she worked for twelve years. From her account, Kathlene was responsible for providing care for

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the cats and dogs at the clinic by cleaning out their kennels and making sure they were exercised.

> They were my kids ... and of course, if you look at your animals as if they're you're kids ... they're a part of my life ... I don't want to be taken away from pets. I sure hated everything else, but when it came to animals, I was there ... I was always at the back, talking to the cats or the dogs ... I worked from nine to one ... two days a week ... Wednesdays and Fridays ... I used to do a lot of stuff ... just making sure they were OK ... The doctor brought in one, a Chihuahua ... cute little guy, I've got a picture of him somewhere ... and they didn't expect him to live ... that's why they brought him down. Well, I couldn't stand him in the cage when I was working, so I'd take the dog out. I wouldn't let him jump out, so I'd pick him up and put him down. The next thing I knew he was following me to go for a walk.

Kathlene had people she knew help her find part-time work. Some of her jobs were in the competitive job market and usually ranged from two to eight hours a week, although she often put in extra hours. "I was supposed to get off at one, but sometimes I stayed to three". Her work experience was similar to others who enjoyed their work and often put in extra hours.

Fred also worked in the competitive job market at a variety of jobs during his working career. He described the type of work he did and his understanding of why the jobs did not work out.

> I did two or three different jobs. The first job when I came over here, I worked in a place making heating radiators for houses, for buildings. I did that for about a year, and that was a good job. I really enjoyed that, but the people sold the place, so I lost that job ... I worked in a furniture factory at one time, and that didn't turn out too good because the guy said I wasn't doing it fast enough ... then I worked, I got a job through some people, to work at [name of business]. I washed cars there for almost fourteen years, and then I started waxing cars and polishing cars ... I got so I could tell the different paints and how much paint was on each car, and I could tell pretty well, if a car came in on Friday, from the factory, I could tell they didn't paint it right, just by the paint. You could see the undercoat under the car. And so, I enjoyed that.

Fred's experience was similar to others in the competitive labour market who

lost their jobs because the business was sold. He also claimed that he did not like it when someone watched over his shoulder, yet in many jobs in the competitive work force, a foreman often supervises the work performance of the employees.

While Fred had been out of the competitive labour force for fourteen years, he was actively involved in the community as a volunteer. "I'm semi-retired, put that down because I'm not exactly retired". Fred was a board member of several non-profit agencies whose main focus was to provide service to people with intellectual disabilities. Fred's volunteer work included public speaking, education, and advocacy work.

> Right now I'm on a couple of boards ... I've been a regular with that ...
> Right now we're talking about elderly people, and what they can do for
> the elderly people ... what they need. I keep busy, I don't like sitting
> around doing nothing ... I think that's what's important to everybody,
> to be able to understand how we feel about things, not reading it out
> of a book. I got involved with [Mike] and doing the kind of work I'm
> doing right now. He was the one that really helped me get in public
> speaking. I really enjoy that, I really enjoy getting to know other
> people, and going out there talking to people, and this is what's
> really important to me. I was involved in writing a few books, public
> speaking. I'm involved in other things. I help out with the government
> ... on committees. I speak at [name of college] quite a bit. I've been
> going there for years and years. The way I look at it is most people
> need to understand how we feel.

Fred's experience seemed similar to that of others who are also retired. Many people become involved with other activities such as volunteer work in different areas of their communities. This kept Fred busy and gave him something important to do with his time. "I like to get out there and do things, and help out whenever I can". His volunteer work gave him an opportunity to do the type of work he had always wanted to do.

The other three participants worked predominantly in sheltered workshop training centres. According to the literature, these workshops offer a safe environment, socialization, work preparation, training, and employment for people with intellectual

disabilities. Sarah was 65 years old and worked for the past thirteen years at

sheltered workshops located in various locations in the community.

> I started working at [name of workshop], doing different kinds of jobs ...
> I worked up on a place on [name of street] and I worked on [name of
> street] at a workshop there, and then from there, I guess I went to this
> brand new building, and I've worked here ever since it opened.

Sarah discussed the different tasks she did at work and how often she worked.

She recently reduced her work schedule to four days a week. She worked three days

a week at the workshop, and one day a week at a community centre.

> Down at [worksite], I did A&W, like napkins and stuff. We had a
> computer disk ... we had to make sure we had 10 to go in the box.
> And I also made up the boxes, the little boxes for them ...   I did
> different things in that room ... doing seeds, medical journals,
> envelopes, anything I like. I just work part-time ... Tuesday,
> Wednesday, Thursday. Monday, I'm not here. I've worked
> here since it opened ... in the summer time, in April. I'm
> semi-retired. I've been working here for quite a long time.
> They taught me different things. I love what I'm doing part-time.

Sarah worked one day a week at a community centre. She mainly washed

dishes and was responsible for loading and unloading the dishwasher.

> I work there on Mondays ... twelve and a half hours. I start as soon as
> I say good morning to all my friends, then I take my bag, and put my
> long-sleeved sweatshirt on, take that off, put my fanny pack here, then
> I put on my plastic apron, then I go straight and go to work with the
> dishes that are sitting in the kitchen ... like I say, I like what I do.
> I do dishes on Mondays ... When I do the cups, I pick the cups,
> they're so many cups in a row, in its own thing, you have to make
> sure it's completely full, and I have a brand new dishwasher.
> I wash dishes, and I'm busy with that. I've got a guy by the name
> of [Jim]. He does the pots and pans. We work together.

While Sarah stated she worked twelve and a half hours at the community centre

on Mondays, she actually left work around two-thirty in the afternoon.

Jack has also worked at a number of different workshops throughout the

community. He began his interview by discussing where he worked.

> Oh, I work for [name of worksite] for a few years, and I like going
> down there ... I used to work down at [name of worksite], from there,
> then the [name of worksite], from [name of worksite], way down
> there, then [name of worksite], making apple boxes ...

Jack sat at a table in a large room at the sheltered workshop and worked on a variety of different tasks. He explained in precise detail the variety of tasks he performed at his place of work. He discussed energizers, but he did not explain what they were. Jack explained that he packaged and sent out medical journals to all the doctors in the province, measured plastic used to make plastic flowers for wedding cars, and packaged latex gloves for hospital personnel.

> ... and we do these things, energizers. You put them in the box
> underneath the paper, and you put the paper in on top of the paper,
> no underneath the paper, and there's a card on top of the paper.
> They go out to hospitals and to doctors, and to nurses and dentists,
> goes out to everywhere you can think of. They go all over the world.
> The books, I have to wait until they come in. I'm putting papers in
> the bags first, and the card on top of the yellow paper first, and
> when that's through, then I'll stop ... plastics, you roll up plastic,
> on rollers, you cut the plastic from one end ... to measure the plastic.
> Different colours, white, dark white, light green, dark green, bright
> yellow, dark yellow, dark pink, light pink, that's for, like, making
> wedding flowers for cars. They're all wrapped up, and they roll off
> the rollers and they cut it in two, and for each boy and girl, when
> they ask how to do it, by different colours, and that. I do all sorts
> of things and when they come in we do them over again ... glove
> packs, you have to put the gloves in the bag, two gloves, you have
> to put them in the same bag, then it's locked shut. They're for
> police, for hospitals and dentists and nurses.

Jack described how he worked with his co-workers in an assembly-like fashion. The worksite had a number of large tables beside each other and sometimes a few of the people would share different components of the same job. For example, one person would count out a specific number of items, a second person would put the items in a box.

> ... she sits at our table, and she helps us and she passes things to us, and
> she puts things and passes it to [Cindy]. [Cindy] passes it to me, and I

put it in the box, that's how it's done ...

Jack described the tasks of one of his peers and the repetitive nature of the
work. This job was similar to the type of work he also did.

> ... [Marilyn], she does that. They take the orange off the white plastic
> and the white goes into the white plastic and the black plastic she gets,
> goes into the black barrel. She puts the orange paper in the orange
> barrel, and the red plastic goes in with the red plastic, orange paper
> in the orange barrel, again. That's what she does all day long right
> until eleven, all day until noon time, and we do that "aaaalllll" over again.

Jack also described his responsibilities to provide support for others who
needed extra help while at the worksite. In one particular situation, one of his co-
workers was injured and required surgery. She was off work for a period of time and
required support when she returned to work.

> [Supervisor] gave that job to me to take care of [Melanie]. Once she
> let me take her upstairs to the play ... and after that I took her down
> the elevator for a hotdog and a soft drink or a coffee, and some chips.
> I was in charge of her. I have to watch her carefully now, walking.

Jack also felt he had a responsibility to teach new employees how to do their
job. I noticed how seriously he took his responsibilities and how important they were
to him.

> They were watching how I was doing it and how we do it. .. so they
> got the swing of it. While watching us, they will get to know how I do
> it, now they'll know how to do it, by watching me, or by watching [Cory],
> or by watching the other girl. It took them fifteen minutes to catch on
> (to) [4] how we did it. That's the way we help them.

Richard also worked in a sheltered workshop training centre. He did not start
working until he was in his early 40s. Starting work for the first time when one is 40
years old is quite different from the non-handicapped population where the
expectation is to find a job and start working after high school or after post secondary
schooling. Richard's first job was at a sheltered workshop, "at a place that had school

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[4] ( ) = Researcher added word to sentence.

books that were torn by the kids in school. They'd be sent to the workshop, take off the covers and put new ones on". Like Sarah and Jack, Richard had worked at several different workshops in the community before he moved to his current worksite in 1992. It seemed that Richard's tasks included sorting packages of mustard and ketchup, counting and boxing medical journals, counting and packaging envelopes, and sorting and counting coins. The sparkles he referred to were sticks of incense that were placed two to a package.

> Well, in '86, some contractor, he A&W, we put ketchup, mustard,
> you know. In '88 ... all electronics will go to [name of worksite],
> then in '92, when we moved in to [name of current worksite]...
> medical juries, the insurance fund, the Christmas cards. Well,
> this year, our job was the envelopes, count the envelopes in
> 10, pennies, sparkles ... Ask [supervisor] what we're doing, OK?

Richard suggested I speak to his supervisor if I wanted to know more about his work. He became frustrated and anxious when I did not understand what he meant. During our second interview, he was more relaxed and I found it easier to understand what he was saying. He explained that some of his work was for "Save the Children's Fund", not the "insurance fund" as I had previously understood. His job involved counting out a specific number of envelopes and putting an elastic band around each group of envelopes. It was important to him that the job was done properly with the right amount in each package.

> If it's eleven, it's too much, nine, not enough. [Supervisor] has to
> count. Now we have a scale to make sure it's ten.

From my observation of the work of Sarah, Jack, and Richard, it appeared their jobs tasks ranged from counting, measuring, sorting, packaging, filling orders, and making boxes. Their experiences were similar because they worked in the same workshops. They worked five days a week with the exception of Sarah who recently reduced her work to four days a week. Their work week was similar to Fred's work

week as he also worked full-time, however, Kathlene had part-time work between two and eight hours a week. Those who worked in the sheltered workshops worked at their own pace and did not have to rush to get their work done. Due to their intellectual disability, productivity did not seem as important as it would be for people who worked in a competitive job. Although Fred had a disability, he worked in the competitive job market was expected to work at a certain pace and to be productive. He supervisor often "looked over his shoulder" to make sure Fred was productive and often told him to "hurry".

Interpersonal Relations

The work experience included interpersonal relations with others such as co-workers and supervisors. The workplace was a place to interact with peers and staff, and a place where friendships often began. Each workplace had its own social and cultural milieu where the whole gamut of interpersonal relations were expressed. As in all work environments, these relationships were positive and nurturing or negative and demeaning. Some of the participants found opportunities to cultivate friendships, while others did not. This seemed to depend on the work location and type of business and whether a person wanted to interact socially with his/her peers.

Interaction With Peers

Jack, Sarah, and Richard worked in close proximity with their co-workers who were also intellectually disabled. Their work environment was in a large open space which provided numerous opportunities to communicate, interact, and socialize with co-workers. It reminded me of workshops or factories such as garment manufacturers where many people work in one large room. Jack was one of the older workers who tried to set a good example for his younger peers. One one occasion, he voiced his displeasure with the behavior and language of one of his co-workers.

> One boy named [Rodney], sees two Chinese girls from Hong Kong, and
> he says, 'Are you Chinese?' And I said to him that's rude manners what

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you just said. You shouldn't have said those words to those two young ladies behind their back, they don't like it a bit. So I went over and I said, 'Don't worry about it' ... and I said to [Rodney], ' that's rude manners, you shouldn't have asked those girls those personal questions at all, because they don't like it at all' ...

One individual was not above expressing thoughts of petty vindictiveness when he became annoyed with one of his co-workers for making fun of another.

[Tim] ran right across [name of street], straight, a car hit him and broke his leg. He's got a broken leg ... that will teach him a lesson, making fun of [John] in a wheelchair, and he swears like the dickens. I'm glad he's got a broken leg, and [Gary's] glad because he can't make fun of [John] now. When he gets back to work, he won't be able to run now. He can't bend his leg now while he's stiff ...

As one of the senior workers, Jack felt he had a responsibility to teach others not only how to do their job, but also how to be polite and use good manners. He enjoyed the social contact with the women he worked with and described a situation when he was talking to a couple of 'girls' and his friend became jealous.

One girl came in from the top floor in our room and she got mad, so she went back up because she thought the two Chinese girls were for a girl friend, but I didn't ... but she walked in and 'OOOOHHH', she 'gaaave' me the dirtiest look and she walked out of our room, poor her, she gave me the dirtiest look you ever saw. I didn't know what to say ...

Another individual who was the oldest working member at the workshop felt some of her co-workers were "a bit too young".

I'm still with some of my friends, but some of these guys here are a little bit too young for me, to be working with me. I'm being the oldest .. I love it up there. I've got lots of friends. I can work part-time and see some of my friends. I've got a blind friend who works in another area ...

Many of Sarah's co-workers were also her friends. Her workplace was also used for social activities.

A lot of my friends work here. We have our own dances at the social club, it's out in the other room ... There's some that don't work here with me like [Jack], [Wendy], and [Lorne], but he's not in the social club ... I have my friends, the one's I have supper with. We come together as a

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group.

The participants had varying degrees of socializing and interacting with their peers. For some, work provided many opportunities to interact and connect with peers. For others who preferred not socialize during the day, work was a place where they did their job and went home at the end of the day. The degree of socialization seemed to depend on the personality of the individual, their level of comfort interacting with others, and their opportunities. Given their work was in a large open room, socialization with others seemed inevitable.

Richard felt more comfortable observing instead of interacting with his peers. He preferred not to attend the social functions organized through his work and did not participant in computer classes which were offered to the workers.

> I don't go to the social clubs, you know. I just stay at home. I come home from work, watch T.V. ... I got no friends ... I didn't sign up, you know ...
> I just go to work, keep on working, you know.

Richard seemed to prefer quiet times at home watching television and travelling alone by bus on the weekend. Nevertheless, his workplace offered opportunities for socializing and interaction with others if he wanted. The opportunities for socialization were similar to the opportunities offered by many companies or businesses that organize company picnics, barbecues, dinners, or golf tournaments.

In spite of his quiet demeanor, Richard enjoyed being with his peers. He shared a story about one of his co-workers that he found amusing. Apparently one of his co-workers was known for his long lunch breaks, in fact, he was often in the lunch room when it was time for coffee or when the Handidart arrived to take him home.

> [Jeffrey], (laugh), he's so slow taking the Handidart. [Kevin] says,
> 'Come on [Jeffrey]' ... He's in a different room, you know ... Well,
> he used to be in the other room ... we start (laugh) at 12 o'clock,
> you know, to eat lunch, and you know what time he's finished eating
> lunch? Two o'clock (laugh). We're starting our coffee break at two
> o'clock, he's still eating his lunch (laugh).

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The two individuals who worked in the competitive work environment did not have the same degree of social interaction as the three participants who worked in the sheltered workshop training centres. Their jobs seemed to be away from the main activities of the workplace. Kathlene worked "in the back" with the animals at the animal clinic. The only contact she seemed to have at the workplace was with the receptionist who worked in the front office. "We only had coffee before nine, then lunch" was how Kathlene described her interaction with the receptionist. This did not seem unusual given the nature of this specific workplace, with the receptionist working in the front office with the customers, and Kathlene working in the back with the cats and dogs.

Fred worked for fourteen years at an auto dealership washing and waxing cars. He maintained that he had a good relationship with his co-workers and felt he was treated "just like everyone else".

> I didn't talk much to the other people, but the people that were there were very nice to me and they treated me like anybody else. They never treated me any different ... they were very nice, and they really enjoyed me, and I had a good time with everybody else, and we got along good with everybody else. Everybody got on good there, you did your job, your work, you know.

While Fred described the positive interaction with his co-workers, he spent little time with them other than coffee before work. "Well, maybe we'd have coffee together, before work, that's all. They never came around to see me or nothing, just my own friends". Fred may have spent little time socializing with his co-workers because of the type of job he had. Washing and waxing cars was more than likely in an area that was away from the main hub of activity. While the social interaction experiences of Kathlene and Fred were different from the three individuals who worked in the sheltered workshop, I do not think their experience was different from others who worked in similar situations. Many people who work independently have little contact

with their co-workers or colleagues.

While Fred had been away from his former place of employment for many years, he still maintained an informal connection to some of the staff.

> I see some of my friends once in a while. I see them on the street to say hello to them. I may have coffee with them, if they got the time, otherwise, I never see them at all. Sometimes I go down to where they work and see them, but most of the people that were there when I was there are retired. Most of them are gone now because they are retired. So there's only a few people there that I know. All the rest of them are gone. Pretty soon there'd be no sense going there at all because there'd be no one there at all. I go down there once in a while to say hello to those I know, but that's all. They all remember me. They always ask how I am and what I'm doing, you know, things like that.

Going back to one's former place of employment to say hello and reconnect with past co-workers may be common for people who have retired. I personally know several people who have retired, yet return to their place of employment to reconnect with past co-workers, to have lunch together, and sometimes to attend special functions.

The experiences of the five participants showed there were more opportunities for interpersonal relations and socialization with peers for those who worked in the sheltered workshop training centres than for those who worked in a competitive job setting. I do not think this was unusual given the nature of the worksite with its large open space which promoted social interaction. Also there were more people to interact with at the sheltered workshop than at the workplace of Kathlene or Fred.

Interaction With the Supervisor or the Boss

The participants had interactions with their supervisors ranging from a positive experience to a negative and traumatic experience. I have attempted to illuminate those experiences by presenting the following excerpts from their interviews.

Sarah felt she had a good relationship with her supervisor because she was

often praised and complimented for her work abilities and achievements.

> They taught me different things. Everybody says I do a good job.
> I always get compliments for doing good work ... But I work here
> part-time just to give [supervisor] a hand with stuff others don't
> know how to do it right, like I do ... She likes my work. She says,
> 'good work'. It feels good.

Richard was a quiet person and a man of few words, but I got the impression that he also had a positive relationship with his supervisor by his willingness to help out in any way he could. For example, when the supervisor asked Richard if he wanted to "help out with the seeds", he replied with enthusiasm, "Yeah sure!"

Jack had a positive relationship with his supervisors at work and was often given extra responsibilities because of his willingness to help out.

> [Supervisor] gave that job to me to take care of [Melanie] ... I was in
> charge of her ... I'm helping [supervisor] and [supervisor] there, too ...

While Jack had a good relationship with his supervisor, he was upset with her for taking away some of his responsibilities because of a problem he had with mobility. He acknowledged that his some of his work activities had been curtailed because of a problem with his leg.

> [Supervisor] won't let me go outside of the room now. Someone else
> has taken over my job. I don't like it a BIT. THAT'S MY JOB. I'm
> supposed to be doing it because [supervisor] gave that job to me
> and I'm supposed to do it ... I talked to her about it about three of
> four times, but no, she won't let me go out of the room and out to
> the hallway and sit down. I might head right on the cement
> foundation and hit my, hit this part wide open again.

Jack reluctantly gave up some of his responsibilities because of health and safety issues. I think many of us would be reluctant to give up some of our responsibilities, especially when the job was an important part of our day. I noted that Jack recognized there was a safety issue, but he seemed to feel his responsibilities to others outweighed his own personal safety.

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Fred's interaction with his co-workers was a positive experience, but his relationship with his supervisor was strained at times. He felt if his boss pushed him beyond his capabilities, he could not do a good job. I do not think Fred's experiences with his boss were unusual. In businesses where production is important, the supervisor or boss often kept a close supervision over his/her employees.

> The only thing I didn't like ... they were always after me, always to hurry, hurry, hurry, go faster, go faster, and which I didn't particularly I like that, right? 'Cause I was going as fast as I could do it and I didn't really like the way they talked to me about it, you know ... Then they'd come to me and say you should be more careful. How are you going to be more careful when there's no paint on it in the first place .... Sometimes I told the boss not to rush me too much ... If you want a good job, fine, if you want to do a bad job, then fine too. And then after that it got so that he didn't bother me, because he knew what I was talking about ... I worked in a furniture factory ... and that didn't turn out too good because the guy said I wasn't doing it fast enough. He kept looking over my shoulder and I couldn't stand that. I don't like people looking over my shoulder.

Fred perceived that he received unequal treatment from his boss. He claimed the other employees were not treated in the same manner as he was.

> One other thing was that if I got sick, they'd phone me up and ask me why I wasn't there, and that I hated. They never phoned up the other guys to see what was wrong with them, but they always phoned me up, 'cause I'd ask the other guys, and they'd tell me what was going on, and every time I'd get sick, the first thing they'd phone me up, 'how come you're not there' ... and I really didn't care for that. Most of the times I'd phone in, but they'd still ask me questions, how come I'm not there.

Fred felt he was singled out and treated differently than his co-workers. He could provide no explanation for why this happened to him. He considered himself to be a good worker who rarely took time off work and was never late.

> I think I was only sick maybe a couple months, you know, in all the years I worked there. I worked there a long time ... All the rest of them had hangovers and say they're not coming in today or tomorrow and things like that, but I never missed a day. I was

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always on time. They can never say I wasn't on time, except
if the bus was late ... I never missed being on time, never, I was
always early. That's the way I was brought up that way and
I've always been that way. To be on time, important to be on time ...

Kathlene had very little contact with her boss, the veterinarian. However, she

stated that she felt comfortable with him during most of her twelve years of

employment.

... that's why I always wanted to be there. I'd be there starting at nine, so
I'd be there at ten to nine.

Sometimes Kathlene and the receptionist "talked" their boss into joining them

for lunch. "We'd talk him into it. We'd joke". However, her relationship with her boss

deteriorated, or as she stated, "it soured" when the receptionist left and a new person

was hired.

... when I first started saying good morning to the doctor when he came
in at ten, and he started calling me 'bitch' and 'bastard' ... that pissed
me off. I don't know what happened, but he was starting to call me
names. One day he put me in tears by this word. He says 'don't
tell my wife'. I thought, well, if that's what you want, OK, I won't,
but you're going to stop. But he didn't, he just kept it up ... called
me 'bastard' and 'bitch' and everything else ...

I wondered if the former receptionist had in some way "protected" Kathlene from

being verbally abused by this man. Kathlene gave no explanation as to why his

behavior changed except to say that it started when her cat died and he wanted her to

take another cat home.

Just after my cat died. Well, before she died, he kept asking me,
"How about trading her in for a different cat?" I just said 'NO, not on
your dead life, would I'. I says I love her and that's the way it is and
that's the way it stays. He didn't like her, but I did.

I was not sure if there were other things going on at work because Kathlene

also felt that she was treated as a "guinea pig".

That's what happened at the end, and I didn't pick it up. They would

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> get me to go to the store. Sometimes I refused, 'cause I knew they
> were trying to use me as a guinea pig at the end. They always wanted
> the same stuff, so this one day, I picked up the wrong (one), took it
> back, and I just sat there, ya sure. This is what you get for trying to use
> me for a guinea pig.

Kathlene was fired shortly thereafter. It would have been interesting to find out from the two parties what had happened and to see if there was a way to resolve the problem because Kathlene's job was very important to her.

Kathlene also described a negative experience with her supervisor when she worked as a janitor. In one particular incident, she felt taken advantage of. Kathlene was hired to work for one hour in the morning, but was kept at the workplace for most of the day. She was so upset that she was unable to do her shopping after work.

> Some mornings I dreaded to go to work, 'cause I only had an hour to do it.
> I had to be there at eight. One day there was one girl, I never liked her.
> She kept me in from eight to five at night. I used to work there and I'd say
> I gotta go shopping. I didn't do my shopping after work, I was too burned
> out, too angry ... and she never did it again because I blew up at her.

The experiences of the two individuals in the competitive workforce suggested they had no one to go to for help when difficulties arose. Both individuals appeared to work in relative isolation, although Fred was able to his compare experiences with those of his co-workers. At times, misunderstandings between employer and employee were not addressed. Without a mechanism to address the problems, or the protection of a union, grievances which are not resolved, end when the employee is fired. The three individuals who worked in the sheltered workshop training centres appeared to have a more personable relationship with their supervisors. This may be due to the fact that their supervisors were trained and understood the needs of people with intellectual disabilities or because there were more individuals to monitor the relationship between supervisor and worker.

When The Job Ended

Part of the work experience of two of the participants included losing their job. They experienced a loss of income, their routine of going to work, interaction with others, and a loss of self-esteem. Kathlene lost her job at the animal clinic after twelve years of employment. Although she worked just eight hours a week, her job was an important part of her life. Kathlene claimed that she was given no prior warning that her job was terminated. When she picked up her cheque, she was handed a note, a severance package, and sent home. Her experience appeared similar to many others who worked in the competitive labour market and had suddenly lost their job. I noted that Kathlene used the words "laid off", "fired", and "early retirement" to describe her ordeal. I wondered if this was her way of making sense of what had happened to her. Her employer told her she was retired, but she knew she was not ready to retire at age fifty-three. She wanted to continue to work with the animals that she loved to take care of. Kathlene described her experience.

> Then one day I got laid off, two months after my first cat died. The day before I got laid off, I went into work, and then I went to pick my cheque up. The guy says, 'Don't come to work tomorrow' ... That's when I went blank, couldn't speak. I had three seventy-five in my cheque and they usually give me seventy-five bucks, but I knew something was up when I saw the big cheque, plus a note. He says, 'Don't read it', but I read it anyway. I got laid off and no one, no one spoke to me about it, they just said, 'Here you are', and gone. The guy didn't want to admit that I was really fired, but to me, that's what it was. Instead of being laid off, to me it's fired. If you don't want me to come back, you might as well admit the truth. I can't remember the words, but I was laid off ... and I just wouldn't look at that as retirement, even though they said I'm retired.

Fred also lost his long-time job when he was in his mid-fifties. He had given fourteen years of his time making sure the new cars were washed and waxed properly. He described his understanding of how he came to lose his job.

> I was forced, sorta forced out. See, when I first went there, they told me I didn't have to drive a car, and all of a sudden, they told

me I had to drive a car. They changed the rules overnight. I worked there for a long time, fourteen years, this is what really, no, they just said, 'You're gone', that's it...

Fred was unable to meet the requirements of the job. His situation was similar to others who had lost their job because the requirements of their job had changed. The employer felt a driver's license had become a necessity for this job and Fred was unable to fulfil that need. As the needs of the labour market change, so must the skills of the employee. Kernan and Koegel (1984 in Castles, 1996) suggest the employment history of people with intellectual disabilities working in the competitive work force is often characterized by instability and change.

Fred and Kathlene discussed their feelings of loss with their co-workers and friends after their job ended. It was important that others listen to them, validate their feelings, and provide emotional support. Kathlene described her feelings after receiving her termination notice.

> Not very good at first. It took me months before I recovered, and feel
> OK. I was always snapping someone's head off, 'cause I got up at six
> in the morning, and some mornings at five-thirty, and I'd wake up at
> every hour... When I first got laid off, and I had the note, I went to see
> [Marvin], and [Marvin's support staff], the girl that was on ... and gave
> her the note. I still had my coat and boots on, and I said, 'OK, don't
> ask me to talk, but here's the note, that'll tell you more'. She read it,
> but she didn't like what had happened. She didn't like the way I
> was laid off.

Fred described his immediate reaction when he lost his job. He too, had his feelings validated by his co-workers.

> Oh, I felt terrible. I didn't like it. I was really upset about it, 'cause
> I didn't think they did the right thing, and all the people that were there,
> all the workers, they agreed with me. They didn't think it was right
> what they did to me. I only had eleven years to go, at that time,
> then I would have retired and I would have got a pension...

Kathlene felt she was not given a chance to share her feelings with her employer. She had no warning that she was about to lose her job. Her work was so

important that she was willing to work for less pay or reduce her hours of work to eight hours a week. Kathlene would have preferred to discuss the situation with her boss and offer him some solutions. She would have started by "talking". Instead, she was not given the opportunity.

> I would have gave him some hints. He could have lowered my pay
> to about nineteen bucks or may twenty, instead of seventy-five, or maybe
> fifty bucks, and one day a week.

Neither Kathlene or Fred had an opportunity to discuss their feelings with their employer. They were told their jobs were over. Their experiences were similar to many others who have been let go with little or no warning. Some organizations have Employee Assistance Programs to help employees cope with their loss, but this was not the experience of Fred and Kathleen. Like many people, they had to rely on their informal supports to help them with their loss.

The experiences of the five participants illustrated the various jobs they held, the number of hours they worked, their tasks and responsibilities, their interpersonal and social relationships at the workplace, and the reality of losing a job. Some worked full-time, while others worked part-time. All participants had certain jobs and tasks they were responsible for. Some jobs allowed more social interaction with peers and co-workers than other jobs. Relationships with supervisors ranged from positive to negative experiences. Those who worked in the sheltered workshop seemed to have a more positive relationship with their boss or supervisor, while the two participants who worked competitively had experiences quite similar to those experienced by non-disabled workers. The experience of losing a job for Kathlene and Fred was similar to the experience of losing a job for people without a disability. What was different about their work experience was the age they started work. For example, Fred was in an institution until he was about 30 years old, Kathlene got out when she was 37, Sarah did not start working until she was 52 years old, Richard was 40 years old and Jack

was probably close to 30 years old.

The work opportunities for people with intellectual disabilities is changing, especially now that the large public institutions have closed in British Columbia. Once children with an intellectual disability have left the regular school system, there are opportunities to attend programs at the local colleges such as job preparation and work experience, and a number of employment options to explore. The remainder of this chapter will examine the meaning of the work experience, and their perceptions of life without work.

The Meaning of the Work Experience

The five participants were a heterogeneous group of individuals with differing levels of functioning, abilities, skills, and experiences, similar to people in the non-disabled population. Their work experiences ranged from competitive work in a variety of settings to the sheltered workshop/ training centres. Although the participants who worked competitively had different work experiences than the three individuals who worked in the sheltered workshop, the meaning of work was similar with several themes common to their experience. The themes were: work as providing opportunities to make use of their special talents, abilities, and interests; work as order and structure to their day; work as providing opportunities for socialization and meeting others; work as providing service to others; as well as work as a source of income. While each of the five themes was common to the work experience of each participant, each had varying degrees of importance.

Work as An Opportunity to Use One's Special Abilities

Some of the participants recognized they had a special ability, talent, or interest in a particular area. One individual was able to perform a certain task her co-workers were unable to do, while another felt he had a special gift to communicate and get along well with others. One person felt she had a special way with animals, while

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another felt he had an ability to teach and supervise others. The participants recognized their abilities, talents, and interests and were able to make use of them on the job.

Kathlene worked for twelve years at the animal clinic by providing loving care to dogs and cats abandoned by their owners. She felt a special bond and connection to the animals because of her own special qualities.

> But if I get another job, it'll still be with animals ... and of course, I've got everything in me that they like about me. I know it's there myself, after all these years ... Apparently, the dog was wanting me, not the doctor.

Sarah's work experience helped her learn skills to become proficient and competent at her job. She acquired proficiency at specific tasks that others were unable to do. Sarah was proud of her ability to "heat seal" because not everyone at the workshop was able to use this machine.

> But I work here part-time just to give [supervisor] a hand with stuff others don't know how to do it right, like I do. I can also heat seal.

Jack described himself as one of the "top boys" at his worksite and claimed he had an ability to supervise others.

> I'm one of the top boys in the workshop. [Supervisor] won't let me go at all. [Ken] keeps one room under control, I keep one room under control ... I have a knack to it, but [Ken] doesn't have a knack to it.

Jack had a way with people and used his maturity and gentle manner to supervise others. If the room became too noisy or "out of control", Jack quietly asked the people to "sit down please". He felt his supervisor recognized his abilities in this area and provided him with opportunities to use his talents.

It also appeared that Jack had good organizational skills as indicated by the log book he kept with important names, addresses, phone numbers, and birthdates of his co-worker friends.

> She's 19 years old. I remember her date of her birthday and I've got

her address and phone number in my log book. I've got everybody's phone numbers on one sheet, even my girlfriend's phone number, all the boys and girls I know.

Fred felt he had a special ability to get along well with others and had good communication skills.

> Well, I had no problems with the people. I got along with people good. I was kind of lucky, I don't know why I was so lucky ... I got along with people very good and I think that's what helped me a lot, 'cause I was able to get along with people ... and I never fought with people or anything, and I think that's why I was able to get along with people, because I knew how to talk to them, and I knew what to say, and things like that was the main thing, being able to talk to people. Trouble was, even ordinary people have a hard time talking to people, sometimes, very hard time, and I think that's where they get into trouble. They have a lot of problems because they're not able to communicate with other people very good ... I was always independent. If I get into difficulty, I always go and ask someone about this, and about that if I want to know something. Because I can't read, so I have to use other means, which means I have to go and talk to other people, find out about this and about that, and I learned a lot through that, just by talking to people, I learned lots.

Fred claimed he was perceptive of others and had intuitive abilities that allowed him to distinguish between "a nice person" and "a bad person". This was important from Fred's point of view because it gave him a clear picture of who he was talking to and who he could trust.

> I can tell real quick about what their personality's like, they just have to say two words and I know right away. I can tell anybody, just what they're like, if they're a nice personality, or they're gonna be a nice person, or a bad person just by talking to them. Because that's just something I was born with. Because I didn't have other things, I was born with that.

Fred used his special abilities to provide information and insight about people with intellectual disabilities to professionals, family members, and others. He loved to talk with people and use his people skills. His volunteer work gave him an opportunity to use those skills in an area he enjoyed. The workplace often gives workers an

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opportunity to use their special talents and creative abilities. Many people have a natural ability or talent they can use creatively at their work.

Work as Structuring the Day

Having a job and going to work provided structure to the day as well as a sense of order, stability, and continuity. Having a routine and a schedule gave each person a chance to plan the events of the day, week, or month. Even for someone like Kathlene who only worked a few hours each week, work provided structure and routine. She knew that she was expected to work Wednesdays and Fridays from nine to one, and scheduled her activities around her work schedule accordingly.

> I was there a few times right to three o'clock. You could never get me
> out the door to go home. I thought being at work was more important,
> and being with the animals was more important than to be on the street.
> I would even leave here at half past six in the morning (to start work at nine).

On the days Kathlene worked, she got up early, took the bus to work, performed her duties and sometimes stayed longer than the time required. However, losing her job changed the structure of her day. She no longer had a reason to get out of bed. It appeared that since Kathlene's day did not have the same structure and routine as it did when she was working, she had to substitute activities to fill her day, even if it meant going to places she was not particularly fond of.

> Well, I don't get up and go to work ... I don't care, I just get up ... I get up
> whenever I wake up, that's when the cat gets me out of bed, play for a
> while, by nine I go upstairs, watch TV with a friend of mine, [Lance] ...
> and then sometimes I go to [306] ... that's where another friend that's
> at [114] ... and so I was going to two different spots, so they gradually
> had me up for coffee, or whatever, breakfast, and now, going on a year,
> I'm still going upstairs. I go to Beans, if we don't go to Beans, we go
> down to the pub down the street. I don't drink, then ... it's noisier than
> Beans, so I don't look forward when we go there ...

I noticed throughout our conversation that Kathlene talked about missing her job, but when I asked her how her day had changed since she was no longer working, she claimed that her routine was still the same and her days were never dull. I

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noticed that she tried to fill her time visiting with friends. This was an interesting comment because Kathlene had claimed that her work was very important. She had worked Wednesdays and Fridays and I wondered if her time with her friends had increased to include the two days she used to work.

> It's still the same old routines ... my days are never dull. In between
> down here and the phone, they always phone to go upstairs. Sometimes
> they phone me at quarter to nine, a few mornings they got me in bed,
> so I'm barely awake. I spend practically all day up there, 'cause there's
> worker, [Karen], she's in [304] with [Lance], and she's such a character.
> I'm there for the whole day it seems, 'till about lunch. Sometimes they
> ask me for lunch, sometimes not, and sometimes [Lance] asks me to
> supper or lunch, so I stay. Or else I come down here and grab my coat
> and I'm gone. There's a restaurant that I go to, and like it. It feels (like)
> home, so I stay for hours. They don't get rid of me ... until I go and
> come back.

Richard provided an example of how work structured his day. He worked five days a week, and began his work day at eight o'clock in the morning. He took the bus to and from work and told me about the bus route he used. He also seemed to have an excellent sense of direction.

> I go to work, then I stop work, and you know ... we work for five days. We
> start at eight o'clock, and then, we leave about, say quarter to three. I
> catch a three o'clock bus, when the bus comes it's quarter after three at
> [Nelson], you know, you come down [Moss] Street ... the [231] comes
> down [Vine] Street, at three o'clock from [Park], then turn on [Gill Street],
> then to [Simon] Street, [Fleet] Street, [Kent] to [Rigby], then there's a
> different schedule, you switch to [Ross], then he goes down [Sixth Street],
> then he turns down [Fourth], over the overpass ... There's a bus stop
> right there.

Like most people who have a job to go do, work gave the participants not only something important to do with their time, it also provided them with structure and routine to their day. Chestang (1982) suggests that without this structure, a person becomes vulnerable to a lack of purpose and order. Kathlene was not working, but her day seemed to be filled with activities with her friends. But I felt she was still

grieving the loss of her job. Throughout our interview she appeared quite angry with her boss over the way she was terminated and she claimed she missed being with the animals.

Work as an Opportunity to Socialize and Meet Others

The workplace can provide opportunities to associate, interact, and make friends with co-workers. People who work for the same company, business, or organization are connected through their work. This experience was similar for all the participants, however, there were varying degrees. For three of the participants who worked at a sheltered workshop training centre, socialization was an important part of the work experience. Work gave them an opportunity to meet with others, to develop and form friendships with others who often became part of their social network.

Sarah loved to be around people and claimed that some of her co-workers were also her friends. She attended social functions, dinners, and other outings such as bowling with her co-worker friends.

> I love it up there. I've got lots of friends. I like what I'm doing up there ...
> I'd like you to come up there sometime on a Monday ... It'd have to be
> at lunch time at eleven thirty, then you could MEET all my friends. I
> have lots of them. They all like me and I like them ... A lot of (my friends)
> work here ... I have my friends, the one's I have supper with.

Jack also made friends with some of his co-workers. He often socialized with his friends by going out to dinner or attending a movie and was even planning a trip to Hawaii with some of his friends from work.

> I take my girlfriend to shows, we saw Star Wars Saturday night.
> I took the girl out for supper, after supper we took her home ... I'm
> thinking of going to Hawaii. I don't know when, what date, but I have
> to get [Mary] and [Paula] on the weekend to talk to her about it ...

The opportunities to socialize with others was not the same for the two participants who worked competitively. When Fred worked in the labour force, he sometimes had coffee with his co-workers, but he did not socialize with them outside

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the workplace. This was similar to Kathlene's experience. Both their experiences seem similar to others who work in the competitive job market. Workers may have coffee together occasionally, but have no other contact with their colleagues or co-workers because of the nature of their job. While each work situation is different, many workplaces offer their employees some interaction with other workers, although the degree of interaction depends on the work environment. Through his volunteer work, Fred socialized occasionally with people he met, but not to the same degree as those individuals who worked at the sheltered workshop training centres. He claimed that sometimes someone would stop over for coffee, but he found most people were "too busy".

> [Paul Smith], he's a friend, a pretty good friend. He came over and
> talked and stuff like that. He's nice and we went out for coffee ...
> but he's not a real close friend. He's busy just like everyone else ...
> [I]t's hard, it's very hard to get people to come over, even for coffee ...
> I'd like to meet some friends that are gonna be our friend and not be
> ascared to walk down the street, go into a store, uh go anywhere,
> without, you know, being ashamed of going with us. Like I dress so
> nice. I always do and I always take care of myself ...

While Fred met people through his volunteer work, he was disappointed that he had not established a close personal friendship with anyone.

> We need friends that aren't staff ... we need somebody that's nothing to
> do with that, not staff because they get paid for doing their job. They're
> not people outside, you know ... This is (why) I get so upset, because
> I can't meet outsiders ... I've tried everything, but it just doesn't work.

Fred had worked with non-handicapped people and found if difficult to make close personal friends with any of them. Fred claimed that he had lots of friends who were "handicapped", but he wanted friendship with people who were not disabled. One of the goals of some of the work programs for people with intellectual disabilities, such as the supported work program, is to integrate intellectually disabled people with non-disabled people in the community. Integration with non-handicapped people

does not necessary lead to personal friendships, as was evident by the experiences of Fred and Kathlene. People can have a working relationship with their co-workers, but that experience does not necessarily lead to a personal friendship.

Based on the experiences of the participants, it appeared that the sheltered workshop training centres provided more opportunities to interact with others and promoted the development of friendships. Possibly people with intellectual disabilities felt more comfortable with their peers. For someone like Fred who worked and volunteered with non-disabled people, it was difficult to form a close personal friendship with people he worked with, yet he told me he had "tried everything" to make friends. This was interesting considering he felt he had a special gift to communicate and get alone well with others. Perhaps the people he met were not willing to become his friend because of his disability. Others with intellectual disabilities have also told me how difficult it was for them to meet and make friends with non-handicapped people.

Work as Service to Others

An important theme to emerge from the data was the need to be of service, assistance, and help to others. Helping co-workers and peers with their tasks, assisting a supervisor, advocating on behalf of people with disabilities, or caring for animals were some of the services provided by the participants. They recognized their work as providing a service to people in the larger community such as businesses and consumers.

Kathlene's work with cats and dogs at the veterinary clinic provided a service to the community as well as to the animals who would have been put down. She wanted to provide care for the animals and felt they wanted to be with her as was evident by her statement, "apparently the dog was wanting me ... It was just like raising something that was important ... just making sure they were OK.

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Jack was one of the senior workers who liked to help "all the boys and girls".
He enjoyed helping his co-workers by making sure they were physically safe at their
workplace and making sure they got on the right Handidart bus to go home.

> I work for [name of agency] for a few years, and I like going down there,
> and I'm helping all the boys and girls. When I finish at two or two-thirty,
> I get the girls and boys in the different Handidarts, ready to go home.
> I said, '[Jennifer], get your coat on'. Her coat was on my chair.
> I told [Paula] I'd go out and see if her Handidart is coming in, and when
> it comes in, I'll come and get you ... That's my job. [Jennifer] will be
> back next week, she (hurt herself). I have to watch her very carefully
> from now on and we cannot rush around no more like we did before.

Jack also liked to help others by teaching them the correct way to do their job. "I
always went into different rooms to help the boys and girls there". He demonstrated
patience and kindness while he showed a co-worker how to put a box together.

> She didn't know how to make it, so I made one for her, so I kept on
> telling her, 'No, that's wrong [Melanie], do it right, please'. So she
> was getting kind of ... all mixed up, so I showed her how to do it again.
> The big one's going along, you put the big one's going along
> this way, and the small one's going along from one end to another,
> and, from one big one, to the big side, to the big one ...

As one of the senior workers, Jack also liked to assist the supervisor by making
sure things ran in an orderly, peaceful manner. He felt that if he was not there, the
place "would fall apart".

> If I go and leave, (the place) would just fall apart. I'm one of the top
> boys in the workshop ... If I left I would have a heck of a time getting this
> room and the other room under control.

As a volunteer and advocate for people with intellectual disabilities, Fred
provided a service by speaking publicly on issues that affected them such as where
they lived, where they worked, and the type of support they needed. Fred offered his
insight and experience to professionals because he felt they needed to understand
how people with disabilities felt about things in their life. His experience reminded me
of someone who provided consulting services.

The main thing I'm interested in is getting something done for the elderly people 'cause I feel they really deserve it. I worked for many years, and I didn't get ... I didn't really have anybody to really help me except a few friends I had. They were the ones who more or less helped me. I couldn't be happy if I was sitting around, that's not me. I'm just not the person to do that. I like to get out there and do things, and help out whenever I can. That's important to me. I've always helped other people, and I've helped a lot of people through the years. I've never asked for nothin', I've just helped them out. I'm involved that way, I was brought up that way, and that's the way I am ... I've always been a person who likes to help people. I do the best I can for what I have ... I like to help people that need to be helped, you know, Ministry people and stuff like that. It's important to me that they understand how we feel about things, instead of going around and reading books. They don't know nothin' about the person, how the person feels, or what he thinks about. The way I see it is most people need to understand how we feel.

Sarah and Richard also provided a service to others through their work. For example, Richard provided a service to consumers in the community by his jobs such as packaging ketchup and mustard for "A & W", packaging "medical journals" for the medical profession, and packaging Christmas cards for "Save the Children Fund". Sarah made sure there were clean dishes for the patrons of the community centre, and also helped with packaging goods for the consumers of "A & W".

The participants recognized their work as service to others. Those who worked in the sheltered workshop knew where the finished product went, to which business, company, or corporation. Work was the source of a meaningful experience and gave the participants an opportunity to be of service to others. Although work is a socially constructed term, Hall (1989) suggests work is an activity performed for the purpose of providing goods and services of value to others, and is considered work by the individual.

Work as a Source of Income

Earning money was important to the participants, although it had varying

degrees of importance. For one individual who worked in the competitive labour force, a pay cheque was needed for survival, to pay rent, to pay bills, and to buy food. For another individual, the pay cheque supplemented her disability pension and allowed her to buy food for herself and her cat. For the three individuals who worked in the sheltered workshops, earning money was important because it allowed them to pay for recreation and leisure activities and extras such as holidays.

Fred equated earning money with independence.

> What (work) meant to me was that I was able to make money, and to
> be independent on my own. So I didn't have anybody telling me
> what to do, where I should go, and what I should do. That was
> important to me ...I've always lived on my own and I've always
> looked after my own place. I've been on my own for years ...
> I was getting about seven dollars an hour ... something around that.

When Fred lost his job and his steady income, he had to change the way he lived. He shared his experience.

> ... then I had to change my life, change my thoughts, change the
> way I was living ... Yeah, change the way I was living. I didn't have
> any money ... I was on welfare for a while. I managed. I had to live
> in places where nobody else would want to live. I had to fix them
> up myself.

The money Fred earned through his work gave him the independence toward which he strived, however, like many who work in unskilled, low paying jobs, there was no money to buy extras. Fred felt his income was inadequate.

> We can't go on a trip, we can't go on a holiday 'cause we can't save
> any money. We hardly even go to a show, we can't afford it. We're
> lucky if we go out to the mall two or three times to have lunch, and
> we may have to go to those really cheap places. You can't go and
> indulge, you can't have steak ... You can't afford nothin' like that.
> Even to buy groceries, we have to be very careful with what we
> buy ... The rent is too high these days, six, seven hundred dollars
> for a dinky little room for God's sake. I mean that's ridiculous! Half
> the people can't even afford that. They get six dollars an hour.
> Now how the heck can they afford to pay five hundred dollars and
> live and work?

Fred's situation was similar to many others whose income barely covers the basic necessities, and who have nothing left over at the end of the month. People who worked competitively and earned a minimum or low wage like Fred, would likely find themselves in a situation similar to his. They also would have little disposable income after paying rent, bills, and groceries.

Kathlene lived on her own and received a monthly disability pension. The money she earned from her part-time job was used to buy food for herself and her cat, and to put a few dollars aside.

> I used to get paid seventy-five dollars a month ... (I'd buy) food for myself, but mostly for the cat. I'd get some things for myself, put some away, mainly for the cat if she ever got sick. The cat comes first in my life, just like kids come first in their parent's lives, my cat comes first.

When Kathlene lost her part-time job, she found it difficult to make ends meet on her fixed disability pension. When she worked she always had a extra money, but after she lost her job, she was short of money by the end of the month. Her situation was similar to others on a fixed income.

> ... but I always run short on money by the end of the month. My bills, paying rent, I'm always a few bucks short ... I don't have any money to get pills for my allergies ... can't afford it. I know when I was working, I always had money, now I don't.

For the two participants who worked in the competitive labour force and lived independently, the money earned from work was used for survival and to pay for the necessities of life. Their experiences were similar to others who had a difficult time making ends meet and lived from pay cheque to pay cheque. For the three people who worked in the sheltered workshop training centres, earning money was important, but not to the same degree as it was to those who lived independently. Richard, Sarah, and Jack lived with others who provided for their basic needs. Two individuals lived in a proprietary care home with a family, while one individual lived in a group

home. Since their food, clothing, and shelter were provided for through government funding, the money they earned was used for things such as recreation and social activities.

Sarah was not sure how much money she earned at her present job because she had recently reduced her work week.

> I don't know how much (I earn). I used to get, along time ago,
> I used to have fifty dollars every month, then it went down to forty-five,
> but I don't know if it's still the same or less because I'm not working
> full-time here. I'm just working part-time, but I still get some money.

Sarah described how she used the money she earned from her job:

> It's my money. I use some of it for lunch. I use some of it up at the Mall,
> and on Thursday nights I go to the social club. I got my two friends and
> I, and my boyfriend, we come back here and go and have our social club.
> On Saturdays, we have to pay for bowling. I buy clothes. I do things
> when I'm out.

Sarah received a monthly disability pension of which a certain portion was used to pay for room and board. "And I have to pay board and room because I'm 65. They get some of the money to look after me." It was important to Sarah that she was paid for her work, but that she was paid the same wage as her co-workers. I was not sure why she would have received a different rate of pay than her co-workers, especially if they did the same type of work.

> When I was in the centre in [name of city], they weren't paying me very
> much money. All I got was fifteen dollars, and the others got twenty-five
> dollars. And that wasn't FAIR. There they make a little more than what
> they gave you up there.

Sarah stated that she had another source of income that allowed her to purchase furniture and take a holiday.

> I got lots of money from when my mom and dad died. And that went
> to a ... trust fund, and that's when I was able to buy that, my furniture,
> and a T.V., lamp, and that's when I went on a ten day cruise with
> [caregiver and family] on the Sun Viking.

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Jack said he earned two hundred and fifty dollars every two weeks, but he said he also had another source of money from his mother's will. I don't think Jack was paid this amount of money every two weeks, but it indicated that he must have felt his work contribution was worth this amount of money. He described his earnings and how he used the money.

> I get paid two hundred, two fifty every two weeks. They raised it up. I used to get fifty every two weeks, now they raised it up to two fifty now. See, all the boys and girls in the same room get fifty dollars ... It's gone up to two fifty every two weeks. Everyone always gets the same amount now ... they put it in their bank account ... I'm thinking of going to Hawaii. I've been there twice before... I've got quite a bit of money. Mother left her will to me. I took some out already. I bought different things ... I took my girlfriend to shows and out for supper ... I wanted to stop at [name of department store] to get something for my bedroom.

Richard worked five days a week at a sheltered workshop training centre. While he did not discuss the amount of money he earned, he did say that he had enough money to purchase the things he needed. Richard received a disability pension and used a portion of it to pay for room and board.

> I cash my GAIN cheque every four weeks, then I take the money out .. I take out fifty-four dollars, walking to the store, buy something, pop or juice ... I didn't buy clothes ... I don't go to the social club ... I just stay at home. I come home from work, watch T.V... On my day off, I like to go someplaces, in the summer time, the spring ... I go all over, to different places.

While earning money was important, it had varying degrees of importance. For example, the two individuals who worked competitively needed their earned income to pay for the basics of everyday living. It seemed that those individuals who tried to live independently, struggled to make ends meet. Their experiences were similar to others in the non-handicapped population whose income barely covered the basics of living. Earning money was important to the participants of the sheltered workshops, but the degree of importance was not the same as it was for Fred and Kathlene. While each of

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the participants from the sheltered workshop and Kathlene received their basic disability pension, those who worked in the sheltered work required more government funding to pay for their support at their residence.

Those individuals who worked competitively were able to earn more money than those working in a sheltered workshop, but the job expectations were greater than for those in a sheltered workshop. Receiving payment for one's work is based on a number of factors such as the type of work one does, the skills and education required to do the work, the level of responsibility required, whether or not the job is union or non-union, just to name a few. Stroman (1989) suggests over 50 percent of adults with mild mental retardation are in the competitive work force, but usually in unskilled or semi-skilled jobs. These jobs would likely pay a low wage, as was evident by the experiences of Fred and Kathlene. For people with a moderate or severe disability such as those who worked in a sheltered workshop, the money they earned was limited because of their disability.

Perceptions of Life After Work (Retirement)

Based on the experiences of the five participants, work played an important role in their lives. It structured their day, provided opportunities to be of service to others, gave them an opportunity to use their special abilities and talents, provided opportunities for socialization, and provided a source of income. Work was so valuable and important in their lives that most of the participants had difficulty envisioning their lives without work. The literature suggests that retirement for people with intellectual disabilities is usually between fifty and fifty-five years of age, however, most of the participants did not wish to retire. Two participants who stated they were "semi-retired" each had a different perception of their semi-retirement. For Sarah, semi-retirement meant working four days a week. For Fred, semi-retirement meant volunteering and working at his own pace. Some individuals thought they would like

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to try a different type of work, while others wanted their hours of work reduced. One individual said no one had discussed the future with him, so he would "keep on working" until he was told otherwise. Most of the participants wanted to keep busy, seek out new opportunities and challenges, maintain contact with their friends, but take life a little slower now that they were getting older. It was apparent they were not ready to give up work completely or retire to a rocking chair.

Although Kathlene was currently unemployed, she planned to find another job working with animals. She weighed the pros and cons of having a job.

> ... I still want to work ... back with animals .. but once I start lookin', I won't
> be around home ... Well, I would have more time to myself, but then again
> I'd be short of money ...

It seemed Kathlene lacked the resources to help her find another job or help her plan for her future. She said she did not have a social worker and felt she might need one someday. "There'd be a day when I need a social worker. Others have more help. That day will come sooner and probably no one's around."

Sarah's plans for the future were to continue working part-time, to stay busy with her present activities, and to pursue new ones.

> I would like to keep myself busy. I bowl. I bowl on Saturday afternoons,
> and I have a team. I'm the captain of the team ... I'm semi-retired.
> But I wouldn't have to come to work on Tuesdays if I didn't want to.
> Then I'd just work Wednesdays and Thursdays. It's up to me if I
> wanna do it, that's what [supervisor] said, 'You don't have to come
> in on Tuesdays if you don't want to.' I'm not giving up my job
> completely, I just feel I need time to myself. I watch T.V., and I try
> to do arithmetic, things like that. I've got a grade three's arithmetic
> book. So then I can try to get myself up to grade four. (If I didn't go
> to work, I'd be) miserable. There wouldn't be very much things to do
> ... sitting around doing nothing .

Like Sarah, Fred was also semi-retired. He stated that his routine had changed now that he no longer worked every day. He received the Old Age Pension, enjoyed life at a more leisurely pace, but wanted to continue with his advocacy work on behalf

of people with intellectual disabilities.

> I usually take it easy ... just go at my own pace. If they don't like it,
> well, that's too bad. When I go out public speaking, I really like to
> enjoy what I say and what I do. I enjoy doing it, it's something I really
> like to do ... Retirement is to relax and enjoy the things around you,
> enjoy going out walking, enjoy the people that you meet ... being
> able to go places and do things without having to rush around ...
> I can quit anytime I want, and go out and walk around, do what I
> want to do. I have no clock to punch, and nothing like that. I can
> go at my own speed and at my own time, and that's what I enjoy,
> same when I do my public speaking.

Jack felt he would be bored if he could not work, but thought he would like to work at something else.

> I'd be bored in this house ... If I don't retire, I'd like to sand cars down
> by hand ... that's what I used to do ... I did that with my cousin. He
> hasn't got a body shop there now. He sold the body shop, but I'd
> like to see if I could get a job sanding cars down again ...

Jack also seemed torn between his desire to try a different type of work, to consider retirement, and his obligations to those he worked with.

> I have thought about it. I could let [staff person] know about it. I'd have
> to have an OK from my doctor ... so I can retire or not ... I could retire
> when I'm sixty-five years old ... If I retire now, [Jennifer] won't have me
> to help her. I have to watch her carefully now, walking. If she doesn't
> want me to, I won't. I can't back out there, she's got me. I can't retire.
> I have to stay there and work, they don't want me to retire at all.

I wondered if Jack could leave work and retire if he wanted to given that his home was not funded to provide support staff during the day. During our interview, he told me he would likely have to move if he wanted to retire because there would be no staff at home during the day to provide support to him.

Richard was uncertain what his future held, although he felt that he would probably continue to work unless he was told otherwise. It seemed that Richard relied on others to plan for him.

> I don't know if I be retiring, I don't know ... I still go out to work .. Never

told me when to retire, never told me (sigh), you know. Never told me
if you want to retire when you're sixty-five ... Well, if comes sixty-five,
then stopped work, they never told me ... Well, if I keep on working,
nobody says there's no jobs, I just keep on working, you know ... I
don't know what I'd do if I retired ...Stay home.

Some of the participants recognized that with aging, they were experiencing
some physical health problems. Jack discussed a problem with his leg that had
curtailed some of his work and leisure activities.

I can't bowl no more because of my right leg. I can't go upstairs to
eat my lunch because of my leg ... [Supervisor] won't let me go outside
of the room now ...

Sarah described a problem with her shoulder: "See, I have this shoulder. I can
move this arm too, but it doesn't (work properly).

Fred discussed a problem with his balance and how it has affected his life.

... It's just that I got this problem now with a balance problem. I hate it. I
don't like it at all. I really hate that because I'm so active and it slows me
down, and it's hard when you're walking in a crowd, people cut me off
and stop, and I have to stop and get my balance. People behind me are
yelling because I stopped. It's not my fault, I can't help it. I can't do nothing
about it. People don't realize that, that sometimes people have problems.
These young people ... They don't understand.

The participant's opinions and feelings they had about their future were similar
to many older workers who anticipate retirement sometime in their future. Some of the
participants were apprehensive about leaving their responsibilities as they felt a
commitment to their work. Others wanted to work, but to take life a little slower, reduce
their hours of work, and explore new areas of interest. Each person had a different
perception of their future, but most felt they wanted to work in some capacity. Some of
the participants recognized they were already experiencing the effects of aging and
these changes could have an affect on their ability to work. It is important that older
workers, including people with intellectual disabilities, have an opportunity to discuss
and plan for their future and not have their work end abruptly.

Summary

The work experiences of the five participants demonstrated the variety of jobs they worked at and the variety of tasks and responsibilities they performed. Several themes emerged from the data that highlighted and illuminated the essence of their work experience. Work allowed the participants to be of service to others, it structured their day, provided social interaction, gave them an opportunity to use their abilities, and gave them a source of income.

Losing a job was experienced by the two of the participants who worked in the competitive job market. They had to make adjustments to their lives and to cope with the loss of income and a structured routine. The loss of a job may also have affected their self-esteem, self-worth, and their identity. Most of the participants wished to continue working in some capacity, either part-time, full-time, or to try a different type of work altogether. Some of the participants recognized they were experiencing the effects of aging. This could have an impact on their future ability to continue working. Based on the findings of this study, the meaning of work was similar to the meaning of work for people from the non-handicapped population. Chapter five presents a discussion of the findings and the implications for social workers.

Chapter Five

Discussion and Implications for Social Work

The overarching theme to emerge from the experiences of the five participants was the notion of work as providing purpose and meaning in their lives. Each individual considered work as a job away from their home and where they received payment for their work. For one individual who was semi-retired after working for many years, volunteer work became his work. While the actual work experience was somewhat different for each person, work provided an opportunity to experience an important aspect of the meaningfulness of life first hand (Chestang, 1982). The five individuals valued their work and felt their contribution was valued by their co-workers, supervisors, and others in the community who received the benefit of their work. The five themes of the meaning of work provided the structure and essence of their experience.

Work provided an opportunity for the participants to demonstrate their special abilities and talents. For example, Kathlene felt she had a special ability to work with animals. Jack felt he had good organizational and supervisory skills, as well as an ability to instruct others. Fred saw his strengths in his ability to get along well with others, an ability to share his experiences, and a willingness to teach others about the plight of people with intellectual disabilities. Richard had an ability to remember dates, an excellent grasp of direction, and an ability to get around on his own. Friedman and Havighurst (1954 in Braude 1975) in their study of different occupations found that work provided opportunities for self expression and creativity. The participants in this study were able to use their own special unique talents and abilities at their places of work.

While these individuals recognized their own special abilities, other people with

intellectual disabilities may need encouragement and support to seek out and identify areas that they too, have an interest in and talent for. Often, people may not recognize they have a special talent or an interest in something until they have been exposed to those areas. Therefore, it is important that people with intellectual disabilities of all ages are provided with a range of learning experiences. Social workers, families, and other professionals can take an active role by making sure people with intellectual disabilities have a wide variety of learning experiences. It is important for social workers to recognize that an individual's area of interest may change as they continue to grow and develop over time, and possibly their job needs will change also.

It is important the job match their interests and abilities. They want to work at jobs that hold their interest and meet their needs, therefore, the job should be personally satisfying and meaningful to the individual. Working at a job that holds little interest, is not personally satisfying, or is not challenging, can lead to boredom, frustration, and anger. It is important that social workers recognize the important role of work in the lives of intellectually disabled adults. People with intellectual disabilities need to receive appropriate education, ongoing vocational and skills training, and support to enable them to work at a job that meets their interests, needs, and special abilities.

Since people with intellectual disabilities are a heterogeneous population with differing abilities, the work opportunities need to be as varied and diverse as the population. Social workers need to learn about their client's areas of interest, their strengths and abilities, and the available resources and options to meet those needs and interests. One way to accomplish this is by getting to know each individual personally. As one participant so clearly stated, "... it's important to me that they understand how we feel about things .... instead of going around and reading books ... get out and meet us, see what we're interested in..." Social workers need to have

manageable caseloads so they can personally get to know their clients.

It is imperative that social workers take the time to get to know their clients, to understand their needs, likes and dislikes. This requires listening to the individual, meeting their family members, friends, and staff. In this way, the social workers learn about their clients, their preferences, likes and dislikes, abilities, needs, strengths, and so on. It is important the individual is involved in planning and decisions regarding situations regarding the type of work they would like to do, how often they would like to work, and where their abilities and interests lie. Social workers can assist by working cooperatively with individuals, family members, and other professionals, including those in the business and service sectors, in providing support services and in seeking out appropriate employment opportunities for their clients.

Social workers can work with employers and agencies to develop plans to vary the responsibilities and tasks of the job or to transfer workers to other jobs as they gain experience and confidence in their abilities. Social workers must be aware of their client's strengths and abilities, but also recognize the limitations caused by their disability. Social workers need a good understanding of the job market and the business community. Fred took pride in washing, waxing, and polishing cars, but lost his job after 14 years because the employer needed someone with a driver's license and he was unable to meet these new requirements. This is a reality of the competitive labour market. It is important that people with intellectual disabilities have opportunities to continue to develop new skills to meet the changing needs of the job market.

Work allowed the participants an opportunity to be of service to others. Helping others seemed to give them a sense of personal satisfaction, a sense of identity, possibly recognition and status among their peers and their supervisors. The participants provided service to others because it was something they wanted to do

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and willingly took it upon themselves. Glade's (1995) research with service providers suggests that clients need to be encouraged to become involved in providing service to others in order to remove the stigma of always 'being served'. Chestang (1982) suggests that acknowledgement of others links the individual and their work to a social context and the sense of social contribution gives the sense of being purposeful and needed, both vital to a person's self esteem. Helping others also gave the participants a sense of pride in their accomplishments and abilities to do for others .

Glade (1995) suggests that work is more than a job, it is their social life and social support system. For three of the participants, the workshop setting provided opportunities for social interaction which often led to personal relationships that continued outside the workplace. For individuals whose only contact is with co-workers and staff, socialization at their worksite may be an important part of their lives.

Human relations theorists recognized that personal relationships have an "impact on workers perceptions of their work, including their feelings of motivation, satisfaction, and alienation" (Auster, 1996:211). For the two participants in the competitive setting, social interaction at work with peers mainly consisted of brief contact over coffee and sometimes lunch. Neither participant formed personal relationships with their co-workers that continued outside the workplace. Their experiences were similar to many who work in the competitive work force where there is a separation of work and personal life. Both individuals may have felt a sense of alienation from others at the worksite, especially Fred because he mentioned on numerous occasions that he could not seem to make friends with non-handicapped people.

Some relationships within the workplace were not positive. Kathlene claimed her experiences with a supervisor and an employer were sometimes exploitive and abusive, as indicated in the previous chapter. Fred's experience with his superiors

were also not always positive. He felt he was treated unfairly on a number of occasions and often discussed his concerns with his fellow employees who verified that he was treated differently than they were. Both Fred and Kathlene worked in an environment that did not seem to have a formal mechanism to address abusive treatment, unfair practices, or harassment. Although both individuals were able to advocate for themselves, they were unable to speak up in these particular situations. Individuals like Kathlene and Fred can easily fall through the cracks of the system because they are often seen as capable and not in need of assistance. There needs to be a way of identifying these individuals so they can be educated about their rights and provided with assistance should they require it. It is important that people with intellectual disabilities are protected against harassment, abuse, and exploitation by labour laws that should apply to all workers.

Butterworth and Straugh (1994 in Castles, 1996) suggest that sheltered workshops offer safety, stability, and opportunities for social interaction with peers. In contrast, competitive employment is often unpredictable and workers rarely interact with non-handicapped workers. The findings of Butterworth and Straugh were evident in the experiences of the five participants. Since the goal of services for community living is to move away from the sheltered workshop models to supported employment in the competitive labour force, social workers must be aware of the possibility of both positive and negative experiences. Social workers can take an active role by facilitating communication between employers, supervisors, and employees. They can help educate both parties as to the needs and expectations of worker and employer. Social workers can liaise between workers with intellectual disabilities and others in the workplace by providing information, mediation, and advocacy. While this is an important role for social workers, it cannot be carried out properly given the high number of cases managed by social workers. It is difficult to

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proactively seek out individuals who may fall through the cracks of the social service system. More dollars need to be provided to hire more social workers and to reduce their case loads. With a manageable number of clients, social workers can do what they were trained to do - to provide social work service by helping their clients interface with their home, their work, and their community.

Another theme that emerged from the data was the importance of earning an income. While earning money was an important benefit of work, it had varying degrees of importance. For example, Fred stated that he worked because he needed to support himself financially and earning money gave him a sense of independence. He was able to live on his own "without others telling him what to do". For others, money was not the primary motivator of work, although receiving a paycheque was important because it was used to pay for extras, activities, and holidays. Rothman (1987) examined a number of studies which found that money was not the primary motivator of work. He found that over 70 percent of workers admitted they would continue to work regardless of the money. While money was an incentive for the participants of this study, it was not the most important factor for consideration.

It is my understanding that effective September 30, 1996 new changes to the Employment Standards Act require people to be paid the minimum wage if their work activity is considered employment. At one time, certain people were excluded from protection under the Employment Standards Act. Under the new regulations, an individual will be exempt from receiving the minimum wage only if the intention of the person's involvement in a work activity is therapeutic, rehabilitative, or supportive rather than employment (Ministry of Labour, 1996). This is an important consideration for people with intellectual disabilities whose intent it is to work, although I do have some reservations with the new changes. While it is a good idea that people with intellectual disabilities who perform work activities are paid at least the minimum

wage, my concern would be if the service providers are unable to meet the requirements of the Act. Agencies may close their facilities because they cannot afford the costs, which would place many people out of work and without a place to go.

Rioux and Crawford (1990) found that people with intellectual disabilities who worked competitively were paid low wages, while those who worked in the sheltered workshops were paid close to pennies for their work. The findings of this study support the research of Rioux and Crawford. Kathlene and Fred who worked competitively earned only enough money to cover the bare necessities. The three participants who worked in the sheltered workshop were paid a small amount of money which allowed them to pay for social outings, recreation and leisure activities. DeBrine and Howell (1989) stated that the money earned allows a degree of independence, choice, and pleasure, however, some of the individuals who worked in the sheltered workshop setting were not sure how much they earned. Social workers need to advocate on behalf of people with intellectual disabilities to ensure they are paid a fair wage for their work, and know how much they are earning.

Employment opportunities for people with intellectual disabilities range from highly sheltered work settings, supported employment which integrates the individual in community work settings, to competitive employment. The participants of this study worked either in a sheltered workshop setting or in competitive employment. I was unable to locate individuals who met the criteria of this study and who worked in a supported employment environment. This study could have been strengthened by their participation. Ross and Cameto (1988) suggest that supported and competitive models of employment offer the greatest potential for handicapped individuals to attain status as working, contributing members of society. The findings of this study indicated that those individuals who worked in the sheltered workshops felt they too, worked and contributed to society. While the sheltered workshop setting may not be the ideal work

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environment, it provided opportunities to work, job training, skill building, socialization, and a sense of community. The tone of voice of the participants indicated they enjoyed where they worked and took pride in their work. We need to look at whose values we are promoting. This is why it is so important that social workers take the time to actively listen to their clients and get to know them well. It is their perception of the experience that is important.

Work as structuring one's day was also a theme that emerged from the data. Work provided order, stability, and continuity to their lives. People need work, a routine, and a schedule. Chestang (1982) suggests that people who no longer work are "threatened by the absence of a way to use one's time, rendering the individual vulnerable to a lack of purpose and order... (p.69). Many people with intellectual disabilities want and need to work, but the opportunities for employment are not always available. While the options of employment services have expanded over the years, there are often long wait lists for people with intellectual disabilities to obtain work in one of the programs. It is important that people on the wait lists for work are matched with an appropriate job that meets the individual's needs and abilities, and not placed in a job because they are the next person in line.

An important consideration in terms of employment for people with intellectual disabilities is the area of fiscal restraint. Sylvestre and Gottlieb (1992) suggest it is inevitable that economic considerations will come into play in determining policy and programming in human services. If economic considerations are given more weight than considerations to the full integration of persons with disabilities, then promises of supported employment will not be realized. Economic restraint may not affect employment programs already in place, but it will more than likely affect any future expansion of employment options for people with intellectual disabilities. It depends on the position of the government and their commitment to the integration of people

with intellectual disabilities as full participating citizens. Given the current situation in British Columbia where the government is in the midst of widespread program and contract restructuring in an effort to reduce costs, the likelihood of expanding employment options and reducing wait lists for people with intellectual disabilities seems doubtful.

Losing a job was part of the work experience for two participants who had worked competitively. They both lost their jobs when they were in their mid-fifties and both felt they were not ready to give up work completely and retire. Fred became involved in volunteer work, while Kathlene had not yet found work, but wished to do so. Like many people who lose their jobs when they are older, it is often difficult to find other work. This may be a time when the services of a social worker can be useful in providing information and referrals to agencies that could help individuals find work. Social workers and others who are connected to people with intellectual disabilities such as financial aid workers can work together to identify potential clients who may require service and support. The findings of this study indicated that older people with intellectual disabilities want to continue to work and had difficulty envisioning their lives without work.

Planning For The Future

Each participant had a different vision of their future, but only one individual suggested he would give up work completely when he became 65 years old. If he was 65 years old and had a choice between going to work and staying home, he would prefer to "stay home". Another individual, in her mid-fifties, had no plans to retire and would like to find another job, while one individual in her mid-60s, planned to work three or four days a week, continue with her present activities, and pursue new avenues of learning. Another participant, who had not worked competitively for fourteen years, volunteered with public speaking and advocacy on behalf of others

with intellectual disabilities. While his daily pace was slower and more relaxed than his working days, his volunteer work remained an important part of his life. A fifth participant stated that should he retire, he would like to work at a different type of job. Like many others nearing retirement age, he was torn between his commitment to his current job and his desire to pursue other endeavours. Several of the participants recognized they would have less money if they did not work, but they would have more time for themselves.

The literature suggests that retirement age for people with intellectual disabilities can be in the 50 - 55 year range (Sutton, Factor, et al. 1993), rather than the typical retirement age of 65. The participant's ages ranged from 53 to 69, yet none of them considered themselves retired. The two participants who were 65 and 69 years of age, considered themselves as "semi-retired. While some of the participants had thoughts on retirement, none seemed willing to give up their work completely, especially at the age suggested by the research.

Several studies have underscored the relation to work and a reluctance to retire (Fillenbaum, 1971 & Streib & Schneider, 1971 in MacDonald & Wanner, 1990). Ashman et al. (1995) found strong positive attitudes toward employment from working people with intellectual disabilities and a concern about retirement. For the participants, work brought them a sense of purpose and meaning to their lives, an opportunity to help others, a sense of belonging to the community, monetary rewards, and intangible rewards such as status, identity, and self-esteem. To give up work would not be easy for people whose lives revolved around their work. The participants indicated they did not want to disengage from their activities and social interaction, but wanted to remain active, busy, and involved in work. Chestang (1982) suggests that people who go to work each day become frustrated and anxious if the opportunity to work is removed for an extended period of time. Chestang (1982) also suggests that

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older workers who contribute as volunteers or work part-time help to keep a sense of identity and self-esteem. A job takes on a deeper meaning. Without this, the absence of a way to use one's time, makes a person vulnerable to lack of purpose.

A question that came from the findings of this study was should people with intellectual disabilities be forced to retire or should they be given the choice to continue working? Each person should have an opportunity to discuss and plan for their future. People with intellectual disabilities need to be part of the planning process with their social worker and with others who are involved in their lives. The participant's experiences and viewpoints about retirement and their future suggest a desire to continue to work, to seek out new opportunities and challenges, to remain active, to continue to do something useful, but to take life at a slower pace.

Cotton (1994) suggests that for people who are intellectually disabled, retirement may be a time to relax, to explore new interests and friendships, and to have leisure time to pursue activities of the person's choosing. However, for those who work in a sheltered workshop (not paid competitive wages) or those who work in a competitive job at low wages, these choices may not be possible because of financial restraints. Should governments make provision for these new choices and experiences for the retired intellectually disabled population? If so, what about the retired poor person who may also have aspirations to relax, explore new areas of interest, and pursue activities, but with no realistic hope for this because of inadequate finances?

Planning for the future with older intellectually disabled people should consist of prolonged discussion and planning with the individual and with other members of their network. Options, choices, and consequences need to be discussed and each situation examined individually. Social workers can assist their clients by understanding their experiences, the importance of work in their lives, and by listening

to and acknowledging their needs, desires, and concerns for the future. Mandatory retirement policies for older working people with intellectual disabilities may not be a good idea. Individuals with intellectual disabilities often missed out on the traditional stages of life such as marriage, having children, and grandchildren. Work provided an important role in establishing their self-identity, therefore, to take work away could have serious consequences to their health and well-being. Older adults with intellectual disabilities need to have a place in society and opportunities to enhance their competencies and self-image gained through work. Forced retirement or forced attendance at programs for seniors with intellectual disabilities does little to protect and enhance their competencies and self-image (Sutton, Sterns, & Schwartz Park, 1993). Aging people with intellectual disabilities do not need overprotective models of support which lead to increased dependence (Walker & Walker, 1996).

Glade (1995) suggests the industry has been taken up by rules, regulations, and funding issues and failed programmatically to prepare intellectually disabled adults for their retirement years. One participant in this study stated that nobody had discussed retirement with him even though he was 60 years old, nor had it been mentioned that he may have to leave work in the future. Social workers need more time to discuss future plans and options long before the transition to retirement takes place. Another participant stated that even if he wanted to retire and spend time at home, he would "not be allowed to". He was told by his support staff that the way the current system is set up, there is no funding to allow him to stay in his own home if he retired. The group home is not staffed during the day, so he would not have the necessary support required should he choose to stay home. From an economic standpoint, it is less costly to send retired individuals to a retirement day program for seniors than to hire support staff to maintain an individual in his/her own home. It is important that aging people with intellectual disabilities plan for their future, are

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provided with information, real choices, and creative options that meet their individual needs.

The individuals in this study have maintained varying degrees of independence. Their ability to maintain their independence and dignity for as long as possible is a concern as they age. Two participants lived independently and were responsible for their own decisions. Four individuals were able to use public transportation, while one individual was unable to because of difficulties with mobility. One individual who spent time in an institution feared a return to institutional living should he become incapacitated. Walker and Walker (1996) suggest that the processes and principles within the health and social services operate to construct dependency on the part of older people with intellectual disabilities. They suggest that "the idea of a service continuum based on increased dependency and the inevitability of decline in the abilities of the older person has dominated policy thinking and service provision" (p.5). While the participants mentioned a decline in their physical ability due to aging, their abilities had not declined to the point where they were unable to work. Rather, they had made adjustments to their activities of daily living to compensate for their physical difficulties. They wished to remain independent for as long as possible.

If a people choose to retire, their day needs to be replaced with something that gives them the same emotional and social benefits they received through their work. Aging people with intellectual disabilities need to be part of the planning, and to work with others to select the best option for them. Social workers and other professionals need to acknowledge the everyday life experiences of their clients, get to know them well, and listen to what they have to say. As stated by one participant, "you can't learn nothin' from a book, you gotta get out and meet us ... and don't be afraid of us...". Social workers need to help their clients talk about their experiences and their

expectations for the future.

Opportunities for meaningful work and meaningful retirement for people with intellectual disabilities requires flexibility and creativity on the part of government funding bodies, service providers, professionals, and the community and responsibility and accountability for spending wisely. Social workers and service providers need to be creative in their approach to meeting the needs of aging adults with intellectual disabilities. As suggested by DeBono (1970), this requires "breaking out of the concept prisons of old ideas. This leads to changes in attitude and approach, to looking in a different way at things which have always been looked at in the same way" (p.11) The individual needs to be the central focus in our approach to planning for the old age of our intellectually disabled senior citizens.

Summary

The purpose of this study was to explore the work experiences of five older adults with intellectual disabilities and to obtain their views of life without work. Through in-depth interviews with five participants, I hoped to discover the personal meanings of their work experience. An understanding of their work experiences within the context of their lives will be beneficial in providing important insights into the needs of this population as they move into the next transitional phase of their life. It is now understood that development occurs throughout the life course and that old age brings to persons with intellectual disabilities new opportunities for development (Janicki & Seltzer, 1991).

A literature review revealed the importance of work in the lives of most people, including people with intellectual disabilities. The personal meaning of work in one's life is shaped by many factors such as earlier life experiences, social learning, role modelling, personality and temperament, environmental, and societal factors. People with intellectual disabilities have been excluded from participation in the mainstream

of society, however, the literature suggests this is beginning to change because of the efforts of the disability rights movement, families, self-advocates, and advocacy groups. While there may be a place on the work continuum for sheltered workshops, the focus today is on supported employment programs which enable individuals to work at competitive jobs in the community.

The literature has shown that people with intellectual disabilities are a heterogeneous population and vary widely in their levels of functioning and abilities. They cannot be broadly categorized, classified, and placed in a one-size-fits-all type of program. With appropriate support and systematic training, people with intellectual disabilities are capable of performing complex vocational tasks (Bellamy, Sowers, & Bourbeau, 1983 in Beirne-Smith, Patten, & Ittenbach, 1994). As people with intellectual disabilities age and reach retirement age, resources will need to be allocated to meet the demands and individual needs of this diverse population. The literature is missing the in-depth personal experiences of older adults who are intellectually disabled. Only two studies were located that asked people with intellectual disabilities about work and retirement, but neither study provided an in-depth rich account of their experiences. An understanding of the work experiences of older adults with intellectual disabilities will be beneficial when planning for their future needs. It is clear that the service delivery system needs to expand the continuum by providing for the needs of aging adults with intellectual disabilities.

To fill the void in the literature by including the experiences of aging adults with intellectual disabilities, the research method of phenomenology was chosen. This method attempts to describe the phenomenon to a certain degree of depth and richness and allows the participants to speak directly of their experience. The goal of the phenomenological method is to discover the meaning of the human experience. This method allowed the participants to describe their experiences, recount both their

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positive and negative aspects of their work experiences, and to give their opinions and thoughts about the future. Understanding their experiences within the context of their lives is necessary so that social workers and other professionals can provide appropriate and timely services. Two questions guided this study: What are the experiences of working older adults with intellectual disabilities? and What would their day be like should they no longer work? Since the term 'work' is a socially constructed term, its meaning was determined by each participant.

Three men and two women were interviewed using a semi-structured interview format. Four participants were interviewed in their home, while a fifth participant was interviewed at her place of work. Four of the participants were interviewed a second time, but only two had their second interviews tape recorded. The transcribed interviews were analyzed in order to gain a holistic perceptive of their experience and to determine any common themes to emerge from the phenomenon under study. While Young (1996) suggests that the analysis and interpretation of data is probably one of the most difficult areas in which to involve people with intellectual disabilities, two participants confirmed the themes as representative of their experience.

The work experiences of the five participants were presented as well as the meaning of the experience and their vision of their future. Five specific themes emerged from the data that attempted to capture the structure and essence of the phenomenon. The themes highlighted the importance of work in their lives and the impact it would have should work be removed from their lives. Social workers, service providers, support staff, and the general public need to be aware of the importance of work in the lives people with intellectual disabilities.

Many adults with intellectual disabilities want to work, but opportunities to work are not always readily available due to long wait lists for jobs and lack of funding to create and explore other options. The participants indicated they wished to continue

to work even though they were past the usual age of retirement as suggested in the literature for people with intellectual disabilities. Services need to expand to address the needs of people with intellectual disabilities as they go through all the stages of the life, including old age.

Future Research

This study examined the work experiences of five participants in the competitive and sheltered workshop training settings. With supported employment programs now part of employment options for people with intellectual disabilities, future research could include the work experiences of people who work in a supported work environment, their perceptions of the job and how they feel about their work. A second study could examine the relationship between non-disabled workers and intellectually disabled workers in a supported work environment. In addition, a further study could examine the emotional well-being of individuals who want to work, but are denied the opportunity to work or have to wait a long time because there are few jobs, long wait lists for current jobs, or lack of funding. While having a meaningful job may not alleviate some of the emotional and behavioral problems experienced by some people with intellectual disabilities, it may provide a meaningful experience that increases self-esteem and satisfaction with life. A final study could use a phenomenological methodology to explore the experiences of retired people with intellectual disabilities now that the first cohort has reached retirement age.

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Appendices

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Notification Requesting Participation

An Exploration of the Meaning of Retirement for Aging Adults with an Intellectual Disability

Dear Participant:

My name is Jean Nakamura. I am presently in the Masters of Social Work program at the University of British Columbia. I would like to invite you to participate in an exploratory research study seeking to understand your perceptions of retirement and what it might mean to you. I am looking for people over the age of 50 who are working, or have worked in the past, and who can share their experiences and thoughts with me.

To date, there is little information about aging adults with a disability. Most of the information available does not include the experiences of people with a disability. The information from this study will attempt to fill a gap in the literature and assist social workers, agencies, support staff, families, and individuals to better understand the experiences of older individuals with a disability, in order to provide better service.

The research will be conducted through 1-2 in-person interviews which will take about one to two hours each. Interviews will be tape recorded to ensure for accuracy and will be erased upon completion of the study. All information you choose to provide will be held in confidence by the researcher, and all individual identifying information will be omitted in the final document.

Your participation in this study is completely voluntary, you may choose to withdraw at any time, and/or not answer questions. Your decision, or information shared with the researcher will in no way affect services you may be receiving now or in the future from Burnaby Association for the Mentally Handicapped (BAMH), or any other agency or association connected with BAMH.

After you have received this letter, the Executive Director of BAMH, Jack Styan, will contact you either in person or by phone to explain and clarify the nature of the study. If you are willing to be a voluntary participant in this study, Jack Styan will ask

Sample Questions

Demographics

Name _____

Age _____

1.   Can you tell me about yourself?
      Probe: Where did you grow up?

2.   Can you tell me about your work experiences?
      Probe: Where do you work? What do you do there?

3.   Can you tell me how your day would be different if you were no longer working?

4.   How would your life change?