

Understanding Leisure in the Lives of
Older Women With Intellectual Disabilities

By Erika Bockstael

A Thesis

Submitted to the Faculty of Graduate Studies
in Partial Fulfillment of the Requirements
for the degree of
Master of Science

Faculty of Physical Education and Recreation Studies
University of Manitoba
Winnipeg, Manitoba

© April, 2000



National Library
of Canada

Acquisitions and
Bibliographic Services

395 Wellington Street
Ottawa ON K1A 0N4
Canada

Bibliothèque nationale
du Canada

Acquisitions et
services bibliographiques

395, rue Wellington
Ottawa ON K1A 0N4
Canada

Your file Votre référence

Our file Notre référence

The author has granted a non-exclusive licence allowing the National Library of Canada to reproduce, loan, distribute or sell copies of this thesis in microform, paper or electronic formats.

The author retains ownership of the copyright in this thesis. Neither the thesis nor substantial extracts from it may be printed or otherwise reproduced without the author's permission.

L'auteur a accordé une licence non exclusive permettant à la Bibliothèque nationale du Canada de reproduire, prêter, distribuer ou vendre des copies de cette thèse sous la forme de microfiche/film, de reproduction sur papier ou sur format électronique.

L'auteur conserve la propriété du droit d'auteur qui protège cette thèse. Ni la thèse ni des extraits substantiels de celle-ci ne doivent être imprimés ou autrement reproduits sans son autorisation.

0-612-51688-1

THE UNIVERSITY OF MANITOBA
FACULTY OF GRADUATE STUDIES

COPYRIGHT PERMISSION PAGE

**Understanding Leisure in the Lives of Older Women
With Intellectual Disabilities**

BY

Erika Bockstael

**A Thesis/Practicum submitted to the Faculty of Graduate Studies of The University
of Manitoba in partial fulfillment of the requirements of the degree
of
Master of Science**

ERIKA BOCKSTAEL © 2000

Permission has been granted to the Library of The University of Manitoba to lend or sell copies of this thesis/practicum, to the National Library of Canada to microfilm this thesis/practicum and to lend or sell copies of the film, and to Dissertations Abstracts International to publish an abstract of this thesis/practicum.

The author reserves other publication rights, and neither this thesis/practicum nor extensive extracts from it may be printed or otherwise reproduced without the author's written permission.

ABSTRACT

The purpose of this qualitative study was to develop an understanding of leisure in the lives of older women with intellectual disabilities. The main criterion for the participants was that they had to be female, aged 50 and older, and that they have an intellectual disability. The participants were selected using purposive sampling. In total, nine women participated in this study, ranging in age from 55 to 84, with a mean age of 65. The factors that affected the leisure of the participants were friends, transportation, financial situation, family, service providers, safety, health, and disability. All of these factors interacted with one another. The life satisfaction of the participants of this study was affected by their access to leisure. It was their leisure that connected them with friends and allowed them to meet new people, and it was their leisure that got them out into the community. These two aspects of the participants lives, friends and being out, were the two things that they placed the greatest importance on. When they engaged in community-based leisure, they met new people and were happy. Most of the women would like to have an increase of community-based leisure in their daily lives.

ACKNOWLEDGEMENTS

Firstly, to the women who participated in this project, you are an inspiration. Thank you for welcoming me into your homes and sharing your stories.

To my thesis committee, Dr. Michael Mahon, Dr. Jennifer Mactavish, and Dr. Zana Lutfiyya. Thank you for your unwavering support, commitment, encouragement, and friendship. Thank you for the time and energy that you've invested in me and in this research.

Mike, you have truly been a mentor to me. I hope that you will see parts of yourself and your teaching reflected in any success that I achieve. Thank you for always encouraging me to follow my heart, and for putting up with my timeline! And thank you for always believing in me, and for encouraging me to do the same. Maureen, thank you for always having an open door, an open mind, and for always having the right words. I hope you know how much I appreciate you.

Thank you to my family for all your support, without which I certainly would not be where I am today. Erin, you're almost there, and you're the smartest kid in the whole University! To my grandparents, aunts, uncles, and cousins, thanks for the encouragement, the kind words, and the motivational emails!

To Janis and everyone at the Health, Leisure, and Human Performance Research Institute, I would like to thank you for your support and friendship over the last few years. Sandy, Amanda, and Cheryl, it was fun sharing the experience with you, and of course sharing the office!

To Katie, Brennan, and Seann:

You have brains in your head

You have feet in your shoes

You can steer yourself

Any direction you choose!

Oh! The places you'll go!

(Dr. Seuss)

TABLE OF CONTENTS

Abstract	<i>i</i>
Acknowledgements	<i>ii</i>
Chapter One	
Introduction	
Operational Definitions	6
Delimitations/Limitations	10
Assumptions	11
Chapter Two	
Review of Literature	
Introduction	12
Leisure and Older Adults with Intellectual Disabilities	23
Leisure and Older Women without Disabilities	28
Leisure and Older Women with Intellectual Disabilities	31
Conceptual Framework	33
Chapter Three	
Methodology	
Research Paradigm	37
Participants	38
Method	47
Pilot Study	50
Analysis	52
Trustworthiness and Credibility	52
Chapter Four	
Findings	
Nature of Leisure	57

Factors that affect the leisure of the participants	70
Life Satisfaction	89
Summary	97
 Chapter Five	
Discussion	
Nature of Leisure	100
Factors that affect the leisure of the participants	109
Life Satisfaction	126
Summary	129
Recommendations	131
 References	135
 Appendix A	146
Interview Guide - Pilot	147
Appendix B	149
Final Interview Guide	150
Appendix C	152
Interview Guide - Third Interview	153
Appendix D	154
Consent Form	155

CHAPTER ONE

INTRODUCTION

Women with disabilities, be they intellectual or physical disabilities, have numerous challenges to overcome. In seemingly every facet of life, women with disabilities face greater adversity as compared to men and women without disabilities, and men with disabilities. "Women with disabilities appear to be more likely both to internalize society's rejection of them as disabled people and to accept the label of disabled more than do men with disabilities" (Bullock & Mahon, 1997, p.157). They are employed less, earn less when employed, are married less often, and are more often divorced (Sands & Kozleski, 1994; Fine & Asch, 1981; Fulton & Sabornie, 1994; Bedini & Henderson, 1994; Deegan, 1981, Wilkins & Cott, 1993). Women with disabilities are often not included in research, and receive fewer services by disability agencies, as compared to men with disabilities (Fulton & Sabornie, 1994; Henderson, Bedini, & Hecht, 1994; Deegan, 1981).

In a book on recreation and disability, Bullock and Mahon (1997) reviewed the literature on women and disability, and concluded, "women with disabilities may be less able to engage in satisfying leisure experiences. They may not see leisure as a human right, but as something that one deserves if one works hard and cares for a family" (p.158). Women with disabilities, who are often unemployed and without families, may therefore not see themselves as having earned the right to leisure. There is a "paucity of hobbies, marriages, volunteer work, disposable income, romantic partners, children, bed partners, and grandchildren" (Garwick, 1992, p.3) for people with intellectual disabilities.

Researchers have established a connection between successful aging and leisure involvement (Riddick & Daniel, 1984; Sneegas, 1986). There is also evidence of a relationship between life satisfaction of older adults and leisure involvement (Siegenthaler, 1996). There is however little understanding of how leisure participation actually influences health and quality of life. (Coleman, 1993). It is not evident if the difficulties faced by women with disabilities continues into the 'older adult' stage of life, although Carter & Foret (1991) found that older adults with intellectual disabilities spend considerably more time than their peers without disabilities either alone, with nothing to occupy them, or involved in routine, idle tasks.

Traditionally, research about people with disabilities seemed to assume that gender, race, ethnicity, sexual orientation, and social class were irrelevant (Asch & Fine, 1988). Researchers typically have taken a gender blind approach when exploring issues in the lives of people with disabilities, (Fisher & Galler, 1988; Traustadottir, 1990). Hanna & Rogovsky (1991) were surprised to find that the majority of the literature on people with physical disabilities was either based upon studies of men, or it did not differentiate between men and women. In the early 1980's, researchers began to consider the relationship of gender and disability, although research on the topic of women and disability tended to focus on women with physical disabilities (Olney & Kuper, 1998). The literature indicates that the needs of women with physical disabilities versus men with physical disabilities are vastly different (Olney & Kuper). Danek (1992) asserted that men and women with disabilities have unequivocal differences, stating that "to deny that women and men with disabilities frequently have issues and needs that are dissimilar is to deny the very real differences that exist between men and women in general" (p.7).

Women with disabilities have been ignored by both the disability movement and also by the women's movement, and by those examining these groups (Asch & Fine, 1988; Blackwell-Stratton, Breslin, Mayerson & Bailey, 1988). The feminist movement is particularly criticized for ignoring the issues facing women with intellectual disabilities (Boyle, Rioux, Ticoll, & Feske, 1988). Women with disabilities are often perceived as being "helpless, childlike, dependent, needy, victimized, and passive" (Traustadottir, 1990, p.5). This description fits with the traditional stereotype of women, which is a possible explanation for why the feminist movement chose to distance themselves from this population. The feminist movement strives to project an image of powerful, competent and appealing 'female icons' (Asch & Fine). However, Danek (1992) describes the situation of people with disabilities as paralleling the situation of women without disabilities in that they are "devalued, patronized, and marginalized" (p.9).

There are clear differences in opportunities and life experiences of people with and people without disabilities. For example, Sands and Kozleski (1994) reported that only 5% of people with intellectual disabilities were or had been married, whereas 42% of people without disabilities were currently married, and 11% were divorced or widowed. They further reported that the mean income for people with intellectual disabilities was \$10,500, whereas the mean income of persons without disabilities was \$17,500. Fine & Asch (1981) maintain that women are more 'handicapped' by disability than are men. They conducted an in-depth examination of the manner in which women with disabilities are at a distinct disadvantage in terms of economic, social and psychological constraints, in relation to men with disabilities, and women without disabilities.

People with intellectual disabilities are a minority group who do not have a strong voice. Women are also considered a minority group, so we can deduce from this that women with disabilities do in fact belong in two minority groups. Deegan (1981) defines a multiple minority group as being "any group of people who are singled out from the others in the society in which they live for differential and unequal treatment because they are defined as members of more than one minority group, and who therefore regard themselves as objects of this combination of collective discrimination" (p.276). In accordance with this definition, women with disabilities are members of a multiple minority group. This means that these women face discrimination and oppression by society in general, and they may contend with these prejudices within the two groups to which they belong. The oppression of women is magnified when a disability is present.

As women with disabilities age, they become members of yet another minority group. These women now face the possibility of discrimination based on sex, disability, and age (Boylan, 1991). Older women make up 72% of the aged poor, and approximately 75% of patients in nursing homes are women (American Association of Retired Persons, as cited in Danek, 1992). There is a lack of research about women and disability, and there is a need for research focused on older women with disabilities. (Rehabilitation International, 1980). Danek suggested that researchers should explore various issues in the lives of women with disabilities, because to "ignore the special circumstances and concerns of women with disabilities is to deny them validation as both women and women with disabilities" (p.7).

The literature on recreation and leisure that focuses on women with disabilities suggests that there is a need for more research in this area, and that women with

disabilities present a challenge to service providers. It has been suggested that the lack of role models for women with disabilities leads to their alienation and feelings of inadequacy (Fulton & Sabornie, 1994). Henderson et al. (1994) suggest that through leisure, we can have a positive impact on the lives of women with disabilities. Leisure can empower women to take control of their lives, and it can help reduce the isolation of these women by providing opportunities to share with others. Also, leisure can have an impact on women's self-identity, and assist a woman in identifying her role in society as there is "potential of leisure for social and personal change through identity development or personal freedom and empowerment" (Henderson, Bialeschki, Shaw, & Freysinger, 1989, p.8). In order to enhance the leisure in the lives of women with disabilities, we need to understand how disability and gender interact.

It is clear that women with disabilities fare worse than men with disabilities. Much of the literature also indicates that people who have intellectual disabilities fare worse than those with physical disabilities. Thompson (1985) explains that:

"Probably the lowest on the general hierarchy of disability, set up by the able-bodied society and mirrored in the disabled community, are those individuals labeled mentally ill or mentally retarded. Both groups are still routinely referred to as incompetents, vegetables, basket cases, and, thanks to the media, dangerous threats to society. Frequently considered to be "better off" in institutions, we are often drugged up, locked away, shocked out of our minds, and totally rejected by both the able-bodied and otherwise-disabled communities"(p.83).

There is a need for qualitative research with people with intellectual disabilities in order to understand their views on quality of life issues (Neumayer & Bleasdale, 1996), and to understand the role of leisure in their lives. There is also a great need for research focusing on the experiences of women, particularly as they age. This has led to the topic of this thesis, which was to develop an understanding of leisure in the lives of older women with intellectual disabilities.

Operational Definitions

Intellectual Disability

For the purpose of my study, I will equate the American Association on Mental Retardation definition of mental retardation with the term intellectual disability. The definition of mental retardation as presented by the AAMR is as follows:

"Mental retardation refers to substantial limitations in present functioning. It is characterized by significantly subaverage intellectual functioning, existing concurrently with related limitations in two or more of the following applicable adaptive skill areas: communication, self-care, home living, social skills, community use, self-direction, health and safety, functional academics, leisure and work. Mental retardation manifests before age 18" (as cited in Bullock & Mahon, 1997, p.176).

The term "intellectual disability" is preferable, as it is more current and inclusive.

Many changes in the diagnosis of disability have occurred over the lifespans of the participants. I am not aware of the exact diagnosis of the participants, or if they would be considered to have a disability by today's standards. However, whether or not the

women actually fit the definition presented, they have carried the label of disability with them, and it has influenced their lives.

Older Adults

The participants in this study were all over the age of fifty. The age range that was chosen is based on the fact that people with varying levels of disability have different lengths of life expectancy. For example, as the severity of an intellectual disability increases, the life expectancy of a person decreases. This is because “differential mortality, i.e. the tendency for frailer members of the population to die earlier, operates very strongly in this population” (Moss & Patel, 1997, p. 67). Furthermore, people with intellectual disabilities, particularly people with Down Syndrome, tend to experience dementia at an earlier age as compared to the population without disabilities (Moss & Patel). Scholars in the field of aging and disability are not in agreement as to which age cutoff is appropriate to place someone in the ‘elderly’ category (Heller, 1997). Heller states that for people with moderate to profound intellectual disabilities who are receiving state services (in the United States), the life expectancy range is from 4 to 55 years. For people with intellectual disabilities who are not receiving state services and who have a mild level of disability, the life expectancy is likely to be in the 70s, which is comparable to the life expectancy of the population without disabilities. This information led me to select 50 as the cutoff age, in order to include people with varying levels of disability.

Leisure

Glausier, Whorton, & Knight (1995) suggest that "more than any other single factor, society in the United States may regard leisure and recreation as indicative of quality of life" (p.46). In order to explore the role of leisure in the lives of older women with intellectual disabilities, we must first have a definition of leisure. Leisure scholars are not in agreement on a single definition of leisure. There are three main schools of thought that scholars have worked within in order to define leisure.

The psychological perspective focuses on the state of mind pertaining to the leisure experience (Horna, 1994, Neulinger, 1981; 1987, Kelly & Godbey, 1992). The crux of this type of definition of leisure is that an experience is subjectively defined by the individual as leisure, according to the cognitions that they sustain. This definition leads to some criticism and some questions, such as when exactly this state of mind occurs, and how much of this 'correct attitude' is required in order for an activity to be defined as leisure (Kelly & Godbey, 1992). Focusing solely on the mental state of the individual ignores the social effects of leisure. It seems evident that cognitions play a role in our experiences of leisure, but it seems that this definition of leisure is much too narrow.

The definitions put forth by those working within the sociological perspective all have one or more of the components of leisure as time, experience, and/or activity. Within this theoretical framework, the emphasis is placed on the outside social influences having an effect on an individual. There is some theorizing about the cognitive processes around leisure, and perceived freedom is also an integral part of these definitions. However, the emphasis is on the social effects and the extrinsic influences in determining the levels of freedom, rather than internal determinants and cognitions. Van Moorst

(1982) questions the idealism behind the notion that leisure is a feeling of freedom over one's time. Similarly, Goodale and Godbey (1985) argue that this category of definitions does not explain what free time is, but rather tells us what free time is not, such as time not spent at work or other obligations.

The third perspective is the social psychological perspective. All social psychologists start from the same place: an individual as a participant in a social environment. Social psychology is "based on the assumption that cognitions are critical determinants of a person's relationship to fellow human beings" (Iso-Ahola, 1980, p.16). There are a variety of definitions that fall under this heading, but the majority of them have one or more of these components: objective and subjective groupings, notions of discretionary time and freedom of choice, activity, experience, and individual perceptions (Horna 1994). According to Horna, most theorists have moved away from utilizing unidimensional definitions of leisure. The multidimensional definitions incorporate the concepts of freedom, a state of mind, specific activities, or residual time.

The definitions put forth by theorists in the social psychological perspective are comprehensive, as they seem to consider all possible aspects of leisure. For instance, Horna's (1984) definition considers leisure in terms of action, time, and experience, and also considers the motivations underlying the experience and the importance of perceived freedom. This definition also takes into account the effects of culture, socio-economic factors, and gender. It seems logical that leisure should be defined in relation to cognitions and to social influences, and therefore it seems that this perspective is a reasonable one to uphold.

The definition of leisure used for this project is the definition put forth by Horna (1984), which falls under the social psychological perspective:

“Leisure is an enjoyable experience in which people choose to participate with relative freedom in terms of discretionary time and particular activities, within the context and limitations of culture, socio-economic factors, and gender. Leisure experience can be objective and/or subjective, long-lasting or brief, planned or spontaneous, an end in itself or therapeutic/compensatory, sociable, or solitary” (p.47).

This is a very broad definition of leisure, which is suitable for this project. It encompasses many of the different components of the definitions of leisure suggested by the different schools of thought. As this is an exploratory study, we do not want to limit our findings by using a very narrow definition. This definition provided guidelines as to what concept was being explored, although the focus of the research was the participants subjective description of their experiences, and the participants were never presented with this definition of leisure.

Delimitations

This study was limited to women with intellectual disabilities, who were over the age of 50, and who communicated verbally, in English. The sample was a purposive one, and all the participants lived in the same city. There was a small number of participants, and I was limited in the amount of time I had to spend with the participants. I was also limited by my ability to communicate with some participants and really get at their perspectives.

Assumptions

As explained by Pedlar, Haworth, Hutchison, Taylor, & Dunn (1999), “Researchers always have a point of view that in various ways influences the research they do” (p.4), and I will briefly list some of my assumptions that may have influenced this research project. I believe in the inherent right of all people to equal opportunities and to quality of life. I believe that people with disabilities are the best source of information to learn about their own experiences, which is why I chose to interview the women with intellectual disabilities themselves. The review of literature, my research experience, and my personal experiences with individuals with disabilities led me to expect that the women in my study would have had oppression in their lives and unequal opportunities. All of these factors, combined with my recreation background, also led me to expect that leisure would have a positive role in the lives of the participants. I believe that leisure is an integral component necessary for achieving happiness and quality of life.

CHAPTER TWO

REVIEW OF LITERATURE

Introduction

Women with intellectual disabilities face many issues - low expectations, stereotypical views, deep prejudice and fear, isolation and low self-esteem (Olney & Kuper, 1998). These women experience double discrimination due to both their gender and their disability, which affects all areas of their lives (Rehabilitation International, 1980; Blackwell-Stratton et al., 1988). Leisure may be an area which has the potential to affect positive changes in the lives of women with intellectual disabilities; "It may also be that through leisure, in which the essence of the experience is one of choice, women can learn to value themselves as individuals and challenge some of the societal restrictions and stereotypes surrounding women" (Henderson et al., 1989, p.7).

Women with disabilities do not have a clear position in society. Fine and Asch (1981) describe this experience as 'rolelessness', meaning that these women do not fit into the economic/job world, and they do not fit the role of the nurturing, motherly, sexual women. They postulate that the condition of rolelessness is likely to create difficulties in terms of career and personal options, personal development, and will limit free choices. Others assert that the rolelessness of these women lead them to live as 'social nomads', having no real place in society (Blackwell-Stratton et al., 1988).

Harper, Mahon, Foreman, & Godbey (1999) reported that people with disabilities are restricted from participation in local parks and recreation services due to limited access, unemployment, limited income, and poorer health, as compared to their peers without disabilities. They also reported that people with disabilities see less benefit in

parks and recreation services, which may be related to these constraints. Traustadottir (1992) reviewed the literature of the previous decade on women with disabilities, and found that these women “fare less well than both men with disabilities and non-disabled women in education and employment; in receiving economic security and social support; and in their access to sexuality and intimacy” (p.7). All of these factors are related to the ability to experience leisure. The remainder of this section examines these issues in relation to women with intellectual disabilities.

Employment

In order to access a diversity of leisure opportunities, a person needs to have some discretionary income. As many people with intellectual disabilities live on very limited allowances, their leisure is restricted to what they can afford. This means that their leisure often consists of things that are close to their place of residence and that is inexpensive (Hutchison, 1994). There has been some suggestion that participation in supported employment is related to improved leisure opportunities, such as number of activities and use of leisure time, improved self-esteem, and greater income (Sinnott-Oswald, Gliner, & Spencer, 1991). Women with disabilities fare significantly worse than men with disabilities in this domain, regardless of the type or level of disability (Traustadottir, 1992).

Olney & Kuper (1998) reviewed the literature on women with intellectual disabilities and supported employment and found evidence of gender discrimination. Traustadottir (1990) stated that men with disabilities are twice as likely to be employed, and earn 44% more than women with disabilities. Boyle et al. (1988) indicated that the

unemployment rate for women with disabilities was 74%, and that 49% of Canadian women with disabilities receive less than 10,000 dollars a year from all sources of income. Wilkins and Cott (1993) reported that women with disabilities tend to have lower incomes than men with disabilities. As a result of these differences, women with disabilities are considerably poorer than men with disabilities, due to both the fact that they are less often employed, and that they receive substantially lower wages (Traustadottir, 1992). This information is largely based on research done on people with physical disabilities, as minimal research on employment has looked at people with intellectual disabilities, and very few of these studies have examined gender differences (Traustadottir, 1992). Boyle et al. indicated that there are no accurate statistics for the employment rate of women with intellectual disabilities, and estimate that between 80 to 90 percent of all people with intellectual disabilities are unemployed. Chronic poverty is the status quo for people with intellectual disabilities.

Current research has begun to examine the situation of women with intellectual disabilities. Fulton and Sabornie (1994) reviewed 15 different studies about employment and people with intellectual disabilities, and found gender differences in all of the studies, with the women faring worse than their male counterparts. Levy, Botuck, Levy, Kramer, Murphy, & Rimmerman (1994) examined the placement outcomes of 33 men and women with intellectual disabilities who were enrolled in a supported employment program. They found that women were employed for less time than men, were more likely to be fired, and were more likely to leave the supported employment program after a job separation. Twice as many women tended to be placed in jobs that had the lowest wages and the least comprehensive benefits. Olney & Kuper (1998) also found that many

women with intellectual disabilities are placed in jobs that are 'gendered', meaning lower wages, less hours, poor benefits and job security, and low prestige.

Botuck, Levy, & Rimmerman (1996) found some dramatic differences in employment rates for men and women with intellectual disabilities. Within the first six months of an employment program, 46% of the men had obtained employment, versus a mere 1% of the women. The authors suggested, as a possible explanation, that perhaps parents are overly protective of their daughters with intellectual disabilities, due to concerns surrounding vulnerability, lack of good judgment, and the risk of pregnancy. These concerns may lead to parents having more ambivalent attitudes about employment for their daughters. In support of this explanation, Grbich & Sykes (1990) found that parents of young adults with severe intellectual disabilities were more likely to encourage community based work or living placements for their sons, versus more segregated settings for their daughters. The authors compared access to programs and teaching time for male and female students, and found that males received considerably more small group or individualized teaching time, and had more access to integration and work experience programs, as well as had more support staff during work experience programs. The results of this study led the authors to hypothesize that disparate access to home skills, school curricula and work placement causes double disadvantage for young women with intellectual disabilities. In support of this conclusion on employment, Hasazi, Johnson, Hasazi, Gordon, & Hull (1989) suggested that the same factors that negatively effect women without disabilities ability to gain employment, such as discrimination, lower aspirations, lack of self-confidence, and role-conflicts, may also effect women with intellectual disabilities in a similar manner. The authors also cited

evidence that indicates that women with intellectual disabilities may have less opportunities for community self-sufficiency as compared to men with intellectual disabilities, due to differential treatment by parents.

Women with disabilities who were able to obtain full time employment earned fifty-seven cents for every dollar earned by men with disabilities. Women with disabilities are typically poor; 61.7 percent have an income of less than four thousand dollars per year. They are also much less likely than men with disabilities to have a pension or a health plan (Russo & Jansen, 1988). The employment situation for women with disabilities seems to change as they age. Russo & Jansen stated that more than one in three women between the ages of 25 and 44 was either employed or looking for employment, as compared to less than one in six women between the ages of 45 and 64, suggesting that as women with disabilities age they are less active in the labor force.

As in other areas of their lives, women with disabilities have few role models to look up to in the work force. "The lack of role models for disabled females is especially serious because stereotypes of dependency, passivity, and incompetence are applied to both women and disabled persons" (Russo & Jansen, 1988, p.238). If nothing is done to change these stereotypes, these women will continue to be channeled into 'dependency roles' and occupations that are traditionally female, of low status and which provide poor wages and benefits. The literature clearly shows that women with disabilities fare far worse than women without disabilities and men with disabilities in the economic realm. This in turn impacts on their ability to experience leisure, as they face many economic constraints (Hutchison, 1994). It certainly leads us to believe that the discretionary income of women with disabilities that is available for leisure will be less than that of

their non-disabled peer groups. The unequal access to work may also lead to less opportunities to form friendships, as most of the friendships of people with intellectual disabilities are made at work (Neumayer & Bleasdale, 1996).

Friendship, Marriage, and Sexuality

The leisure experiences of women are affected by their social support systems (Bedini & Henderson, 1994). In a study by Hoover, Wheeler & Reetz (1992), they found that only 20% of their participants with intellectual disabilities (male and female) were satisfied with the amount of friends that they had. Women with disabilities in particular may have difficulties forming friendships, as "Many disabled girls are sheltered, kept from activities and opportunities where they might manage mastery of skills for acquiring of friends (Asch & Fine, 1988, p.24). Bedini & Henderson found that lack of friendships was a barrier to participation for some women. The women felt that not having someone to partake in activities was what prevented them from participating. Women who were interviewed in this study put a very high importance on friendship, and were happiest with relationships that were reciprocal and in which they were interdependent. The data indicated that instead of asking for assistance, many women would simply not participate in leisure. Friendships between women, where at least one of the women has a disability, are influenced by the manner in which society integrates or fails to integrate people with disabilities into its activities. In developing friendships, women with disabilities often have to 'go more than halfway', due to the fact that they have less opportunities to make friends (Fisher & Galler, 1988).

Although sexual identity, sexuality, and filling the roles of lover, wife or mother are considered vital to a women's self-concept, these areas seem to be significantly compromised or completely ignored by professionals in dealing with women with intellectual disabilities (Olney & Kuper, 1998). Women with disabilities are not presumed to fit many of the traditional roles of women, such as "mother, wife, homemaker, nurturer, or lover" (Traustadottir, 1992, p.8). They are less likely to be married and have a higher rate of divorce than women without disabilities (Kutner, 1987). In 1980, 33 American states had laws that made it illegal for people with intellectual disabilities to be married, although by 1960 they were not broadly enforced (Scheerenberger, 1987). Rousso (1988) found that many parents viewed their daughters with disabilities as being "unable to fill the typical female role of marriage and childbearing" (p.162). Surprisingly, Asch & Fine (1988) found that women with intellectual disabilities are more likely to marry than women with physical disabilities, and more likely to marry than men with intellectual disabilities. It was suggested that this may stem from the perception that these women are passive, loyal, and dependent, and therefore would fill the role of a subservient wife.

Women with intellectual disabilities receive mixed messages about their sexuality. At times they are treated as being 'gender free', whereas at other times they have been perceived as "sexually uncontrollable, sexual victims, and asexual" (Olney & Kuper, 1998, p. 5). They were subject to forced sterilization for many years (Blackwell-Stratton et al., 1988; Scheerenberger, 1987). It was not until 1986 that the Supreme Court of Canada ruled that no person, including guardians, doctors, and judges, could order the sterilization of a person with an intellectual disability (Boyle et al., 1988).

Women with disabilities are often counseled by professionals against having children. When women with disabilities do become pregnant, they often have difficulties receiving appropriate medical care and accessing the information that they need. When they have children, they are often considered unfit to be mothers due to their disability, and many lose custody of their children (Traustadottir, 1992). The literature surrounding motherhood and disability has almost solely been based on mothers with physical disability. There is minimal information about mothers with intellectual disabilities, and as such very little is known about their experiences (Traustadottir).

Women with both intellectual and physical disabilities have a greatly increased risk of being victims of sexual abuse or rape (Asch & Fine, 1988; Boyle et al., 1988; O'Toole, 1990). In fact, studies show that women with disabilities have the highest risk of being victims of sexual abuse as compared to any other group of women, yet professionals in social services continue to disregard this problem (Traustadottir, 1992; Boyle et al.).

Self-Concept, Independence, and Self-Determination

Women with disabilities perceive themselves and are perceived by others more negatively than men with disabilities (Asch & Fine, 1988). They have virtually no role models to imitate or look up to, leading women with disabilities to feel not only different but also inferior (Fine & Asch, 1981). "Societal tendencies to perceive some women with disabilities as "sexless" and "roleless" may be internalized by these women, resulting in lowered self-esteem, anger, and withdrawal" (Danek, 1992, p. 11). The self-esteem of these women may also be negatively influenced due to their socialization by their

families and in their schools which are “unclear about what norms to suggest or what hopes to give her for her future” (Asch & Fine, 1988, p.24).

Women with intellectual disabilities may experience a ‘role clash’, in that women are typically supposed to be giving care, not receiving it (Grbich & Sykes, 1990). According to Wehmeyer (1993), women with intellectual disabilities hold the self-concept that they are helpless and that they have a lack of control. Henderson et al. (1994) conducted in-depth interviews with 30 women, aged 25-57. One of the themes to come out of this study was that a woman’s self-identity corresponds to her personal circumstances, and it is influenced by social norms and stigmas. The authors concluded, among other things, that women tended to define themselves more by their disability than by their gender. On the other hand, Weinberg-Asher (1976) concluded that gender had a greater influence on self-perception than did disability, in a study that only included people with physical disabilities. There is apparent disagreement in the disability literature, as some of the literature indicates that disability has a greater effect on a person’s identity than does gender, while in other instances authors suggest that disability may not be a central component of a women’s self-concept (Fowler, O’Rourke, Wadsworth, & Harper, 1992). Fine & Asch (1981) further surmise that men with disabilities have a better self-image than women without disabilities. They explain this finding by stating that male roles are more valued in society than female roles, so if a male with a disability identifies with these male roles, he will have a more positive self-image than a woman whose self-image is not impacted on by disability.

Because the voices of women with intellectual disabilities have typically gone unheard, little is known about how they feel about their bodies. McCarthy (1998)

interviewed 17 women with intellectual disabilities and found that they had a negative body image. Henderson et al. (1994) identified the potential of leisure in enhancing women's self-identity. The authors suggest that leisure and self-identity are intertwined and that both are affected by women's traditional and changing roles in society. Unfortunately, women with disabilities do not appear to have the same opportunities to experience leisure, as compared to men with disabilities. In a study by Grbich & Sykes (1990), they found that in the home environment, males with intellectual disabilities had more access to all independent skill areas as compared to women with intellectual disabilities. Women with intellectual disabilities face a risk of being controlled by professionals, society, and family members that may force them to lead severely restricted lives (Olney & Kuper, 1998). In order to make free choices, which is often considered a critical component of the leisure experience, a person must have some independence. Sands and Kozleski (1994) surveyed 86 people with disabilities, primarily intellectual disabilities. The participants indicated that independence was important, but felt that they had a low to moderate amount of independence. They were not satisfied with the amount of recreation and leisure that they participated in, or with their involvement in the community.

Many people with intellectual disabilities have limited opportunities to make decisions and to exert personal control, and therefore these concepts are unfamiliar to many people (Olney & Kuper, 1998). For example, in some parts of the United States, people with intellectual disabilities are prohibited from voting. This is based on the belief that these individuals are unable to make rational decisions (Blackwell-Stratton et al., 1988). In fact, all but 10 States have some limitations on the rights to voting for people

with intellectual disabilities. Janicki (1990) stated that the key difference between people with and without disabilities is that people without disabilities can delimit and decide the events of their day, as opposed to a person who is disabled and dependent. One of the key components of a quality leisure life is making personal choices (Hoover, Wheeler & Reetz, 1992). All of the factors discussed in this section limit the ability of women with disabilities to make choices (Fine & Asch, 1981), and therefore limits their ability to experience leisure.

Summary

As we have seen through the literature, women with disabilities face many inequities. Parents are more protective of their daughters with disabilities, young women receive less attention in school, and they have less access to work experience programs as compared to their male counterparts. These factors may lead to less community self-sufficiency. Women with disabilities have less access to employment opportunities, make a lower wage when they are employed, work in more tedious jobs and receive fewer benefits. As these women age, their situation only seems to worsen. They have fewer opportunities to develop friendships, face restrictions in the areas of marriage and sexuality, and are certainly not encouraged to consider having a family of their own. These women have virtually no role models, are unsure of their roles in society, and many hold poor self-concepts. Lack of funds, lack of friends, low self-esteem, low levels of independence, and a lack of choices in many areas of their lives are common denominators in the lives of many women with disabilities.

Leisure and recreation are major contributors to quality of life for people with intellectual disabilities (Hoover, Wheeler, & Reetz, 1992; Neumayer & Bleasdale, 1996). Much of the social lives of people with intellectual disabilities are centered around leisure (Landesman 1986). Whorton, Morgan, and Nisbet (1994) compared the leisure interests of adults with and without intellectual disabilities, and found that they had essentially the same leisure interests and desires. Unfortunately, as we have learned through the literature review, women with disabilities suffer “economically, socially and psychologically more than their disabled male and nondisabled female counterparts” (Fine & Asch, 1981, p. 241), and all of these factors inhibit their leisure experience.

This section can be summarized with the following quotation from the book entitled Women and Disability:

“In an era marked by highly visible opposition to the infringement of human rights, disabled women are systematically denied the most human of rights - the right to love, the right to marriage, the right to motherhood, the right to personal fulfillment. While disabled men are more likely to marry, to enjoy the blessings of family life, in some societies it is considered shocking that a disabled women should marry, and families are usually the most vehement in discouraging any aspirations disabled women may have to fulfill a woman’s destiny” (Boylan, 1991, p.52).

Leisure and Older Adults with Intellectual Disabilities

Some of the factors associated with successful aging are: being socially included, being independent, and having control over your own environment (Seltzer, 1993).

Seltzer further stated that “given society’s propensity for overprotecting and restricting the autonomy of persons with mental retardation, one wonders how and under what conditions successful aging occurs for them” (p.161). The implications associated with being disabled and aging are only beginning to be acknowledged and understood (Wilkins & Cott, 1993). This is because people with intellectual disabilities are living longer, bringing their life expectancy more in line with that of the population without disabilities (Hogg, 1997; Browder & Cooper, 1994; Brown, 1989; Salvatori, Tremblay, Sandys, & Marcaccio, 1998).

Sison and Cotten (1989) stated that the literature has clearly neglected the needs of older adults with intellectual disabilities. The authors felt that the majority of studies conducted have focused on the elderly who are living in institutions. This becomes problematic, as policy decisions are based on the information gleaned from studies which are not representative of the experiences of those people with intellectual disabilities not living in institutions. A review of the literature conducted by the authors reveals a necessity to further examine the characteristics and the fundamental needs of this segment of the population. At this point, little is known about how leisure affects life satisfaction for older adults with intellectual disabilities (Hawkins, 1993). In this section, we will look at literature that examines the role of leisure in the lives of older adults with intellectual disabilities.

Glausier, Whorton, & Knight, (1995) conducted a study that examined the recreation and leisure preferences of seniors (50+) with intellectual disabilities, and the frequencies of participation. They administered a survey in the format of an interview with 32 yes/no questions about whether or not they participated in specific activities, and

asked about the frequency of participation. The sample consisted of 46 participants fifty years or older, who had the ability to express preferences, and who lived in a variety of settings. Participants were 29 males and 17 females. Results indicated that senior citizens with and without intellectual disabilities seem to have similar recreation and leisure interests, but senior citizens with intellectual disabilities have a greater amount of time with fewer activities to fill this time, and more of their free time is spent at their residence. Possible reasons provided for this lack of participation were: attitude of the general public, lack of opportunities, lack of friendships, lack of skills for participation, lack of time-management skills, as well as difficulties traveling to events. The authors further questioned the participants' ability and opportunities to make decisions.

Ashman & Suttie (1996) used an Australian national database to identify all known persons with an intellectual disability aged 55 years and older. The study accessed 446 participants, living in five different settings. The researchers were interested in the participants' levels of involvement in recreation and social programs. They also explored how their results compared with the results of studies done in other countries. Data were gathered through the use of an interview questionnaire developed by the authors. The data showed that the participants rarely accessed community facilities, and had infrequent contact with family and friends. The authors stated that "lack of access to community-based experiences seems to reflect the participants' lifetime of dependence and separation from the broader society", and that "loss or irregularity of family connections was an expressed concern of a sizable proportion of those interviewed in our survey, and this has been reported by other researchers" (p.127). The authors concluded that the conditions

under which many of the participants in the study lived did not allow them to increase their access to services and programs.

Tedrick (1991), concerned about policy and service issues, suggested that existing services for older adults need to adjust to accommodate the needs of older adults with intellectual disabilities. "Children and adults with mental retardation or learning disabilities are served at a much lower rate than are senior citizens by public recreation providers...one could estimate that far, far fewer aged adults with mental retardation are engaged in programs offered through public recreation entities" (p.149). Due to this, there is a need for services to involve older adults with intellectual disabilities in recreation and leisure programs. For people without disabilities, it has been shown that satisfaction and involvement in leisure predicts life satisfaction. Older adults with intellectual disabilities and allied staff need to take advantage of the possibilities for leisure to increase satisfaction in later life (Tedrick).

A number of authors have examined the contribution that leisure makes to perceived life satisfaction for older adults without disabilities. Hawkins (1993) listed 14 studies that investigated the influence of leisure on perceived life satisfaction in this population. Only recently have researchers begun to look at this connection for older adults with intellectual disabilities. Hawkins investigated leisure and life satisfaction in older adults with intellectual disabilities. A life satisfaction measure was used to assess satisfaction with: friends and free-time, services, the community, concerns over retirement and work, death and dying, growing older, finances, and health. A leisure measure was used to assess: self-reported activity participation, preferences for increased involvement, interests in new activity participation, and constraints on leisure. The

sample included 128 adults, 64 with Down Syndrome, and 64 with intellectual disabilities, with an equal number of males and females. The results indicated significant negative effects for age on perceived life satisfaction and leisure activity involvement, meaning that as participants aged, their leisure involvement decreased and so did their life satisfaction.

Edgerton and Gaston (1991) edited a book that consisted of the life stories of nine older persons with intellectual disabilities. The authors concluded that although the older persons had some things in common, it was also quite clear that they were individual men and women with highly varied lives. They found that many of these individuals were searching for well-being, even if it meant sacrificing some autonomy. They found that all of the individuals were for the most part satisfied with their lives. It was also noted that these individuals contributed to the well-being of others, an element of their lives which is not often discussed in literature on people with intellectual disabilities. Achieving independence was not the foremost goal of the individuals written about in this book, in contrast: "What matters most is the quality of life they can enjoy" (p. 272).

Due to the increasing numbers of older adults with disabilities, service providers are increasingly concerned with providing services for this population. Browder and Cooper (1994) provide a description of some of the obstacles that people with intellectual disabilities face in achieving leisure satisfaction during their retirement years. The authors list six categories of challenges that they feel interfere with inclusion in leisure for older adults with intellectual disabilities. These are: changes in health status, changes in social networks, limited community access, underdeveloped leisure skills, limited opportunities for choice making, and lack of support services to participate in existing

opportunities. The authors take the stance that inclusion of people with intellectual disabilities in all stages of the lifespan is necessary, as this can lead to increased opportunities and to personal empowerment. It is unclear whether women and men are equally affected by these challenges to inclusion in leisure, as there were no distinctions made for gender. In summary, it is apparent that older adults with intellectual disabilities are not satisfied with their participation in leisure, and experience barriers to participation. Possible barriers to participation include: negative attitudes by others, lack of friends and family support, lack of necessary skills, lack of ability or opportunity to make decisions, difficulty accessing facilities, lack of available services, and health problems.

Leisure and Older Women without Disabilities

Little attention has been paid to older women's leisure (Mason, 1989). The literature that does exist on women and leisure indicates that women do not experience leisure in the same manner as men, and they may not have as many opportunities for leisure. "Lack of leisure is a problem for many women" (Henderson et al., 1989, p.9). Society's oppression of women may restrict their freedom of choice for leisure experiences (Henderson & Rannells, 1988). Much of the feminist literature on women without disabilities and leisure indicates that the definitions of leisure as 'time' or 'activity' are inappropriate for the realities of women's lives. Rather, a definition of leisure as experience is more fitting (Wearing & Wearing, 1988). Many feminists believe that males dominate in every institution in society, and due to this women are oppressed and, therefore, so is their leisure. In this view, there is limited opportunity for women to

experience freely chosen leisure. Wearing & Wearing further suggest that men have access to leisure activities, time, and resources which women do not, that leisure serves the interests of men, and that it is serviced by the labor of women. They also suggest that women's belief that they do not have a right to leisure is one of their greatest obstacles to their arrangement of time for leisure.

Riddick and Daniel (1984) administered a life satisfaction index and a leisure satisfaction index to 1101 women over the age of 65, who were either retired or a homemaker. They found that participation in leisure had the greatest impact on life satisfaction of older women. The authors also looked at variables that had an indirect effect on life satisfaction, and found that income had the greatest indirect effect on life satisfaction, due to its influence on participation in leisure. One of the ramifications of the results suggested by the authors is that "Given that leisure activity participation had paramount influence on the life satisfaction of older women...decision-makers should - if well-being is a concern - at least maintain if not increase recreation or activity resources targeted for this group" (p.146).

Mason (1988) interviewed 18 long married couples aged 50-70. She found that the majority of the women's leisure was home based, and consisted of reading, watching TV, gardening, knitting, and sewing. Many of the older women mentioned that they were afraid of going out alone at night, which had an impact on their leisure. The women in this study also maintained primary responsibility for housework, which impacted on their time for leisure. For most of the couples, the husband controlled the finances.

Leisure is usually not distinct from other components of older women's lives. It tends to blend into daily routines and is integrated with work (Wilhite et al., 1994,

Henderson & Rannells, 1988). Hong and Duff (1994) found that for widows living in retirement communities, the greatest predictors of life satisfaction were frequency of participation in group activities and frequency of seeing friends. Thompson (1992) asserted that for most elderly people in Britain, the greatest threat to their physical and social well-being is loss of life purpose and boredom. One of the ways in which these older adults find meaning in their later years is through leisure. Interestingly, the widows in this study were far more likely to participate in organized social activities as compared to the married couples. Most of the participants maintained the same leisure interests as they had over their lifespan, while a very small group developed some new leisure skills. The most discontented group in the study were those who had very few leisure pursuits.

Wilhite et al. (1994) as well as Henderson & Rannells (1988) found that the older women in their studies had difficulty defining and describing leisure. Henderson and Rannells suggested that because women do not experience the freedom of choice that is central to most definitions of leisure, the traditional definitions of leisure do not fit their experiences. Henderson et al. (1989) published a feminist perspective on women's leisure, in which they suggested that the current definitions of leisure have been based mainly on the role of leisure in the lives of men, and it is simply assumed that women experience leisure in the same way as men. Therefore, "the degree to which the voices of older women, particularly those living alone, have influenced the availability, design, and delivery of recreation and leisure services is unclear" (Wilhite, Sheldon, & Jekubovich-Fenton, 1994). Wilhite et al. found that older widows primarily faced constraints to leisure in the domains of money, companionship, safety, and health. Siegenthaler (1996) includes lack of transportation and perceived opportunities as possible constraints.

In order to develop appropriate definitions of leisure and access to desirable leisure, we must understand the meanings that women give to this concept, and the role it plays in their lives. The “intended recipients of leisure services should be viewed as the experts on their own lives and their opinions should be consistently solicited through formal and informal interaction, feedback, and evaluation” (Wilhite et al., 1994, p. 76). This would allow for the provision of appropriate leisure services based on the role and meaning of leisure for older women. In this way, leisure may enhance the life satisfaction of older women and increase the possibility of successful aging (Wilhite et al.).

Leisure and Older Women with Intellectual Disabilities

Research into leisure patterns for older adults with intellectual disabilities is in its “embryonic stage” (Boyd & Tedrick, 1992, p.20). Corresponding to the general population, the life expectancies for women with intellectual disabilities are greater than those of men (Boyd & Tedrick). The role of leisure specifically in the lives of older women with intellectual disabilities has remained largely unexplored. These factors lend further support to the need to examine issues in the lives of these women.

Wilkins & Cott (1993) stated that “Those elderly individuals most likely to be institutionalized are: 85 years of age or older; female; without a spouse; no longer physically or mentally competent to continue living independently in the community; and either have no families or their families are unable to care for them” (p.370). Although Wilkins & Cott are referring to women without disabilities, these characteristics describe much of what we have seen through our literature review about women with disabilities.

Women with disabilities have even fewer economic and social resources that would enable them to continue living in the community.

Garwick (1992) indicated that there is a lack of supports for women with intellectual disabilities as they age. According to Garwick, although things may be improving for these women on the job front, it is “candlelight dinners, proms, marriages, and baby showers which are most lacking for people with major disabilities” (p. 6).

Garwick goes on to state that this situation may be a fortunate escape from “entangling myths” for these women, however it also delimits a life experience that is dramatically different from that of other women. “Most of the personal and social resources seen by mainstream society to be the epitome of the happy, stable life in later, post-retirement years are rare or absent for many people with major disabilities” (Garwick, p.3). Garwick recommends that older women with intellectual disabilities be offered a range of recreational opportunities, among others, by their employers or the agency that supports them. Garwick also states that these women should receive a pension that would provide funds for recreation and leisure in their later years.

Older women have begun to speak out for economic, social, and personal recognition, however older women with intellectual disabilities continue to exist without out a distinctive voice (Garwick, 1992). There is a definite gap in the literature in the area of older women with intellectual disabilities. It is apparent that leisure participation has a great impact on life satisfaction for older women without disabilities, as discussed in previous sections. Whether or not this is the same for older women with intellectual disabilities is unknown. In order to appropriately plan and provide services for these

women, it is important that we understand factors that have an impact on their quality of life.

Conceptual Framework

All good studies need to be grounded in an appropriate conceptual framework. This research will be grounded in symbolic interactionism. Symbolic interactionism has to do with the meaning that people attach to things: "Objects, people, situations, and events do not possess their own meaning; rather, meaning is conferred on them" (Bogdan & Biklen, 1992, p. 36). When we consider the goal of this research, it is clear that this is a suitable framework within which to operate. The most obvious reason for the suitability of this framework, which comes out of the literature review, is that we are not starting with a clear definition of the concept that we are attempting to investigate - leisure. Rather, we are looking for how the participants experience leisure in their lives, and effectively the meanings that they attach to these experiences. This clearly fits in with the definition of symbolic interactionism.

The meaning of symbols are not necessarily the same for every individual and every cultural group, and some symbolic meanings are gendered; "gender is a crucial part of these cultural systems of meaning, transmitted and performed through the basic tools of symbolic interaction: symbols, meaning, and interaction" (Howard & Hollander, 1997, p.93). Denzin (1992) explained that the "gendered identity is an interactional production", and that "gender and sexuality arise out of the complex interactions that connect the texts, meanings, and experiences that circulate in everyday life with the things the members of our culture tell one another about what it is to be a man or a

woman” (p.30). Therefore, women may have very different life experiences than men, and are expected to fulfill different roles in society. As such, the meaning of leisure may be very different for them, as they most likely have had different interactions with leisure.

Symbolic interactionism also takes into account the “self”. As Bogdan & Biklen (1992) explain, the self is seen as “the definition people create (through interaction with others) of who they are” (p.37). Identities are based on “memberships in social groups”, both voluntary and ascribed (Howard & Hollander, p.94). For the women in this study, their identity may be affected by virtue of being women, being older, and having an intellectual disability. As was indicated in the literature review, women with intellectual disabilities often have a poor self-concept, and it was suggested that leisure might have a positive impact on this negative element. Through questioning these women on the role of leisure in their lives, we will learn about the way leisure impacts on how they view themselves.

Summary

It is evident that previous research has not adequately examined the lives, needs, and experiences of older women with intellectual disabilities. Much of the literature discussed in this review highlights the importance of recreation and leisure, so it seems reasonable to examine leisure in relation to older women with disabilities. Whether in the area of employment, family/marriage, or leisure, it is evident that women with disabilities are at a disadvantage compared to the rest of the population.

Older women with intellectual disabilities need to be understood as a group, and as individuals. Brown (1989) states that “Elderly and disabled people are people first.

Professionals must ensure that people are not depersonalized and categorized and robbed of control over their lives because they are old and have a disability...Individual variability should be recognized and encouraged, and form the basis of individual program planning". These statements by Brown lend further support to the fact that more research needs to be conducted about older women with intellectual disabilities, especially more in-depth qualitative research. If we are to give control to older women with intellectual disabilities, and if we are to provide appropriate services for them and recognize variability, then we must have an appreciation of these women.

In order to meet the leisure needs of older women with intellectual disabilities, there is a need to understand them. We have seen that women with disabilities and older people with disabilities experience many barriers to leisure, and are not satisfied with their leisure participation. Satisfaction with leisure in turn impacts on life satisfaction. It is not clear if the difficulties encountered by these two groups effect older women with intellectual disabilities in the same way, or if they have different experiences. It is also left to question whether older women with intellectual disabilities have the same leisure interests, and how leisure impacts on their life satisfaction. It is clear that "the importance of leisure to quality of life must be recognized and women's right to a leisure of their own advocated" (Henderson et al., 1989, p.9).

In order to create improvements and opportunities in the lives of older women with intellectual disabilities, we must understand what is important and meaningful in their lives. "Devalued as she is for being a woman, subject to deep prejudice due to her disability, and dismissed for the unaccepted manner in which she may articulate her needs and desires, the woman who has a mental handicap is at enormous risk of being

invisible and without a voice” (Boyle et al., 1988, p.10). This has significant effects on the quality of life of women with intellectual disabilities, and on the options available to them. It is necessary to understand the role of leisure for these women to ensure that policies and services adequately address their needs, concerns, and interests. If we are to understand the circumstances of older women with intellectual disabilities, we will be more capable of assisting these women in experiencing successful aging.

CHAPTER THREE

METHODOLOGY

There is a need to develop a body of knowledge surrounding older women with intellectual disabilities (Garwick, 1992). The purpose of this study was to develop an understanding of leisure in the lives of older women with intellectual disabilities.

Research Paradigm

Qualitative research does not attempt to look at cause and effect relationships, but rather it endeavors to delve beneath the surface for a more in-depth understanding and for the 'subjective interpretations' of the meanings that people give to their behaviours (Dawson, 1984). A comprehensive definition of qualitative research is given by Thomas and Nelson (1996):

"Qualitative research focuses on the 'essence' of the phenomena. The view of the world varies with one's perception and is highly subjective. The objectives are primarily description, understanding, and meaning. The researcher does not manipulate variables through experimental treatments but takes more interest in process than in product. The researcher observes and gathers data in the field, that is, the natural setting. There are no preconceived hypotheses...Rather, qualitative research strives to develop hypotheses from the observations" (p. 367).

For the purposes of this study, I was interested in the participants' subjective descriptions of the role of leisure in their lives, and the meanings that they gave to leisure.

My goals were to describe and to understand the experiences of these women. Howe (1985) stated that researchers interested in leisure who follow the qualitative paradigm tend to focus on the meaning that underlies leisure behaviour. This statement lends support to using the qualitative paradigm for the purposes of exploring this research question. Using this approach will not allow us to make any causal claims or vast generalizations, but it will give us a clear understanding of the role of leisure in the lives of the women who participated in this study.

Participants

The main criterion for the participants was that they had to be female, aged 50 and older, and that they have an intellectual disability. The participants were selected using purposive sampling. This is a common method used to recruit participants, as “Qualitative inquiry typically focuses in depth on relatively small samples, even single cases ($n=1$), selected purposefully” (Patton, 1990). This simply means that I selected the participants based on my judgment of who would be the most appropriate. In order to obtain names of possible participants, I contacted service providers from various agencies, and asked them to recommend people who would be appropriate for this study. I also asked people who were involved in the disability field to recommend women who they knew personally, and who were not necessarily receiving services. In total, nine women participated in this study, ranging in age from 55 to 84, with a mean age of 65.

During the initial interview, the purpose of the research was explained to the participants, in order to obtain informed consent. It was stressed to the participants that they were not required to participate, and that they could withdraw at any time. All of the

participants signed the consent form, and it was not necessary to seek the consent of a legal guardian.

The following is a description of the nine women who participated in this study. Pseudonyms are used in order to maintain confidentiality.

Joanne

Joanne is 84 years old. She lived in an institution for a number of years, and then in a home for women. When she was younger she had a job cleaning someone's house, but stopped working in her early forties when her boss died. Currently, Joanne shares an apartment with a roommate who is 44 years old, and who also has an intellectual disability. Her community based activities include bowling with Special Olympics, attending church and going to church functions, occasionally visiting her sister, and going out to look around at stores. Joanne's home-based leisure includes listening to music, watching TV and movies, talking on the phone with her sister, and doing crafts, such as painting and making wool flowers.

Joanne's roommate has a service provider, but Joanne does not have one. Joanne expressed that she did not have good experiences with social workers in the past. Currently, the public trustee manages her money. Joanne only has contact with one of her three sisters, who also has an intellectual disability. This sister is supported by a community living agency. They do not see each other very often. Joanne has never been married or in a long-term relationship, and she does not have any children. Joanne has cataracts, and her sight is very reduced. She is waiting to see a doctor, and hopes that

surgery will improve her vision. Her leisure is very affected by her deteriorating vision. She is unable to do her painting or make wool flowers.

When I asked Joanne if she had a disability, she said that she had heard the term before, but she did not know what it meant. She then questioned how she could be handicapped if she could bowl, and thought that handicapped had to do with being able to use your hands.

Leslie

Leslie is 55 years old. She lives in an apartment with her pet cat. Leslie worked at a sheltered workshop for 19 years. She left the workshop and had a couple of paid positions, but she was terminated a few times, and decided to try volunteering instead. She currently volunteers three days a week at three different schools. During the summer, she volunteers one day a week at a food bank. She doesn't volunteer there in the winter because she finds it too cold to wait for the bus (she has a long wait for one of the connections). Volunteering makes her feel good. She likes helping people, and it gets her out of her apartment. Some of the other things that she does in the community include going to the library, going to church, singing in the choir, attending Bible study, going to travel shows, and walking around in a mall. Her home-based leisure consists of playing with her cat, reading travel and romance books, having a friend over for coffee, watching TV, and listening to sports on the radio.

Leslie has a service provider, who she meets with once a week. She has a brother and a sister-in-law, and she usually goes to their place for dinner once a week. Her brother takes her to the occasional hockey or football game, and will pick her up if she

goes out in the evening, because he is concerned for her safety. She occasionally visits an aunt in another province. Leslie has a friend over fairly regularly for coffee, whom she met at a sheltered workshop. Her mother passed away a few years ago and it was very traumatic for her. Leslie is very involved with church, and it was through her church that she recovered from the loss of her mother. Leslie has never been married or in a long-term relationship.

When I asked Leslie if she had a disability, she said that she has a mild disability, that her feet were clubbed. She had one of her feet straightened, but one is still clubbed.

Leanne

Leanne is 58 years old. She lives alone in a house that she owns. Her husband of 17 years passed away approximately three years ago. She does not have any children. Leanne attends a day program for older adults with disabilities once a week, and volunteers at a food bank once a week. Leanne also goes to church and attends choir practice, plays Bingo, visits a friend, goes shopping, goes for coffee, walks, and chats with neighbours. She used to curl and to bowl, but stopped these activities after her husband passed away. Her home-based leisure includes gardening, reading the paper, watching TV or movies, reading books, talking to people on the phone, cleaning her house, and playing with her cat.

Leanne has a service provider who she meets with once a week. She receives assistance with shopping, paying bills, and banking. Leanne is very involved with her father and her sister. Her sister does the heavy work around the house, such as the major cleaning and the yard work. Her father takes her to doctor's appointments, mows her lawn, and looks after her bills (she gives him the money). Leanne has a friend who is not

well whom she visits about once a month. She met her at a day program for seniors with disabilities.

When I asked Leanne if she had a disability, she responded that she has a 'bad hand', due to having had polio as a child.

Rachelle

Rachelle is 67 years old. She lives in a group home with Alice, who is also a participant, and another older woman with an intellectual disability. Rachelle attends a seniors program with Alice one day per week. Her community-based leisure includes shopping, going for coffee with roommates and staff, going to church, visiting with an aunt, goes to a friends house for dinner, and going for manicures. Rachelle is planning a trip to Hawaii with a staff member. Her home-based leisure includes drawing, baking cookies, making her bed and washing clothes, and playing with her pet birds.

Rachelle's parents and siblings have passed away, and she misses them. Her only family contact is with one aunt. She was never married or in a long relationship, and does not have any children. When I asked Rachelle if she had a disability, she answered that she did not know.

Mona

Mona is 57 years old. She lives in an apartment with her husband of 15 years, who she met in an apartment block that they were both living in. Mona worked at a sheltered workshop for 28 years. She left the workshop to work as a receptionist for a community living agency. She worked there for a couple of years, but they were not

satisfied with her work, and she was terminated. She tried to go back to the sheltered workshop, but she was told that they would not take her back because she had left of her own free will. After this she started volunteering, which she has been doing for about 10 years. She volunteers at a soup kitchen in the morning and at a drop-in center in the afternoon, which are both run by a church. Mona enjoys volunteering and she likes helping others, but she would prefer to have a paying job. Mona also goes out with friends, visits with people in her apartment block, attends church and church functions, goes to movies and out for dinner with her husband. She mentioned that she has been to the Planetarium and to the Art Gallery, but these are not things that she does regularly. Her home-based leisure consists of having company over, watching sports on TV or watching movies, listening to music, and talking to friends on the phone.

Mona does not have a service provider. She was on social assistance until recently, when her husband's father passed away and left them a trust fund. Her parents live in another province, and she occasionally visits them. She sees her two sisters and two of her three brothers, and is upset that one of her brothers' wants nothing to do with her. Mona is very involved with the church. She helps out at church functions and attends church regularly, and she sometimes goes to different churches to learn about different religions.

Mona does not have any children. She explained that this is because she married later in life, and she regrets that she did not have children. Mona does not think that she has a disability.

Alice

Alice is 61 years old. She lives in a group home with Rachelle, (one of the participants), and another older women with an intellectual disability. Alice worked at a sheltered workshop for 28 years. She retired in 1998 because she was getting tired of working and because of health problems. Her regular community-based leisure activities include ceramics, bowling with Special Olympics, going to a seniors club once per week, and exercising at a gym once a week. She also goes to movies, goes out for coffee or supper, and goes for walks. All of these activities are done with a staff from the group home. Her home-based leisure includes watching TV, and having her sister over. She has a pet cat.

Alice has never been married or in a long term relationship, and does not have any children. Her only family contact is with one sister, who comes over once a week or so for dinner. Alice does not think that she has a disability.

Margaret

Margaret is 77 years old. She worked as a live in housekeeper for approximately 20 years. When her employer passed away, she worked at a sheltered workshop for about seven years, but she didn't care for it. Margaret uses a walker since breaking her hip about four years ago. She fell in her previous apartment where she was living alone, and she lay on the floor for nearly two days before someone found her. Now she lives in a seniors apartment complex, and her room has an emergency pull cord. She is unable to take the city bus since breaking her hip, as she has difficulty with the stairs. She attends a seniors day program once a week, and plays Bingo in her building once a week. Every

couple of weeks she goes to a store downtown, where she has lunch and then gambles on the video lottery terminals. Her other community-based activities include going for walks, having lunch with a friend, going for boat tours on the river, and going for excursions around the city on the tour bus. Her home-based leisure includes watching TV, listening to the radio, visiting with a friend who stops in once a week, reading the paper, and socializing with the delivery persons who bring her meals.

Margaret does not have a service provider specific to individuals with disabilities. She does get home care through her residence, and she also gets meals delivered daily. She doesn't know if she has a social worker, but she does attend some meetings at a group that is focused on later life planning for older adults with intellectual disabilities. Margaret has four sisters, but only one of them lives close by. She has minimal contact with her sisters, and does not want to see them more often. Margaret has never been married or in a long-term relationship, and she does not have any children.

When I asked Margaret if she had a disability, she said that she did in that she is unable to get around as well as she used to, and because she doesn't catch on to everything that other people might catch on to. She explained that she needs to mix with people who are at the same level as herself, and not people who are 'higher' or 'more normal' than she is.

Rhonda

Rhonda is 65 years old. She lives in a group home with two other women who also have intellectual disabilities. She worked at a sheltered workshop for a number of years. She recently tried volunteering at a pet shelter, but it was too noisy. She may try to

volunteer at a quieter location. Rhonda loves going shopping, and she collects stuffed animals. She goes out for lunch or coffee with friends who she used to live with in a group home, and with former staff. She occasionally goes on outings with group home staff. Her home-based leisure consists of watching TV and movies, and collecting stuffed animals and toys.

Rhonda has two sisters who she almost never sees. Both of her sisters live in different cities. Rhonda has never been married or in a long-term relationship, and does not have any children. She did not answer when I asked her if she had a disability.

Renee

Renee is 57 years old. She lives in a supported apartment, and has a roommate who is quite a bit younger than she is. Renee volunteers five days a week at a sheltered workshop. She does not think that this is leisure, but thinks that it is hard work. She would like to get paid for working there. Renee is very involved with church. She attends services and social events, goes to Bible study, and plays in two different musical groups. Renee bowls once a week with Special Olympics, and attends a seniors drop-in one afternoon per week. She also spends some time with staff members, and attends baby showers, socials, and good-bye dinners. There is quite a bit of staff turnover within her support agency. She occasionally goes to sporting events, and sometimes goes for walks with a staff member. Her home-based leisure includes watching sports on TV, and watching movies with some other individuals in her apartment complex who are supported by the same agency.

Renee is very involved with her mother. They lived in separate apartments in the same building until a year ago when Renee changed service providers. Renee speaks to her mother every day on the phone, and assists her mother with shopping and cleaning her apartment. Renee was married for two years, but the marriage didn't work out. She does not have any children.

When I asked Renee if she had a disability, she said that she had a "money disability", and explained that she had difficulty with counting and managing her money.

Method

Data Collection Strategy

In this study I used open-ended interviews as my primary data collection method. I was interested in the subjective description of the role of leisure in the lives of older women with intellectual disabilities, and interviewing is the one of the best methods for exploring this subjective description. The type of open-ended approach that I followed is what is known as the general interview guide approach. An interview guide consists of a list of questions that are to be investigated during an interview (Patton, 1990). An interview guide is created in order to ensure that basically the same information is gathered from a number of people by following the same framework for each interview. Patton provides a clear description of this type of approach:

"The interview guide provides topics or subject areas within which the interviewer is free to explore, probe, and ask questions that will elucidate and illuminate that particular subject. Thus the interviewer remains free to build a conversation within a particular subject area, to work questions

spontaneously, and to establish a conversational style-but with the focus on a particular subject that has been predetermined" (p. 283).

Using this type of approach when interviewing a number of people ensures that there is some consistency across the interviews by outlining in advance the issues to be explored. In summary, the interview guide provides a framework from which the interviewer develops questions, decides on their order, and decides which topics to pursue in greater depth (Patton).

With the consent of the participants, all of the interviews were tape recorded. The participants did not seem to be nervous or self-conscious when the tape recorder was turned on. Following the open-ended interview, field notes were recorded. Notes were made regarding such things as the setting and the atmosphere of the interview, the mood of the participant, our rapport, and any distractions or unusual occurrences. I also kept a personal journal for the duration of the study. In this I recorded my thoughts and my feelings, questions that I wanted to further explore, and notes on the progress of the study. These two sources of data were used to inform the analysis.

Procedure

The first step of the process was to identify the participants, based on the criteria previously described. All of the interviews took place at the residences of the participants. The purpose of the first interview was to meet the participants, establish a rapport, and collect some information on their background and their current situation. In this first interview I clearly explained the research to the participants, in order to obtain informed consent. The first interviews lasted an average of thirty minutes. At the end of

this interview, we scheduled the next appointment. The second interview usually took place about a week after the first one, and in this interview I asked the questions outlined in the interview guide. These interviews typically lasted about forty-five minutes.

The data from the first two interviews informed the development of the questions for the third interview. In order to create the third interview guide, which was individualized for each participant, I reviewed the first two transcripts of their interviews, and I listed all the leisure activities in which they were involved. A sample third interview guide is presented in Appendix C. In the second interview, I asked questions like ‘what are some things that you do that make you feel good’, and ‘what do you do for fun’. For the third interview, I took the answers to these questions, and asked, for example, ‘why do you go shopping’, ‘why to you volunteer’. After asking them why they participated, for each activity I asked them to describe how it made them feel, and if they thought that this was leisure. The other questions on the third interview guide were the same for all the participants. When necessary, I also asked some individualized questions to fill in any gaps from the previous interviews.

The objective in the second interview was to ask questions in order to develop an understanding of the participants’ experience of leisure. I was making an assumption that the questions would elicit answers about the leisure of the participants. The questions in the third interview were really a way of checking with the participants to see if I was in fact getting at this concept. For example, when I asked the question, ‘what are some things that you do that make you feel good’, the participants typically gave answers that I considered to be leisure experiences. In order to confirm this, in the third interview I asked the participants why they did these things, and if this was leisure. The responses in

the third interviews confirmed that what I considered to be leisure was consistent with what the participants identified as leisure.

Pilot Study

A pilot study was conducted in the fall of 1998. The purpose of this pilot study was to develop and test the interview questions for the overall research project. This was accomplished by interviewing five women over the age of fifty with intellectual disabilities. The research was explained to potential participants, and they all agreed to participate, and signed the consent form after I read it out loud to them. Ethics approval was obtained for this pilot study, and the research was conducted under the guidance of a university professor.

Initially I developed a set of nine questions, with some accompanying probes, which were used for the first interview. The questions were then modified as the study progressed, based on the responses of the participants. I was concerned with whether I was asking the correct questions to obtain the information I was looking for, and whether or not the questions were understood by the participants.

The initial questions that were used are attached (Appendix A). These were used as a guide for the first two interviews. I added some questions to the originals upon completion of the first two interviews, and these modified questions were used for the subsequent interviews. The final interview guide can be found in Appendix B. The following is a list of some insights I had while interviewing, and the reasons for the changes to the questions.

In all of the interviews the participants would not expand very much on their answers to the questions. It also seemed like some of the questions were not being understood, so I had to use examples and try to ask the questions in different ways to elicit a response. I added some specific questions in order to get more information, and a more complete picture of the women's lives. In the third interview these questions seemed to act as good memory cues, and after asking the more specific questions, the participant mentioned some other activities that she did not mention when answering the more general questions. In the fourth and fifth interviews, these probes also brought out more information that the women had not mentioned as a result of the more general questions. The most effective manner of questioning is to be as concrete as possible, and to ask simple, straightforward questions. This was also apparent when considering that the women had some difficulty with a question about what they would do in a day if they could do anything they wanted, as well as with a question about doing something that they are not doing now. It seemed that the difficulty with these questions stemmed from the more abstract questions that required some imagination, and I found that it worked best to give concrete examples.

After reviewing the first couple of transcripts, I added a question about disability, and I think this was an interesting and important question to ask. The way the women perceive the impact of their disability may lead to further insight about the role of leisure in their lives. I also realized after the final two interviews that I did not ask a question about the significant relationships in their lives, such as partners or husbands. This was an oversight on my part, and a question was added to get at this information.

Analysis

All of the interviews were transcribed verbatim. Data analysis began upon the completion of the first interview, and continued throughout the duration of the study. In doing this I was able to determine if there were any areas I wanted to focus on in subsequent interviews. This allowed me to effectively direct the data collection, and helped ensure that there were not any gaps in the data (Thomas & Nelson, 1996).

The method of data analysis used in this study was constant comparison. “By continually comparing specific incidents in the data, the researcher refines these concepts, identifies their properties, explores their relationships to one another, and integrates them into a coherent theory” (Taylor & Bogdan, 1984, p.126). Effectively, this involved reading and re-reading a transcript, and then organizing the participant’s responses into categories. When this process was completed, I re-examined all of the categories and identified any themes within or across the categories. This process was completed with each individual transcript. After analyzing each transcript independently, I then did a cross-case analysis, meaning that I compared and contrasted the themes across the different participants. This allowed me to determine whether some themes were common among many participants, or if they were indicative of differences between the participants. All of this was completed manually, without using a computer program.

Trustworthiness and Credibility

According to Patton (1990, p. 461), a credible qualitative study needs to address the following three issues:

- (1) What techniques and methods were used to ensure the integrity, validity, and accuracy of the findings?
- (2) What does the researcher bring to the study in terms of qualifications, experience, and perspective?
- (3) What paradigm orientation and assumptions undergird the study?

Patton (p.470) stated that “Triangulation is a process by which the researcher can guard against the accusation that a study’s findings are simply an artifact of a single method, a single source, or a single investigator’s biases”. Two forms of triangulation techniques were used in this study to ensure the integrity, validity, and accuracy of the findings. As described by Patton (1990), triangulation contributes to the validity and verification of qualitative analysis. The first type of triangulation used was triangulation of qualitative data sources, which means verifying the consistency of different data sources within the same method. This was achieved by “checking for the consistency of what people say about the same thing over time” (Patton, p.467). According to Stumbo & Little (1993), it is useful to compare participants’ responses at different intervals, because their responses may not always be consistent. Therefore, conducting multiple interviews over time with the same participants increased the validity and reliability of the data. The second type of triangulation used was analyst triangulation, which means “having two or more persons independently analyze the same qualitative data set and then compare their findings” (Patton, p.468). This was achieved by having an independent analyst review a selection of the transcripts. The findings of this analyst were consistent with the findings of the primary researcher.

The second issue that needs to be addressed has to do with the credibility of the researcher. Over the course of designing the study, data collection, and analysis, the primary researcher maintained the mindset that Patton (1990) named 'empathic neutrality'.

"Empathy...is a stance toward the people one encounters, while neutrality is a stance toward the findings. Neutrality can actually facilitate rapport and help build a relationship that supports empathy by disciplining the researcher to be nonjudgmental and open. Empathy communicates interest in and caring about people, while neutrality means being nonjudgmental about what people say and do during data collection" (p.58).

This means that as a researcher, I entered the study with a desire to gather and understand information, not to try to prove a predetermined conclusion. In essence, I developed a rapport and was empathetic with the participants, but I attempted to remain neutral about the findings. A second method used for enhancing the credibility of the research is to describe one's professional and personal beliefs and experiences, so that the reader is aware of how these factors may have influenced the overall study and the findings. As stated by Patton (1990), "the trustworthiness of the data is tied directly to the trustworthiness of the evaluator who collects and analyzes the data" (p.476). In order to address this issue, a section outlining my assumptions and background was included in the introductory chapter of this thesis.

The third issue that needs to be addressed has to do with the perennial debate surrounding the use of qualitative research methods. One of the specific concerns has to do with objectivity in qualitative research. As Patton (1990) explains, however, most

researchers now agree that it is highly improbable that any person or method will ever be totally objective. "The point is to be aware of how one's perspective affects fieldwork, to carefully document all procedures so that others can review methods for bias, and to be open in describing the limitations of the perspective presented" (p. 482). These factors are all documented throughout this thesis.

The two other issues related to using a qualitative paradigm have to do with the researcher's perception of truth, and the issue of generalizability. Firstly, in order to work within a qualitative paradigm, a researcher must not be preoccupied with finding one absolute truth. Rather, the researcher should believe that we exist in a world of multiple realities and perspectives. In doing this research, I was interested in understanding leisure from the perspectives of the participants. I worked within the conceptual framework of symbolic interactionism, which is founded on the premise that people interact with objects according to the meanings that they attach to them. As a qualitative researcher working within this framework, I am comfortable with the idea of a world of multiple realities, rather than absolute truths.

The final issue to be addressed in this section has to do with generalizability, which refers to applying the findings from your research to other real world situations. For qualitative research, this is best described in terms of 'user generalizability'. In this case, "the reader evaluates the findings of the carefully described and interpreted study and asks what things apply to his or her situation" (Thomas & Nelson, 1996, p.380). The researcher is not concerned with how the results can be generalized, but rather leaves this up to the reader. The rich descriptions given by this type of research make it possible for readers to recognize the situations in which this research is applicable (Locke, 1989).

Patton (1990) describes the concept of 'extrapolation', which seems to be a more useful concept to be concerned with in qualitative research. "Extrapolations are modest speculations on the likely applicability of findings to other situations under similar, but not identical, conditions" (p.489). By providing rich descriptions of my participants and about every aspect of the study, the reader can extrapolate segments from the findings and apply them to similar situations.

CHAPTER FOUR

FINDINGS

Most of the women were very willing to participate in the interviews, and welcomed me into their homes and into their lives. Some, like Rhonda and Alice, took a little time to warm up to me, but in the end they seemed comfortable with the process. They knew from the beginning that there was a set amount of interviews, but some of them clearly would have liked to spend more time together. For the most part, the women seemed to enjoy talking about their life experiences, and seemed to appreciate that I was taking an interest in what they had to say.

In this chapter, I present the major findings of the study. I have divided this chapter into three sections. The first section examines the nature of leisure in the lives of the participants, from their personal perspectives. Throughout the interviews it was clear that there were a number of factors that influenced the participant's leisure experiences. The second section outlines the themes that impacted on the leisure experiences of the participants. The final section looks at the themes that relate to the life satisfaction of the participants.

Nature of Leisure

Meaning of leisure

The overall research question of this study was concerned with understanding leisure in the lives of the participants. All of the women identified leisure as being a very positive aspect of their lives. The two most important roles that leisure had for the

participants was that it allowed them to meet people and to make friends, and it enabled them to get out.

Mona: It helps me to...to get to know other people. And helps me to make new friends.

Margaret: I don't know, going places I like, things I like to, meet with, meet with people... Well I think it makes me feel good, it doesn't make me feel as if I can't do anything. That's the way I think, the only way I can think of it.

Leanne: And, ah, things that I can do lots for myself. I get out places. And, ah, like I said I go downtown shopping, I go meet people, and that keeps me going.

Leslie: Well, it's got me talking to more people and that's what they...wanted me to do and my brother wanted me to, to meet more people...I'm happier when I meet people, than sitting around doing nothing.

Mona recognized that leisure has a very important role in her life, and emphasized the importance of making time for leisure. She also said that leisure is not just the things that you do, but is the time spent with friends.

Mona: Um, well I think it, it has a very important, important role in my life. Um, I think it, it's all part of, of life in general, and being married and things like that.

Because even if you're married or you're not married, um, you have to have time to do, to just settle down and, and enjoy the good things of life. That's what I think, to me that's what leisure is. It's not just, not just going to a movie, it's not just going to a museum or art gallery, you have your friends to think about, and, and to me that, that takes leisure time too, to be with your friends. You just can't be a workaholic all your life.

Some of the participants recognized that leisure played a part in helping them cope with some anxiety or unhappiness in their lives. For Leanne, leisure helped her to not worry, and to cope with the loss of her husband of 18 years.

E: So it's the things that you do that make you happy?

Leanne: Well that keeps me going away from all the worrying I used to have.

E: The worrying?

Leanne: Like ah, my husband's gone, it's pretty hard to take. And my family all surrounded me, that makes a difference. And my sister said, told me a lot times, it would make a lot difference, if you go around people and try to make yourself useful eh? But I enjoy being here [seniors club].

When Rachelle is feeling lonely, she draws to take her mind off of how she's feeling.

Rachelle: I draw to take my mind off you me.

E: To take your mind off you, okay...How does it make you feel to draw?

Rachelle: Well, I draw when, when I get lonely.

E: You draw when you get lonely. Okay, great. So it makes you feel better to draw?

Rachelle: Yeah.

The participants also recognized what their lives would be like and how they would feel if they did not have these things to do. They clearly felt that they would be bored, lonely, and miserable.

Leanne: I would go bored and I wouldn't know what to do with myself, you see. That's the reason I go out places...I wouldn't feel right.

Mona: Oh geez. I think, if I didn't have friends, or go out and do things, and just sit around home all day, I think I'd lead a real boring life...boring, miserable, nasty.

Alice: I'd be sad.

Rachelle: I'd feel lonely...Tired.

Joanne: Well you'd be lonesome, you wouldn't have nothing to do.

Joanne: Miserable I guess.

Leslie: Bored...I'd try getting busy.

Renee: Grumpy and miserable.

The two most important roles of leisure for the participants was that it allowed them to meet people and make new friends, and it got them out of their residences. All of the woman repeatedly indicated how important it is to go out and do things, and throughout the interviews it became very clear that most of these women would like to go out more than they currently do. Leisure was a way for them to be active and feel capable. It definitely brought happiness to their lives, and helped them deal with sadness. From the interviews there is a real sense that these women want to be as busy as possible, want to be out and about, and do not want to sit around at their residences with little to do. The participants are also quite clear that they would be very discontented if they did not have their leisure pursuits.

Categories of leisure

In doing the data analysis I realized that there were three areas of leisure that were very prominent for some of the participants. Firstly, there was definite agreement among the participants indicating that they strongly preferred to have community-based leisure over residence based leisure. The reason that the participants did many of the things that they did was because it got them out, and most of them wanted to increase their time in the community. The two other areas examined in this section are volunteering and

church. Both of these areas had very significant impact on the lives of some of the participants, and merit further examination.

Community based

Community based leisure was clearly the preferred type of leisure. One of the strongest themes to come out of the interviews is that through their activities in the community, participants are able to meet new people and socialize with their friends. The importance of getting out was also reinforced when the women were asked what they would do if they could do anything in a day. Most of the women said that they would like to go out. They would visit with people, go shopping, walk around. They did not express a desire to do something new, but wanted to do more of what they liked.

Joanne: Ah, if there was something I wanted to do, is I wanted to go out. I like to go out sometimes, go out with people, or go out with someone, and have a coffee or something with them and that.

Rhonda: Maybe shopping.

Leanne: I'd go shopping.

Alice: I would do, go out more.

Margaret: What would I do if I ah, had one thing, well I think I would go out and look around, with my walker or something like that. Look around at stores. Just around here, I wouldn't go downtown.

Margaret was clear that her preference is to be out in the community, and that being out among people is more enjoyable than being at home watching TV or reading the paper.

Margaret: Well I would just have to put up with reading the paper or looking at Sally, or something like that.

E: Yeah. So how do you think you would feel if you didn't have.

Margaret: Well I'd rather be out amongst the people. You get to know what each one has to say...

Leslie's first response was that she would do housework, but when pressed she said that she would go out.

Leslie: Like I'm waiting until spring break comes and then I can hit my bedding.

...E: Okay, but is there something that you've always wanted to do or somewhere that you've always wanted to go, or just something crazy that you've always wanted to try?

Leslie: Oh I usually just walk around, like go around Eaton Place or sometimes, now Eaton's is shut down.

For the most part, leisure in the home occurred due to an inability of the participants to get out as often as they would like. Rachelle was the only one who would do a home based activity, as she said that she would bake. The only people who gave wishful, imaginative answers were Mona, who would be a millionaire for a day, and Renee, who had a few ideas about what she wanted.

Mona: If I could do anything I wanted to do, I think I'd be a millionaire for the day.

Renee: Be a movie star.

E: Be a movie star, okay, that's a good one.

Renee: Be a movie star and go to Silver City.

...E: Anything else that you would want to do?

Renee: Go see Ricki Martin.

This was not an easy question for many of the participants to answer. They seemed to have trouble with the abstract nature of the question. It also seemed that many of them had not really thought about what they wanted or what they really like. Perhaps nobody has ever really asked them what they wanted. They may not have had much chance to try different things to see what they would like. In any case, the answers they gave reinforced how important 'getting out' is for this group of women.

Volunteer work

Many of the participants do a fair bit of volunteer work. They explained that it gives them something to do, and it is a way to meet people. It makes these women feel good about themselves. They enjoyed being able to help others. People with intellectual disabilities are typically a group that is perceived as needing help, but those who volunteer indicated that they like helping others and find great success doing so.

Leslie: My volunteer work, I'm liking it, and keeping busy all the time.

Mona: Cause it's something I like to do...It makes me feel good to be able to help other people.

E: Okay. Why do you volunteer at Harvest?

Leanne: It gives me something to do and meet other people.

Volunteer work was an avenue for some of these women to find success when they were unable to do so in the realm of paid employment.

Leslie: And then they got me in [supported employment agency], and I used to work at McDonalds. That didn't turn out. I have had so many job experiences that I just gave up, said I want to volunteer. And then I just, here I am I'm volunteering.

E: And it worked out better for you?

Leslie: And it's a lot easier too. I can go my own speed and that.

Renee had worked for a few years in a paid situation, but she retired because of problems with her back. When she changed service providers, she started working full-time at a sheltered workshop. She is clearly dissatisfied with the fact that she is not getting paid for her work.

E: Okay. How long do you think you'll work there?

Renee: I don't know but I'm not getting paid for what I do.

E: How do you feel about that?

Renee: Not a bus pass or anything.

E: No. How do you feel about that?

Renee: Probably taking advantage.

E: That they're taking advantage of you?

Renee: Well they're not taking advantage of me, it's just that I have to wait until it goes through her board. She has a board meeting or, boardroom or something. But she put it on her, um, list that I was a good worker.

E: Okay. So then they might start paying you?

Renee: I don't know.

E: So if they don't start paying you are you going to stay?

Renee: Yeah. Cause I have friends there.

She undoubtedly would be happier if she was being paid, but admits that she will stay on regardless because of her social contacts. Renee calls herself a volunteer, but she does not think this is leisure.

E: Why do you volunteer at the workshop?

Renee: Get out of the house.

E: Get out of the house, okay. How does it make you feel?

Renee: Busy.

E: Busy, yeah. Is that a good feeling?

Renee: Yeah.

E: Do you think that is leisure?

Renee: No.

E: No?

Renee: That's work. And it's hard work.

Mona expressed that she would like to find paid employment. She worked at a sheltered workshop for 28 years, and when she started working there she was making five dollars a month. She worked at a community living agency for about two years, where she was paid. Unfortunately this did not work out.

Mona: Well, ah, I stopped working there because they told me that I wasn't, they told me they weren't satisfied with the work I did there.

Mona tried to get back on with the sheltered workshop, but they would not take her back. She now volunteers five days a week at a soup kitchen and at a drop-in center. She greatly enjoys volunteering, but would prefer to have paid employment.

Church

For the women who are involved with a church, it plays a big role in their lives. Church gives them opportunities to meet friends, be a part of a group, be connected, and learn different things. All of the women who attend church do more than attend service once a week. For example, they are in the choir and go to practices, they go to church dinners, and they go to meetings and Bible study. Leslie started going to church after a major event in her life, her mother's passing. Going to church helped her get through this traumatic event (she did not speak for seven months after her mother passed away), and it allowed her to open up and meet people.

E: So you didn't go before your mom died, to church?

Leslie: No.

...E: So you started going as a way to meet people?

Leslie: Yeah.

Leslie: Well getting to know people, and know myself. I was shy at first but now I'm not as shy. I think that's what the building did for me, I met lots of people.

Rachelle also sees church as a place to meet friends. In fact, her only friend other than her roommates and the staff who work with her is an individual who she met at church. They socialize outside of the church setting, with the friend having Rachelle over for dinner.

E: Yeah. Where do you meet friends?

Rachelle: I go to church.

E: So you make friends at church?

Rachelle: Yeah.

Joanne finds church to have emotional benefit.

E: Okay. How about going to church, why do you go to church?

Joanne: Cause it's, it eases, it eases your mind.

Joanne is not as involved with church as some of the other participants, but she does attend church dinners with her roommate. Mona clearly goes to church for spiritual reasons, but she also goes to make friends and to be part of a community.

Mona: Because it...I think it's not only the, only the calling from God himself, but I think it's, um, something you have to do because you have to, ah, it's something, something you're brought up with in a family, um, I think that's part of it. Another part of it is, is, to keep the, keep, make friends and, and the thing is you have to keep your faith in God and, and not only in God but in the church and

in the community too. I think that being in a community is also another part of the reason why I go to church because I see so many different people at church every time I go. Like there's always, always new people coming in, and that's what I like about it.

Renee is another participant who is very involved with church. Her service provider is in fact a religious organization, and Renee spends most of her evenings and weekends in activities operated by this group. Most of her community-based leisure is through these activities. For five of the participants in the study, church had a positive impact in their lives, and connected them to a community. Most of them do not simply go to church once per week, but they get involved in other groups and celebrations organized by the church.

Factors that affect the leisure of the participants

Most of the women who participated in this study indicated that they were not satisfied with the amount of leisure that they had, and it was clear that a number of factors affected their leisure. The remainder of this section will present the eight factors that had an effect on the leisure of the participants. They are not listed in a particular order, because they are not completely distinct categories, but rather they all impact on one another.

Friends

Some of the women interviewed preferred to do things on their own, but most of them preferred to do things with other people. Only two of the women did not want to

have more friends. The others all indicated that they would like to have more friends. The participants identified that they have friends who they see when they are doing certain things, such as working, bowling, etc., but these friendships are confined to only that particular area of their life, and do not transfer to other contexts. For example, Leslie worked in a sheltered workshop for nineteen years, and since having left, she does not keep in touch with anybody from the workshop. Mona, who also worked at a sheltered workshop for 28 years, only maintains contact with one person who she worked with, and their contact is limited to occasional conversations on the phone. Alice worked at the same sheltered workshop, also for 28 years, and she misses her friends from work, as she doesn't see them now that she's retired.

Alice: I miss working.

E: How come?

Alice: Cause they're friends of mine there.

E: Oh your friends there, so you miss your friends?

Alice: Yes.

E: Okay. Do you still see any of the friends from work?

Alice: No.

Some women, like Joanne and Rachelle, did not really have any friends. In Joanne's case, the only time she socialized with other people, aside from her roommate, was when she went out bowling or at church functions.

Joanne: I don't do nothing with my friends cause I don't have nobody around.

E: How about with friends, do you ever do things with friends?

Rachelle: No.

All of the participants derived happiness from meeting people and socializing with them.

Leisure pursuits allowed many of the women to meet people and potentially make friends, although as stated previously, the friendships were typically limited to the context in which they were formed.

E: How does it make you feel to go bowling?

Joanne: Happy. You meet people.

E: Why do you volunteer at Harvest?

Leanne: It gives me something to do and meet other people.

Margaret: Well I've met so many nice people down there.... Well they don't know me by name, but they know me, you know what I mean? Here comes our friend again, good for her.

E: Why do you go to the club on Fridays?

Alice: To meet friends.

When questioned about friendships, the women typically responded that they have friends, but as the conversations progressed it became clear that they have a limited number of friends. The participants did not indicate whether their friends were individuals with or without disabilities. Most of the women acknowledged that they would like to have more friends. The friendships that they do have are for the most part specific to the setting in which they are formed, and do not transfer into other settings.

Transportation

The level of involvement that the participants' had with a service agency impacted on their access to transportation. Rachelle, Alice, Rhonda, and Renee were very involved with community living agencies. Rachelle and Rhonda only go out with staff, and the staff arrange transportation. Alice is a little more independent, and takes Handi-Transit to her bowling. Renee takes the bus during the day, and the organization that supports her provides a van that brings her to her activities.

E: Yeah. What about getting there and back to those things?

Renee: No we have transportation.

E: The church provides transportation?

Renee: No, [name of service agency].

E: Okay, so they come and pick you up.

Renee: Well Deena has the van, so she'll be taking us.

E: So the staff takes you?

Renee: Yeah.

Leanne meets with a service provider once a week, who takes her shopping. Leanne is very capable with the bus, and she also gets rides from her father and her sister. None of these five women mentioned transportation as being an issue for them.

Of the remaining four women, Leslie is the only one with a service provider, who she meets with once a week. Her agency also provides her with a bus pass, at no charge. She is very capable of taking the bus, but sometimes she limits her activities because of having to take more than one bus and having to wait in the cold.

Leslie: But I don't go in winter time, I just go in summer, cause in winter it gets awful cold...It's just that you have to take two buses and sometimes wait quite a while for a Notre Dame.

Fortunately for Leslie, when she goes out in the evening her brother will provide transportation. Otherwise she would not go out in the evening, because of safety concerns.

Mona, Margaret, and Joanne were the three women who had to limit their activities the most due to transportation. For Mona, this is due to the cost of transportation, as she cannot always afford to even pay for the bus.

Mona: But I like, I'd like to, but my problem, my other problem is I can't afford to go on the bus or um, or I can't get the transportation to get there because my husband doesn't drive.

Margaret and Joanne, the two oldest women in the sample, cannot take the bus anymore due to health reasons. The only options available are Handi-Transit and cabs. Having to take a cab is obviously the most expensive alternative, and both women have to limit their activities because of this expense. Joanne complained that Handi-Transit is not always available to provide transportation, such as on the evenings when she bowls.

Joanne: And then you see the Handicap will take you, but they have this idea now if one person cancels their ride not to come home or something, well then you can't have it... You have to have the ride to go and back, but otherwise no... You have to pay another taxi to bring you home... And that takes money.

Joanne: I wasn't going to do nothing. Cause see I got no way of going anywhere you see, unless I get a ride.

Now that Margaret is unable to take the city bus, her activities are limited by the cost of transportation.

Margaret:...I says I can get in the taxi all right. I can't get on the bus very well with that... It takes too long, it holds up the people eh.

Margaret: Yeah. The reason I don't go now is because it would cost me too much for a cab.

Lack of transportation is a large barrier for some of the participants. One of the transitions that has taken place for two of the women is that as they have aged their modes of transportation have changed, so that they are now less able to get around. The two oldest women are unable to take a bus. Therefore, when these women go out, they have to take a taxi or Handi-Transit. The price of cabs can be prohibitive, as can be the scheduling of Handi-Transit. Transportation to recreation activities are a low priority for this service. Joanne was quite clear that not being able to afford transportation prevented her from pursuing relationships with friends, and from going out as much as she would like.

Financial Situation

There is a lack of clarity about money. Although many of the women expressed that they couldn't do things because of the cost, when asked directly about whether they felt that they had enough money to do things, they responded positively. None of the women worked in a paid situation, so clearly they do not bring in a lot of money. Also, through the various topics that were discussed, it was clear that lacking money was a barrier to their leisure experiences, but that the women did not entirely realize this.

Mona: Um, um, there's nothing stopping me, it's just that I can't afford it right now.

E: Do you feel that you have enough money to do the things that you want to do?

Margaret: Oh yeah.

E: Yeah. Has not having money ever stopped you from doing anything?

Margaret: No, when I don't have much money I don't do much.

Leslie: Cause my mom and I used to travel and that, but now I can't travel.

E: Why can't you travel?

Leslie: Cause it costs a bundle.

Renee did identify that the cost of an activity prevented her from doing it. She gave up curling because the prices increased.

E: Well, I remember last time we talked you said for example you used to curl, but you don't curl anymore cause it's too expensive.

Renee: Yeah...Some curling is sixty dollars.

E: And that's too expensive for you?

Renee: Some curling is thirty-five dollars, forty dollars.

E: And that's too much?

Renee: If there was one for twenty-five I would take it, but there isn't.

For some of the other women, if a connection was made about lack of money being a barrier to leisure, the connection made was usually between money and transportation

Margaret: Yeah. The reason I don't go now is because it would cost me too much for a cab.

Joanne: Well it's like the going there and coming home. It's not, it's not the doing the thing.

This may be because the activities that the women usually participate in usually have little, if any, cost associated with them. The women do not seem to recognize that not having much money limits their choice of activities, which could indicate that they lack awareness about or exposure to alternative leisure opportunities.

Family

Most of the women had little if any contact with family members. Those who do have relationships seem to only have relationships with one family member. Leanne has the most contact out of all the woman, as she is very involved with her sister and her father. Laura lived with her mother until her mother passed away 13 years ago, at which time her life changed dramatically. She now sees her brother and sister-in-law about once a week. Rachelle listed all her family members who have passed away, and talks about missing them. She describes being lonely as a result of their deaths. Now Rachelle only has regular contact with some of her aunts. Most of the participants have experienced the loss of some family members. Familial relationships are identified as being a positive aspect of their lives, although many of those who do have relationships said that they would like to see the family member more often.

E: She comes to see how you are. Okay. How does it make you feel when she comes over?

Alice: I feel nice.

E: ...Would you like to see your sister more than you do?

Alice: Yes.

E: You see your auntie sometimes, right, that's what you told me?

Rachelle: Yes. Sometimes I phone her up.

E: Oh, you phone her up?

Rachelle: When I'm lonely.

Joanne talked on the phone regularly with one of her sisters, but did not see her very often due to problems with transportation.

E: So do you ever see any of your sisters?

Joanne: Well I just see the one now and again if I can get a ride by Handi-Transit.

Mona sees most of her siblings on a regular basis, but she is upset by her treatment by one of her brothers.

Mona: Well, I have one brother, he doesn't, (sighs), he doesn't talk to me, or phone me, or...Or visit me, or things like that.

Margaret had minimal contact with only one of her siblings, but unlike the other participants, she expressed that she did not want any more contact.

E: Okay. Would you like to see her more, your sister?

M: No...She'll be going away soon anyway.

The reason that I am highlighting the lack of family involvement for the participants is because this may be one of the greatest differences between older women with and without disabilities. As will be discussed in the following chapter, the majority of the leisure of older women without disabilities revolves around their families, and they place great importance on this. This was not the case for the women in my study. Family typically provides many opportunities for leisure that the women in my study are missing out on. Although family leisure is the primary context for leisure engagement for most women, family could also be a constraint to women's leisure due to their role as primary caregivers, and due to the tendency for women to put their families needs before their own. In any case, most of the women in my study had never experienced long-term relationships, and none of the women had children, and as a result they had minimal opportunity for family leisure.

Service Providers

The women who were in community living programs, such as Renee, Rhonda, Rachelle, Alice, were very affected by being involved with these agencies. Their leisure and recreation was controlled and facilitated by the group home staff. Some of the women identified staff as being friends, even though they may lose contact with the staff when they leave their positions.

Staff: Jane's her best friend.

E: I forget, how did you meet Jane, did you used to live with her?

Rhonda: Long time.

E: You've known her for a long time. Did you work with her at [sheltered workshop]?

Rhonda: Um, I don't know.

E: You don't know.

Staff: Jane used to work with you like I do.

Alice: Tara...A friend of mine.

E: A friend of yours?

Alice: Yes.

E: Okay. Do you see her a lot?

Alice: She don't work here no more.

It is widely acknowledged that one of the difficulties in service provision for people with disabilities is the high rate of staff turnover, largely due to low wages and lack of benefits. Renee has only been with her current service provider for a year, and she certainly has seen a lot of staff turnover in that time.

E: So do you do other things with your friends?

R: Sometimes when one of the staff is leaving we take them out for supper and buy their supper, and, you know.

E: Does that happen a lot that the staff leave? (nods). You're shaking your head, yeah.

R: Well Joan left and so did Martha. Martha left because she was having a baby. So then there's a baby shower coming up.

Mona, Margaret and Joanne had no service providers and were much more independent in their leisure pursuits. Leslie and Leanne lived independently, and received some assistance with budgeting and shopping. For the most part, the women who had little or no contact with service providers were more active, more connected in the community, had wider social networks, and they were certainly more in control of their lives.

Safety

The independent leisure pursuits of the participants are generally restricted to the daytime. Most of the women rarely ventured out at night, as they felt that it was unsafe to do so, as explained by Joanne.

Joanne: No, I think we're a lot safer at home. Well she wanted to go out herself and I keep saying no, not alone. She says that, and I say no, she says nothing's going to happen, she says, it's all in your head, I says yeah it might be in my head, but then I said, what's in your head?

E: What are you worried about that will happen to her?

Joanne: Well you never know who's on the street anymore. There's all these shootings that's going on.

Some of this was due to family influence, which unfortunately reinforces some negative stereotypes.

Leslie: Well my brother comes and picks me up on the nights I go to the Travel Log. But I let my brother know what time the Travel Log ends and he comes and picks me up. Cause he doesn't trust me coming home because of the Natives around drunk or that. There are always a lot of Natives.

E: Do you ever go out in the evenings by yourself?

L: No just the nights I go to the Travel Log, I'm out till 9:30.

E: Do you feel that it's not safe, or is it just him who feels that?

L: Well if he thinks it's dangerous, he comes, he just says I just don't trust you out on Main Street at night with all these Natives drinking and stuff, so.

E: But how do you feel?

L: I think he's right.

Joanne, Leslie, and Margaret all stated that they do not go out in the evenings, unless they have a ride with someone to and from the activity.

Margaret: Not much in, no I don't go out in the evening unless I go down there.

E: No, how come?

Margaret: You can't see where you're going in the evening. Unless you're going out with somebody. I wouldn't go out anyway unless I went in a car. Can't walk. Well I mean I can walk a while, but not much.

Renee does not feel comfortable going for walks in the evening, unless she is accompanied by a staff member.

Renee: Well I can't go for a walk by myself, usually it's not safe to go by yourself, so you have to get one of the staff to go with you.

E: How about, even during the day, or just at night?

Renee: Just at night.

Leanne, who was the only women in the study who owned her own home, explained that she didn't go out at night because it's too dangerous, and because she was worried about her house being broken into.

Leanne: No I don't go out in the evenings because it's too dangerous...It's a bad area where I live. It has break-ins.

Rachelle, Alice, and Rhonda, who live in group homes, did not bring up safety as a concern. This is not really surprising, as they virtually never venture out without being accompanied by staff.

For some of the participants, this theme relates to transportation, as some of the women will go out at night, but only if they have a ride, take a taxi, or take Handi-Transit. They would never go out for a walk or take a bus. It is unclear whether or not the safety concerns expressed by the participants have been constant over their lifespan, or if they have changed as the women have aged.

Health

As they are aging, health is becoming an issue for some of the participants. For Joanne in particular, the presence of cataracts is having a huge impact on her life and her leisure.

Joanne: I don't see anything. Just lying around, nothing to do.

Breaking her hip had a big change on Margaret's life. She can no longer take the city bus, so transportation costs have gone up significantly, and she is not able to walk as much as she used to. As a result, she goes to less places than she used to.

Margaret: Well I did go to lots of places when I was all right. But I feel, at present I'm going to enough. That's the best I can say.

Alice was forced to retire when she was having some health problems.

E: So then, when did you retire?

Alice: I wasn't well.

E: A while ago?

Alice: I wasn't well.

E: Oh, you weren't well.

Alice: I was in the hospital.

At one point, Renee was working at a paid position at Pizza Hut, but she had to retire because of problems with her back. These problems still inhibit some of her activities.

E: Pizza Hut, okay.

Renee: The one in St. James, doing dishes.

E: And you got paid for that?

Renee: Yes.

E: Okay. How long were you there?

Renee: Well I was supposed to be there for five years but I retired. Cause my back couldn't take it no more.

Renee:...but I didn't go because of my back was being sore. I was supposed to go last night but I didn't feel up to it.

E: Okay. Does, your back sometimes stops you from doing things?

Renee: Sometimes.

Looking at health from another perspective, four of the participants did engage in programs specifically for exercise, albeit only once per week. Alice and Rachelle went to an exercise program once per week at a gym; Margaret and Leanne exercised once per week at their respective seniors day program. Leanne said that she exercised because it gave her something to do, whereas Alice said she exercised because she liked to. Alice also said that the reason that she bowled was for exercise. A couple of the other participants mentioned that they walked, such as walking to the bus stop or walking around in the library. Renee said that she walked in order to lose weight. All in all, the participants were fairly active, and certainly placed great importance on being active. When I asked the women why they did the activities that they had said were exercise, none of them said that it was for their health.

Disability

The general perspective of the participants is that disability did not have an impact on their lives. Most of the women did not think that they had a disability. Those who did identify a disability identified a physical disability.

Leslie: No I don't. Just a mild one though...Both my feet were clubbed, and this one's still clubbed. But I had the other one straightened out.

E: Do you think that you have a disability?

Leanne: Yes, my bad hand...I had polio when I was eight months.

...E: Does that affect your life?

Leanne: Not really. Cause I can use it.

When asked whether she thought she had a disability, Joanne brought up that the label “handicapped” was given to her bowling team. She didn’t understand the term, and associated it with people’s hands.

Joanne: Oh. Well the, the bowlers they have handicaps, so I don’t know, then that, well that I’m handicapped. But how can I be handicapped if I can bowl?...I don’t know why they’re saying this cause how can a person bowl if they’re handicapped? They must have something with their hands. I know I can use both my hands, well I can use them but I have to be careful of the one, cause I had it broken.

Renee has trouble dealing with money, and identified this as being her disability.

E: No. Okay, great. Do you think that you have a disability?

Renee: Money disability.

E: A money disability, okay, what do you mean by that?

Renee: Well I can’t count money, and I don’t look after money very good.

Margaret was the only participant who talked about disability for any length of time. She expressed a sense of having to belong to certain groups based on your ability to ‘mix’ with them.

Margaret: In a way yes. I can't get around as good, that's a disability isn't it...And I can't just catch on to everything that other people might catch on to, you know?...Like there's certain things I can do and certain things I can't do.

E: Because of, do you mean physically?

M: Yeah, I think you would call it physically, I don't know. Like I mean I don't think I could go into what you call, it has to be people like myself I don't think it could be people that's very normal or something, like, like you or anybody like that. I mean I don't mean your not nice don't get me wrong, but I mean you can't get in with people that's higher than yourself or you don't seem to, you have to get in with people that knows, like you can feel as if you can mix in with them. That's what, I don't know how to explain it better than that.

Overall, there was no indication that the participants perceived that disability had an impact on their leisure. There were some indications that physical disability had a minimal impact, such as Leanne needing help with yard work, and Margaret being unable to take the city bus due to her walker. Margaret was the only person to recognize that having an intellectual disability had impacted on who she was and whom she identified with.

Life satisfaction

This section looks at themes related to life satisfaction. Overall, the women indicated that they were happy with their lives, although most of them felt lonely at

times. I also tried to ascertain the impact of leisure on the life satisfaction of the women by asking some other types of questions that would allow me to get at the concept in a more indirect route. I asked the women questions regarding what was important to them, and what they cared about, because I was interested to see if their answers would correspond to their leisure experiences. I did find that the participants placed great importance on their leisure.

Happiness

Most of the women said that they were happy with their lives. For many, this was because of going out and the things that they do.

Leanne: Yeah... Well, the things that I do, I'm quite pleased.

E: Are you happy with the way your life is?

Alice: Yes.

E: What are you happy with in your life?

Alice: Going out.

E: All those leisure things that you do, what do they do for you in your life?

Renee: Make me more happier.

Mona is happy because of her marriage, Leslie expressed overall happiness, whereas Joanne expressed happiness about the things that worked out positively in her life.

Mona: Yeah...My marriage.

Leslie: Yeah I am...I've had an exciting life right up till now.

Joanne: I'm just happy that's all. About everything that turned out good.

Margaret expressed that she is happy because she is able to do things now that she couldn't in the past, and because she is able to talk and 'mix' with people.

Margaret: Oh I'm happy that I can even talk to people. And ah, they're not any smarter, well the ones here's not any smarter than me, I don't think so.

Margaret: Well I'm happy I can get around. Happy that I can do little things that I never could do. I never used to know how to mix as much as I do. So I think that's an honour. I'm beginning to speak up more for myself, not let people walk over ya.

Only two of the women stated that they were not happy with their lives. Rhonda indicated that she was unhappy in two different interviews, but it is unclear why she is unhappy. Rachelle answered yes the first time I asked her if she was happy, but said that she was unhappy in a later conversation, due to her loneliness.

E: You don't know, okay. Are you happy with the way your life is?

Rachelle: No.

E: No, what are you unhappy, why aren't you happy.

Rachelle: I'm happy, I'm happy, no, I'm, sometimes I get lonely.

It is obvious that for many of the participants in this study, it is their leisure pursuits that make them happy. The next section on loneliness further supports this finding, because for most of the participants, their experiences of loneliness were tied into a lack of leisure opportunities.

Loneliness

Most of the women experienced some loneliness in their lives. Some had methods of coping with this emotion, while others did not. The loneliness was caused by having nothing to do, by having few friends, if any, and because of missing loved ones who had passed away.

E: Why do you get lonely sometimes?

Joanne: Because I have nothing to do.

Alice: I get lonely, I have no friends.

E: You get lonely because you have no friends?...So sometimes you get lonely because you have no friends.

Alice: Not much friends.

E: Not much friends.

Alice: Yes.

Rachelle: A bad life and you lose all your folks, your daddy and them, your daddy and them.

...E: What about now?

Rachelle: Well I, I feel lonely now.

Joanne, Leanne, Renee, and Mona have ways of coping with loneliness, whereas Rhonda does not. Joanne and Leanne get busy and go out.

E: Yeah. What are some things that you do when you are lonely?

Joanne: Well that's what I'm saying, I go to the stores, I don't stay home.

E: Okay. What are some things that you do when you are lonely?

Leanne: I try to keep myself occupied.

Renee and Mona get in touch with family or friends if they are feeling lonely.

E: What are some things that you do when you are lonely?

Renee: Phone my mom.

Mona: Um, when I'm lonely, my oh my oh my. I, well if I get lonely I go talk to my friends that are downstairs.

Rhonda does not have a method of coping with loneliness.

E:...Do you ever get lonely?

Rhonda: Sometimes.

E: What do you do when you're lonely, do you do anything to make yourself feel better?

Rhonda: No.

Leisure has an impact on the loneliness of these women. They are lonely when they do not have anything to do, and because they do not have contact with friends, which as we have seen mainly occurs through leisure. Some of the women cope with their loneliness by engaging in leisure. Simply put, if the women are satisfied with their leisure, they are happy, and if they are not satisfied with their leisure, many of them experience loneliness, therefore it would seem that leisure does impact on the life satisfaction of these participants.

Most important thing/Care about the most

The most important things to the participants were either the things that they did, or people who they were close to. When I asked them what they cared about the most, the answers here were also typically that the women cared about getting out and doing

things, and about the people that were close to them, especially family and friends. For Joanne, the most important things in her life were bowling, which was one of the only occasions for socialization in her life, making wool flowers, and getting out.

Joanne: Well, my bowling, and, and what I said about the wool. That's about the two things. And to try and get out.

Joanne: Well there's nothing I care about, it's just that I would like to get out.

Leanne talks about both the things that she does and the people who she meets as being the most important, and what she cares the most about.

Leanne: Oh I like doing everything.

Leanne: It depends on how a person is... You see, if a person's okay, I'll associate with that person. If a person's no good, I just don't bother.

Leslie and Mona both indicated family as being the most important thing in their life.

Leslie: Well I like my brother and sister-in-law, now there only my next of kin and that so. Because my mom's death I didn't say a word after about seven months straight.

Mona: I think my marriage.

Mona: Well I care about my family, my friends.

Rhonda, Alice, and Margaret both answered that it was friends that were most important. Rhonda had virtually no contact with her family, whereas Alice did have regular contact with one sister, so evidently not a wide family network. Rhonda's only friends are the people who she lives with, or used to live with, and staff. The friend mentioned by Alice is a former staff of her group home, and it sounds like she may have lost touch with her.

E: What do you care about the most?

Rhonda: Umm...my friends.

E: Your friends, great, great. So your friends are pretty important to you.

Rhonda: Yeah.

Alice: Natalie...A friend of mine.

E: A friend of yours?

Alice: Yes.

E: Okay. Do you see her a lot?

Alice: She don't work here no more.

The friend mentioned by Margaret is someone whom she has known for years, who used to be a neighbour.

Margaret: Well this lady that comes to see me on Wednesday she brings me groceries, of course I pay her for the groceries, and we have a long talk, and maybe a cup of tea or coffee. And I've known her for years and years. I'm sure about, oh ah, I'm, I think I knew her by the time I was twenty, twenty something. Ah, I could be wrong. Ah, maybe when dad died, I guess I was about twenty-two when I knew her, and I still know her.

This last section reinforces what has regularly come out in the data, that is, the importance of friends and of getting out.

Summary

Throughout this chapter, I have divided the findings into sections and categories. This was not done to indicate that the findings are separate or mutually exclusive, rather it was quite clear that the elements that impacted on the leisure of the women also interacted with one another. The women are caught in a cycle. Not having money means they are unable to pay for activities or transportation; not having things to do means not meeting people or making friends; when they do meet people and make friends, they cannot afford the transportation to go visit them; when they do not have friends, they do not have people to go out with.

The life satisfaction of the participants of this study was affected by their access to leisure. It was their leisure that connected them with friends and allowed them to meet new people, and it was their leisure that got them out into the community. These two aspects of the participants lives, friends and being out, were the two things that they

placed the greatest importance on. When they engaged in community-based leisure, they met new people and were happy. Most of the women would like to have an increase of community-based leisure in their daily lives. In the next chapter, I will discuss the findings in greater detail, and I will discuss some relevant literature.

CHAPTER FIVE

DISCUSSION

Gerontologists indicate that for older adults without disabilities, leisure is an important element in quality of life. Leisure is used to fill time and to deal with the changes of retirement, and it can also lead to personal growth and development. They acknowledge that activities can be a powerful positive force in the lives of older adults (McGuire, Boyd, & Tedrick, 1999). For older adults with disabilities, particularly women, little is known about their leisure. In the second chapter of this thesis, the literature review, I highlighted what little is known about older women with intellectual disabilities. In doing this study, by no means did I expect to fill the numerous gaps in the literature. Rather, this is a small first step towards understanding leisure in the lives of the older women who participated in the study.

When I embarked on this project, I did have some expectation that the women would be somewhat unhappy with their lives, and that some would be fairly isolated. Instead I found women who are resilient and who certainly do not feel sorry for themselves. What I found was that there are a number of elements that impact on the leisure experiences of these women. Money was an issue, but the desires that these women expressed as to what they wanted to do were not grandiose, expensive whims, but simply the desire to be out in the community and to have social contacts. The limiting factors were the difficulties surrounding transportation, and the lack of friends that transfer through different settings. The women did express that they had difficulties and that they were unhappy with certain areas of their lives, but when asked directly about

their happiness, most of them said that they were happy overall. They seemed to really try to have a positive outlook about their situations. Even Joanne, who repeatedly stated that she had no friends and nothing to do, said that she was happy because of all of the good things in her life. All of the participants were very cognizant of the role that leisure has in their lives, and especially what their lives without be like if they did not engage in their leisure.

This chapter is divided into the same categories as the previous chapter. In each section I will speculate on some of the possible reasons for the findings, and I will discuss some of the implications. I will also include comparable findings and observations from the literature. This chapter will conclude with a summary and with some recommendations based on what I have learned.

Nature of Leisure

Meaning of Leisure

Although the women who participated in this study may not have been able to articulate a theoretical definition of leisure, it was interesting to see that the participants really recognized the meaning of leisure in their lives, and what their lives would be like if they did not have their leisure pursuits. An important finding of this study has to do with communication and the ability of the participants to express their needs and desires. When asked questions directly about aspects of their lives, such as if they feel they have enough money to do the things they want to do, they would generally reply that they did, even though they may have mentioned that they did not do certain things because of the cost. Another example was that when asked directly if they were happy with the amount

of friends that they have, they would answer yes, but with further probing it would become clear that they were not happy with the amount of friends that they had and would really like to have more friends. Communicating their needs could be an issue, as asking a few direct questions would not really elicit accurate information about what these women want and need. Boyle et al. (1988) warned that women with intellectual disabilities are often dismissed because of the manner in which they may communicate their needs and desires. The participants in this project are clearly at risk for not being properly understood. Benz & McAllister (1990) reported similar findings with the older adults whom they interviewed. The participants in their study reported overall satisfaction with their leisure activities, but with further probing, the participants voiced their opinions as to what would make their leisure more meaningful, such as wanting to have more to do in order to alleviate the boredom they were feeling.

In this study, the three women who recognized the term leisure described it as meaning 'doing things'. In order to elucidate the meaning of this concept, as described in the methodology section, I asked numerous questions, and asked them in different ways. In the third interview the women were asked why they did the activities that they identified in the second interview, and how these things made them feel. Their responses demonstrated that they did in fact realize the impact of leisure in their lives, and particularly what their lives would be like without leisure. Clearly, leisure afforded them the opportunity to go out, which was of paramount importance to the participants. Other studies report similar findings, such as the one by Benz & McAllister (1990). They interviewed older adults with intellectual disabilities, and found that many of their

participants “demonstrated an overwhelming desire to be doing something during the day that was personally meaningful” (p.238).

Another role of leisure that is of enormous importance to the participants had to do with friends. Margaret was the only participant who did not want to have more friends. The other eight participants all wanted to have more friends, and they recognized that it was through their leisure that they were able to socialize and to meet new people. The issue of friendship will be discussed in greater detail in the remainder of this chapter, along with some of the other roles of leisure that the women described. Overall, leisure had an overarching and pervasive role in the lives of the women in this study. Leisure allowed them to get out, to keep busy, to meet friends and to socialize. It helped them deal with the loss of parents and with dwindling family contact. It gave the women feelings of happiness and helped appease feelings of loneliness. It allowed the women to feel like they did not have a disability, to feel needed, and it gave them a valued social role. Leisure connected them to the community, and gave them something to care about. All of these factors will be discussed in the remainder of this chapter.

Categories of Leisure

Community Based

The women who participated in this study expressed a clear preference for community-based leisure over residence based leisure. Margaret plainly indicated that her preference is to be out in the community. It sounds like the residence based leisure pursuits that she mentioned are things that she does to pass the time, and not what she really wants to do.

E:...so all these things that you have to do that we were just talking about, how do you think you would feel if you didn't have all these things to do?

Margaret: Well I would just have to put up with reading the paper or looking at Sally [talk show], or something like that.

E: Yeah. So how do you think you would feel if you didn't have.

Margaret: Well I'd rather be out amongst the people. You get to know what each one has to say.

Benz & McAllister (1990) stated that "the real issue for a high quality of life is not how much leisure time one has, but whether that time is spent doing things of one's choice, with others of one's choosing, and as often as one would like" (p.238). When I think about the lives of the participants and compare them to this statement, I realize the participants certainly do have a lot of leisure time, and that they are not doing things of their own choosing as often as they would like, and certainly do not always have people to choose to do it with. The majority of the participants indicated that they would like to go out more than they do. The reason that some of them gave for doing activities was to get them out of the house. This is the reason that Leslie gave for volunteering.

E: Is that leisure for you?

Leslie: Oh yeah. Gets me out of here.

According to the criteria put forth by Benz & McAllister, the participants would not be thought of as having a high quality of life. I think the personal perceptions of the participants would differ from that of a person without a disability in comparing their life experiences to established 'standards'.

The second issue that I wanted to discuss in this section is the participants' responses to the question regarding what they would do in a day if they could do anything they wanted. If they could do absolutely anything in a day, most of the women would go out and do something such as shop, or have coffee with a friend. On some level, it is unfortunate that the women tended to choose such commonplace things for their day. Mona was the only one that gave a dreamers answer. I am well aware that I am judging this through the lens of my preferences and experiences, however it would be nice to see that these women were not completely limited in their thinking and resigned to their daily lives, that they do not have some dreams or fantasies. I do not have information about what older women without disabilities would answer, but it is likely that people with broader experiences would choose more varied options. It is possible that this question was more abstract than most of the other questions that I had been asking. The difficulty might also lie with the lack of experience that the women have with choosing among undefined options.

Volunteer work

Volunteering has been a very positive experience for the participants. It is interesting to note that these women are of a population that is not generally perceived as being in a position to give help, rather they are seen as needing help. The women who

were involved in volunteer positions expressed feelings of satisfaction because they were helping other people. As Pedlar et al. (1999) also explained, volunteer work differs from sheltered workshops in that the people are in more integrated settings, and they tend to do more meaningful work and are recognized for their contributions. Volunteer work is also typically more individualized and flexible. "While volunteer jobs could confine people to more menial tasks than people might typically pursue in the community, many were viewed as more stimulating and rewarding alternatives to the workshop" (p.72).

Renee worked for a number of years in a sheltered workshop, and then did have some success in paid employment, but had to retire because washing dishes was too hard on her back. She is now once again working in a sheltered workshop. As mentioned in the previous chapter and as shown in the following quote, she has some feelings about being taken advantage of, and does not want to remain a volunteer. She hopes that she will eventually be paid for her work, even though she realizes that the salary will not be very much.

E: That's right, and you were retired last time I talked to you, how come you decided to go back to work?

Renee: Well, like it's volunteer work...But I'm not going to be a volunteer.

E: No?

Renee: And there, they're trying to, um, [supervisor at workshop] is working on it to get me on her board members, and if they accept me as a workshop worker, then I will be getting a pay check.

E: So if they accept you as a worker you'll get paid?

Renee: Well it's not very much money, but...They don't even pay my bus pass.
My monthly Handi-transit bus pass.

However, because this position gives her a chance to be with friends, and gives her something to do during the day, she will stay in the position irregardless of if they start to pay her or not. She also makes the distinction that this is not leisure, it is hard work.

Leslie, who is 55, and Mona, who is 57, worked in sheltered workshops for 19 and 28 years, respectively. When they changed service providers, they both became employed for pay. Leslie worked in a few different places, and was terminated from several positions. After about two years of this, she changed service providers once again, and chose to do volunteer work, where she has achieved much success. Mona left the sheltered workshop in order to work for a community living agency, where she worked for about two years. She was told that they were not satisfied with her work and she was terminated. She tried to go back to [sheltered workshop], but they would not take her back because she had left 'of her own free will'. So she now volunteers five days a week, but she would prefer to have paid employment.

Pedlar et al. (1999) considered the matter of paid employment versus volunteering. The participants in their study also enjoyed the socializing and the sense of helping others through volunteering, but the authors did see some negative aspects to this. They stated that "The use of people to perform tasks for payment in kind obviously raises questions of equity, and at times dignity, for the person" (p. 64). However, they acknowledge that it is the experience of the individual that is the most critical factor to consider, and that these opportunities allowed individuals time away from the sheltered

workshops. Interestingly, when they discuss paid employment, they indicate that very few of the people involved in their study find success in this realm, but that those who do feel a great deal of pride in their achievements. For those individuals who are competitively employed, they have the opportunities afforded to them by virtue of having an increased income, and they have the opportunity to volunteer if they so choose.

It is important to consider whether volunteer work is something that is chosen, not something to do as an escape from a sheltered workshop or because of failures in competitive employment. Pedlar et al. (1999) stated that there is very little opportunity for people with disabilities to pursue competitive employment, and therefore “people used volunteer opportunities whenever possible to help bring a sense of purpose and worth to their daily situations” (p.65). Many older adults without disabilities volunteer (McGuire et al, 1999). Volunteering provides these older adults with an “opportunity to serve, to achieve recognition, to be active, to use skills, and to exhibit mastery and competence” (p.112). It also allows individuals to feel like they are contributing members of their community, which is considered to be crucial to successful aging. The difference for the older adults in this study is that the choice to volunteer is most likely a choice among options, or something done after a career has ended, and not something done because they could not get a job for pay.

Church

Church had a large role in the lives of some of the participants. Mona, Renee, and Leslie go to services regularly, and are very involved in things like choir, volunteer dinners, and bible study class, for example. Leanne also goes to church and attends choir

practice once a week. Rachelle made the only friend that she has, other than the women and staff in her group home, at church, and Joanne told me about an upcoming church dinner that another parishioner was giving her a ride to. Being involved with a church has afforded these women with numerous leisure opportunities, and has played a really positive role in their lives. I think this could be a great resource which could help deal with some of the difficulties in the lives of these women, such as problems with transportation. The church could be a great place to recruit volunteer drivers. These findings really underscore the benefits of being part of a group. I am not suggesting that everyone should attend church, but it may be very beneficial to help connect people to other groups. For example, the women who do crafts could go to a knitting circle or a painting class, where they could meet people with common interests; those who bowl with Special Olympics could join a woman's bowling league. Meeting people with common interests may be conducive to forming friendships, which the women in this study clearly need opportunities to do so.

The one concern is the potential of a group's ideals to overwhelm someone who has an intellectual disability. Renee's leisure is dominated by the agency that supports her, which is owned and operated by a religious organization, and almost completely revolves around church activities. Renee moved to this support agency about a year ago, and before this she was not as involved with the church. Her attitude appears to have been quite influenced by this, as seen in her comments about dating a Christian.

E: He's not her boyfriend?

Renee: No...Because he's not a Christian. Ah, he doesn't go to church, and ah, he doesn't know how to treat a woman or a girlfriend. And, you know, what kind of life, I mean, I said to Patty, what kind of life is that?

E: So if somebody's not a Christian then they shouldn't be your boyfriend?

Renee: Right, you got to be a Christian to have a boyfriend.

E: Have you been learning that with [service provider]?

Renee: Yes.

Factors that affect the leisure of the participants

Aging is usually thought of being a phase of life in which a person slows down (McGuire et al, 1999). The women who participated in this study did not want to slow down, rather they all wanted to do more than they were currently doing. Those who were slowing down or who were not as active as they would like to be were not doing so by choice, but were forced to by circumstances. Benz & McAllister (1990) conducted a qualitative study in which they interviewed older adults with intellectual disabilities. They reported that 90% of the participants were satisfied with the kinds of leisure activities in which they participated, and that the majority of the participants indicated that they usually chose for themselves the types of activities that they participated in. However, participants indicated that they were not satisfied with the frequency of their leisure involvement. They gave three reasons for not being able to participate as often as they would like. The first reason they gave was that no one was available to go along with them during leisure time. The second reason they gave was that there was a lack of available transportation. The third reason given was a lack of activities in which to

participate. These findings are congruent with the findings with the participants in my study.

In the literature review I indicated that older women with intellectual disabilities may have difficulties in developing and maintaining friendships. This was clearly the case for the women who participated in this study. The next section will outline what the participants taught me about their friendships.

Friends

McGuire et al. (1999) stated that being needed is an important part of friendship, and friendships are very important in later life. "Friendships provide support for coping with adverse events in life, feelings of attachment based on reciprocity and equality, can validate feelings of self-worth and social integration, and provide a role and meaning in life" (p.112). They suggest that leisure is a means that can be used to counteract the threats to friendships for older adults, threats such as moving and retirement. This is important, because the friendships of older adults with intellectual disabilities tend to be context specific. One of the findings in a recent study by Mahon, Mactavish, and Bockstael (In press) was that the friendships of the majority of the participants' were confined to the contexts in which they originated, and they seldom transferred to other situations or settings. Bigby (1997) also found that the participants' social networks were context specific, meaning that the participants usually did not have contact with friends outside of the context in which they were made. An explanation offered by the authors of the first study was that "Limited opportunities and other constraints (e.g., transportation), therefore, resulted in context specific friendships that made it difficult for the participants

with a disability to socialize with their friends across different settings and situations” (Mahon et al, In press). The authors called these compartmentalized relationships “islands of social integration”.

Most of the friendships of the women in my study were also context specific. Three of the participants worked at sheltered workshops for many years, and when they left lost all contact with their friends. Joanne clearly illustrates this in a statement she makes regarding making friends at her Special Olympics bowling group.

Because then you get to know the people, you get to know them. You make friends with them. But the only thing is you make friends with them but they live too far away from you to talk to after.

Heyne, Schleien, & McAvoy (1994) state that one of the common barriers to making friends for people with disabilities is that they are unaware of recreation/leisure’s role in facilitating friendships. This research was done with young people with disabilities and their families. In my study, the participants were well of aware of recreation/leisure’s role in making friends.

E: Okay. What role does leisure have in your life?

Mona: What role?

E: Yeah.

Mona: It helps me to, I have to go, um, it helps me to, to get to know other people.

And helps me to make new friends.

The problem for the participants in this study was not recognizing the value of leisure in facilitating friendships, but was transferring these friendships into other segments of their lives.

There are clearly external barriers to developing friendships without boundaries, such as difficulties with transportation, however there seem to be personal barriers as well, such as the lack of skills to maintain friendships when leaving one setting. It seems that a life skill that is lacking for the women in this study is the ability to maintain contact with friends and to foster ongoing friendships.

E: Do you ever see any of the people from school outside of school?

Leslie: No, I don't see any of my old friends. I don't know where they are.

E: Do you ever talk to them on the phone?

Joanne: No cause see they don't give me their phone numbers.

E: Oh okay. Do you ever ask for their?

Joanne: No. I guess maybe, one way I guess they think it's best that they don't give you their phone numbers.

Referring to women without disabilities, Traustadottir (1993) stated that "Friendships play an important role in women's lives and many women seem to consider close friendships with other women a necessity for their well-being" (p.115). Women tend to put more effort into meeting people, establishing friendships and maintaining

them, than do men. Women without disabilities express love, affection, closeness and emotional attachment when describing their friendships, and they devote a lot of time and energy to their friendships. They have friendships that are “broad and less likely to be segmented” (p.114). They tend to make deep commitments to their female friends, whereas men’s friendships are generally segmented, and revolve around specific activities. Women typically have more friends, particularly close friends, than men. It appears that women with intellectual disabilities have friendships that more closely resemble those of men without disabilities, than of their female counterparts.

As Amado (1993) succinctly put it, “Having friends is not a luxury, but a necessity to life” (p.83). Unfortunately, this is an area that is lacking for many individuals with intellectual disabilities. Traustadottir (1993) stated that “despite more than two decades of community-based services, most people with disabilities continue to be isolated, lonely, and have few friends – especially non-disabled friends” (p.110). This is apparent with the women who participated in my study. They have few friends, and for the most part their friendships are context specific. The participants expressed a desire to have more friends. It was clear that the participants developed many of their friendships in leisure settings. As such, leisure education could play a role in providing these women with a venue where they could meet friends, and then teach them how to maintain friendships and transfer them to other settings and situations. With individualized leisure education, we can focus on what people with intellectual disabilities consider important in their own lives, and not what is deemed important by others.

Transportation

In the previously discussed study by Benz & McAllister (1990), the second reason that the older adults with intellectual disability gave for not participating in leisure as often as they would like is that they experienced a lack of available transportation. This was clearly the case for some of the women in my study. Four of the women who did not identify transportation as a problem relied on staff to take them places or to make arrangements for their transportation. The two oldest women were unable to take a city bus, so they were limited to more expensive and less trustworthy alternatives. Even the cost of taking a city bus was prohibitive for one of the participants.

McGuire et al. (1999) emphasized that transportation is a key concern in relation to older adults without disabilities. "Lack of a car, failure of public transportation to meet needs, poor driving skills, and economic constraints may result in limits in mobility" (p.185). This is a crucial need that often is not met for older adults. The authors gave some suggestions as to how to deal with transportation problems, including "use of volunteer drivers; reduced or subsidized fares on public transportation; a transit system designed for older users and including appropriate routes and schedules" (p.185). These suggestions would certainly improve access to transportation for the women in my study who identified transportation as being a limiting factor to their leisure.

The lack of transportation directly impacts on the leisure of these women in terms of getting to the activities, and it also impacts on their leisure by impacting on their ability to develop and maintain friendships. Mahon & Bullock (2000) identified lack of transportation as one of the barriers to making friends for people with disabilities. Joanne

recognized that lack of transportation was a barrier to maintaining friendships that she made at Special Olympics bowling:

Because then you get to know the people, you get to know them. You make friends with them. But the only thing is you make friends with them but they live too far away from you to talk to after.

Furthermore, Mahon & Bullock noted that "In particular, if an individual relies on others for transportation, her ability to enjoy more spontaneous experiences with friends is curtailed" (p.148). For the participants who relied on staff for transportation, this could very well be an issue, and merits further exploration. It is evident that the financial situation of the women who participated in this study impacts on the transportation options available to them, which limits their access to activities and impacts on their friendships. The following section will more broadly examine the impact of financial situation on leisure.

Financial Situation

In the general population, people are living much longer and many of them have the economic means to enjoy retirement (Brown, 1993). The situation of older adults with intellectual disabilities parallels that of the general population in that they are also living longer, however they certainly do not have the same economic means. Bullock & Mahon (2000) expressed concern over the high rates of unemployment and resulting financial

situation of people with disabilities. "In particular, one of the most concrete results of such high levels of unemployment is the poverty that comes with it" (p.144).

The women who participated in this study were definitely affected by a lack of funds, and seem to have resigned themselves to the impact of poverty. They do not complain about a lack of money, it is simply a reality of their lives. When I asked Mona what stopped her from taking a trip that she said she would like to take, her response was "there's nothing stopping me, it's just that I can't afford it right now". When I asked Margaret if not having money ever stopped her from doing anything, she replied, "No, when I don't have much money I don't do much". It is important to once again recognize that the women were not always able to identify their needs, as previously discussed. It seems as though the women have resigned themselves to the fact that they are limited by their financial situation. A reasonable deduction is that the women have felt the sting of poverty for most of their adult lives, and therefore they have learned to keep their expectations and desires within the realm of what they can afford. They are used to living within these limitations, and have perhaps learned not to want for more. While this is similar for most people in poverty, it is important to recognize that the poverty of these women is due to their disability.

Another impact of poverty may be that the women have limited exposure to the wide variety of leisure opportunities available to most people. In a study by Benz & McAllister (1990), one of the reasons that the older adults with intellectual disability gave for not participating in leisure as often as they would like was that there was a lack of activities in which to participate. Hutchison & McGill (1992) describe this manifestation of financial poverty as being "poverty of experience". The leisure opportunities of people

with disabilities are limited to pursuits that they can afford (Bullock & Mahon, 2000). This seems to be the case with the participants in my study. They did not participate in a wide variety of activities. In fact, they tended to do similar things, and the activities that they were involved in were certainly not expensive activities. This issue was not clearly articulated by the participants, but how can you express a desire to do certain things if you are not aware of them? The participants did clearly articulate that they would like to have more to do, but they were not specific about what they wanted to do. What they were very clear about was that they wanted to go out more, and they certainly never said that they wanted to have more to do in their residence.

This highlights a need for leisure education, as the women were evidently unaware of the variety of leisure opportunities. Since they may not have had the chance to explore many different leisure pursuits over their lifespan, it would be beneficial for them to learn about other affordable activities that might be of interest to them. The onus also rests on recreation professionals to provide programming that is financially accessible to this population. This programming should be available for individuals with disabilities at any age, but because of all the other limitations to the leisure of older women with intellectual disabilities, providing accessible opportunities is of great significance.

Family

There is a lack of literature that looks at the leisure patterns of individuals with disabilities and their families (Bullock & Mahon, 2000). Overall, the participants in my study did not have much contact with their families. Brown (1993) reported that as

parents of individuals with disabilities age, they are less involved with their children. This diminished involvement translates into the "loss of primary advocates for people with intellectual disability" (Brown, 1993, p. 221). It is not clear whether this is the case for the participants in my study, because I am not fully informed about their personal histories. What is clear is that the participants have very little family leisure. Henderson et al. (1989) stated that for many women, "the family is a major contributor to role identity, life satisfaction, and leisure opportunities" (p.122). McGuire et al. (1999) recognized that family involvements are important to older adults without disabilities, particularly for older women: "Women occupied the nurturing or organizational roles in dealing with family, and they spent more time in conversations with friends and family" (p.166). None of the women in my study had children or grandchildren. It is apparent that the older women with intellectual disabilities in my study do not have the same experiences and opportunities as older women without disabilities, although they may very well have the same needs. This may be the area where there is the greatest difference for women with and without disabilities.

Leanne and Mona were the only participants who had significant involvement with family. Leanne was married for eighteen years, and since her husband passed away three years ago, she receives a great amount of support from her father and her sister. Mona spends a lot of time with her husband, and she has regular meals with her siblings. Her parents live in a different province, and she visits them when she can. These were the only two women to have significant, long-term romantic relationships. Renee was briefly married. It is unclear what exactly happened, but the relationship was short lived and she has not had any other significant relationships. It is interesting to note that the three

women who had romantic relationships are also the three women who continue to have the most family contact. The only speculation I have on this is that perhaps the families view the women more as equals and have more in common with them and the relationships are more reciprocal. It is also possible that the women need more assistance in maintaining their relationships. It would be interesting to further explore this finding.

Renee talks to her mother everyday, and because of her mother's advanced age and failing health, she helps her with tasks like laundry and cleaning her apartment. The other participant's parents have passed away. Those who have siblings, like Alice, Joanne, and Leslie, have some contact with them, but they do not have much impact on their leisure. The siblings give them someone to have an occasional dinner with, and Leslie also gets some help with transportation. Rhonda and Margaret have siblings, but have virtually no contact with them. Rachelle does not have any siblings, but occasionally sees some of her aunts. In a study by Botuck & Levy (1995), the majority of the older adults with intellectual disabilities who participated had no parents, and about half of the participants received one or less than one visit from their family per year. The authors pointed out that older adults without disabilities have enhanced life satisfaction when they are able to maintain family ties. These findings, coupled with the findings from my study, "highlight the need for friends and for surrogate families to provide and maintain a social support network which could mitigate the absence of a social/familial support network" (p.10).

Another noteworthy finding of Botuck & Levy (1995) is that there were gender related differences in terms of the location and nature of family visits. The visits with women were of a more passive nature, and usually consisted of the family visiting the

women in their home, whereas the familial visits with men tended to be more active, consisting of outings and involvement in community activities. The authors suggest that these findings confirm “societal expectations of gender role” (p.10), in that women tend to be more passive and men tend to be more active. This is interesting when you consider the findings of my study, where virtually all of the women expressed a desire to get out more. This accentuates the importance of asking people what they want, not relying on expectations and stereotypes.

The impact of family on the leisure in the lives of the women in my study is one of ‘absence of involvement’, meaning that this lack of involvement closes another door of opportunity for leisure. My intention is surely not to cast a negative light on the parents and siblings, who would naturally be dealing with their own aging, rather my intention is to speak to another reality in the lives of the women in this study. Brown (1993) suggested that one way of dealing with the diminishing involvement of the family is to ensure that “adequate advocacy systems for the aging individual are set in place long before the process of ‘family separation’ occurs” (p.223). This emphasizes the importance of having a strong social network that is comprised of not just family, but of friends. Also, it is important to recognize the importance of really knowing what someone wants, and not making assumptions or heeding to stereotypes.

Service Providers

Although I did not question the participants directly about service providers, it became clear that they do have an impact on the leisure of the participants. The four women in community living programs identified roommates and staff as their friends,

and generally any other friends they identified were people who they had previously resided with, former staff, or other people supported by the same agency living in the same apartment complex. Brown (1993) indicated that although friendship networks are difficult to create and sustain, greater exploration within the community tends to lead to natural friendships, as opposed to the more common “institutional friendships” with staff (p.223).

For the individuals in the group homes, the scheduling of the interviews was done with the group home staff, at which time the staff often commented on how busy the women were, and how full their schedules were. However, Alice indicated that she spent too much time in the house, and all four women indicated that they would like to get out and do more. It seems that the staff and the women hold different ideas as to how busy is busy enough. Jurkowski & Amado (1993) described a situation where what was important to residents’ in a group home and what was important to the service agency clearly differed. The resident’s conversations constantly revolved around the importance of having a boyfriend/girlfriend, marriage, children, affection, companionship, and sexual matters. Meanwhile, what the agency had decided to teach the residents were self-help, household, and vocational skills. There is a huge gap between what is important to people with disabilities and the support that they actually receive. The programs they receive are mainly focused on domestic and vocational skills, while less attention is given to “teaching the interactional skills important for developing and maintaining satisfying social relationships” (p.143).

For the participants in this study, those with service providers have different experiences than those without. It is unclear how much of this can be attributed to the

role of service providers, and how much is attributed to the characteristics of the participants. Three of the four participants who lived in group homes required the most support out of the nine women, which may also be explanation for some of the differences identified. Those who did have service providers had fewer difficulties with transportation, as previously discussed, and in Renee's case she became very involved with programs put on by the agency that supported her. However, it was evident that in some cases the staff and the participants differed in their opinions about leisure, which also may have impacted on the leisure of these women. Without a doubt, decisions and planning should be based on the opinions of the individuals with disabilities, and if they are being taught further life skills by the service agencies, it should revolve around their needs and interests, and what is important in their lives.

Safety

Some of the participants in my study expressed concerns about safety, and thus limited their activities accordingly. Brown (1993) stated that older adults without disabilities face some limitations to their activities due to fears about the community environment. These older adults may limit their social activities to daylight hours, and ignore social events in the evening hours, due to their fears, and also because of their diminishing eyesight, hearing, and motor responsiveness. Margaret made reference to diminishing eyesight with her statement that "You can't see where you're going in the evening". It is evident that the leisure of some of the women in my study are similarly limited by safety concerns, as are older adults without disabilities. Women with intellectual disabilities have every reason to be concerned, as they are at greater risk of

being victims of violence than are women without disabilities (Asch & Fine, 1988; Boyle et al., 1988; O'Toole, 1990; Traustadottir, 1992). One solution would be to have the majority of programs offered during the day, although improved access to transportation may also allow for the participants to partake in activities in the evening.

Health

Referring to older adults without disabilities, McGuire et al. (1999) indicated that older individuals are less likely than younger individuals to exercise regularly. The participants in my study certainly wanted to be as active as possible, but they did not exercise extensively. Some of the women did exercise, but none of them exercised more than once per week. Those that did exercise did so because it made them feel good and it gave them something to do. Overall, the participants seemed to enjoy reasonably good health, with some exceptions, as highlighted in the previous chapter. Joanne was very affected by health concerns at the time of the interviews.

Joanne: I don't see anything. Just lying around, nothing to do.

E: What do you do for leisure?

J: Well, if I do anything it will be my painting once I get everything settled with my eyes and that.

She is scheduled to have surgery on her cataracts, so hopefully her eyesight will be enhanced. For some, health problems precipitated major changes in their lives. When Margaret fell and broke her hip, she had to move to a place with a higher level of care,

and she is still not able to do as much as she used to. Her access to transportation was also affected. Renee and Alice both retired due to health problems.

Bullock & Mahon (2000) explained that "In many cases, the vicious circle of chronic unemployment and poverty for people with disabilities can lead to health problems and limitations of personal control" (p.144). Although the participants in my study do not make the connections outlined by Bullock & Mahon, these factors have most likely taken a toll on their health over the years. McGuire et al. (1999) stated that leisure has the potential to reverse this lack of regular exercise and ultimately increase physical health. Leslie was the only participant who talked about some concerns for her health in the future:

L: I was different then my mother. She was a nurse and then when she retired and at the end she slowed down a bit.

E: She slowed down a bit, okay.

L: Yeah, and I said boy I hope that doesn't happen to me.

E: Okay, so you don't want to slow down.

L: No. She was just hoping I don't land up with the arthritis she had.

E: Oh really, she had arthritis.

L: She had it bad. She even an implant done in one of her knees.

There is a push for the population at large to become more active and exercise regularly in order to maintain good health and prevent illness. It does not seem that this

message has reached the women in my study, which underscores another area where leisure education could have an impact.

Disability

It was interesting that only a couple of the participants identified any type of disability, and in doing so mainly identified physical disabilities. Renee's understanding of disability was very functional. She described that she had a 'money' disability, because she had difficulty with counting and managing her money. Margaret was the only participant who felt that she had an intellectual disability, and her explanation was poignant. She seemed to be saying that she should associate with people who are like herself, and not people who are 'very normal', who she identified as being like me, the interviewer. She perceived other people as being 'higher' than her, and felt that she should only mix with people like herself. She did not seem at all disturbed by this, but I felt bad that she had this self-image that she was 'lower' than other people. I do not know how she came to describe herself in this way, and can only surmise that she has felt some of the stigma associated with the label she carries.

I am not sure how to interpret this overall finding, which was that most of the participants do not recognize that they have an intellectual disability. I find myself reacting positively, as there is such negative stigma attached to this label that I venture to say the women are probably better off not to identify with it. As discussed in the literature review, there is some disagreement about the psychological impact of disability. Some of the literature indicates that disability has a greater effect on a person's identity than does gender, while others contend that disability may not be a central component of

a woman's self-concept. A great deal of the literature does seem to point to disability having a negative effect on a woman's self-esteem and self-image, which in turn impacts on their leisure. This was not the case with the participants in my study. However, even though they did not implicitly recognize having a disability and what bearing it has on their lives, this may simply mean that I was not asking the right questions. What is clear is that this issue should continue to be explored.

In this section, we have explored in detail the factors that impact on the leisure of the women in this study. The next section will discuss the life satisfaction of the women who participated in this study.

Life Satisfaction

At present, very little is known about how leisure affects life satisfaction for older adults with intellectual disabilities, particularly women (Hawkins, 1993). In the preceding section I discussed the factors that impacted on the leisure of the women in my study. In this section, I discuss some of the information that the women provided about their life satisfaction.

Happiness

Most of the participants, when directly asked, said that they were happy. Only two of the women stated that they were not happy with their lives. However, given the participants responses to other questions, there is clearly room for improvement. For example, when I asked the women if they were happy with the amount of friends they

had, they said that they were. It became clear, however, that most of them had few friends, and would like to have more.

Notwithstanding this, it is clear that the women are happy with their lives, or at least certain aspects of their lives. When I asked the women what they were happy with, it seemed to be certain segments of their lives. For instance, when I asked Alice what she was happy with in her life, she answered "going out". Leanne said that she was happy with the things that she does, Mona said she was happy with her marriage, and Joanne said that she was happy with the things that "turned out good". Happiness closely corresponds with the closeness of relationships with family members (Amado, 1993). Few of the participants in my study had close family relationships, and Mona was the only participant who answered that her happiness stemmed from a relationship. Happiness also closely corresponds with loneliness, in that the happier a person is, the lower the reported level of loneliness (Amado). Even though most of the women indicated that they were happy, most of them also indicated that they experienced loneliness.

Loneliness

"Loneliness is an aversive and punishing condition for a human being" (Amado, 1993, p.83). Loneliness was an emotion experienced by almost all of the women who participated in this study. Even though it is widely known and accepted that people with disabilities have very limited social connections and very few friends, there has been minimal investigation regarding the effects of this social isolation. (Amado). Amado explained that even if a person has a large amount of social contact, they may still be

lonely. In the context of the lives of people with disabilities, this means that even if people are involved with staff 24 hours a day, they still may experience loneliness.

Amado (1993) summarized some of the factors that are associated with loneliness for people without disabilities. One of the factors was gender. Women were either more lonely than men, or there was no difference between the sexes. Another factor was transportation. "People with adequate transportation were generally less lonely than those without it. People without adequate public or private transportation were isolated and restricted in their social contacts" (p.70). Three other factors of interest are ease of making friends, happiness, and money. In terms of making friends, it makes sense that those who easily made friends were the least lonely. Happiness is correlated with loneliness, in that the happier a person is, the lower the reported level of loneliness. Finally, money is a factor in causing loneliness. "When money was seen as inadequate, activities were often limited, contributing to feelings of inadequacy and loneliness" (p.70). As we have seen, these factors all adversely impacted on the lives of the participants, therefore it is not surprising that many of the women in my study experienced loneliness. Some of them had methods of coping with this feeling, and some did not. The coping strategies that they identified were some of their leisure pursuits. Rachelle said that she was not happy with her life because she was lonely. She did have methods of coping with this loneliness.

E: How does it make you feel to draw?

Rachelle: Well, I draw when, when I get lonely.

E: You draw when you get lonely. Okay, great. So it makes you feel better to draw?

Rachelle: Yeah.

E: So why do you get lonely sometimes?

Rachelle: I get lonely for my auntie.

E: You get lonely for your auntie?

Rachelle: Yeah.

E: You see your auntie sometimes, right, that's what you told me?

Rachelle: Yes. Sometimes I phone her up.

E: Oh, you phone her up?

Rachelle: When I'm lonely.

Loneliness may have serious and even deadly effects. Amado (1993) cited research which indicated that social isolation was a greater mortality risk than smoking, and concluded that "loneliness contributes significantly to poor physical health and increases the likelihood of illness and premature death" (p.72). It is clear that loneliness has great capacity to "interfere with the ability of people with disabilities to have a full, rich life" (p.76).

Summary

Leisure clearly does have an impact on the life satisfaction of the women in this study, and it seems that as their leisure increases, so does their life satisfaction. The women were quite clear about what was the most important thing in their lives. In all cases, it was either the things that they did or the people whom they were close to. It was utterly clear that the women in this study wanted to be out in the community more often

than they currently were. They wanted to go out more, simply to walk around in stores or to have coffee and chat. It is amazing how many things prevent them from doing these simple things as often as they would like. The things that impact on the participants' leisure are money, transportation, friends, family, safety, health, and disability. I am unable to list them in order of importance, because they all interact with one another.

Disability reaches it's tentacles into every life experience. Working in a sheltered workshop for five dollars a month, having hardly any friends or family, living in a group home, not being able to afford to take the bus, and not knowing what you are missing, are all realities of having a disability. Although the majority of the women did not recognize that they have an intellectual disability, having a disability led them down their life paths to the situation that they are in today; low socioeconomic status and isolation, lack of experience and knowledge of the vast realm of leisure pursuits available to most, and the lack of a dream.

As indicated in the literature review, most older adults with intellectual disabilities are not satisfied with their leisure. They have a lack of activities and of community-based experiences, spend more of their free time in their residence, and have diminishing family connections (Ashman & Suttie, 1996; Glausier et al, 1995). The possible barriers to participation identified were: lack of opportunities, lack of skills for participation, difficulties traveling to events, negative attitudes by others, lack of friends and family support, lack of ability or opportunity to make decisions, limited community access, lack of available services, and changes in health status. There are evidently similarities between my findings and the findings identified in previous research. The limited amount of research that has been conducted on leisure and older adults with

intellectual disabilities includes both women and men, and does not make distinctions based on gender. As such, it is difficult to identify differences based on gender, as they are not comparable groups. There is a need for research that is sensitive to gender differences in order to further our understanding about possible differences in experiences for men and women.

The literature on older women without disabilities indicated that leisure has a direct impact on life satisfaction. Most of their leisure is home based. Many older women were afraid to go out alone at night, and this impacted on their leisure. Older widows primarily faced constraints to leisure in the areas of money, companionship, safety, health, transportation, and lack of perceived opportunities (Wilhite et al, 1994; Siegenthaler, 1996). It is interesting to note the similarities between the experiences of older women without disabilities, particularly widows, and the women who participated in this study. It is conceivable that the women who participated in this study are affected by both their disability and by their gender, since they share similarities with both groups. As the body of literature on women and leisure continues to grow, we will have a better understanding of the issues particular to older women with intellectual disabilities.

Recommendations

One of the implications that Amado (1993) outlines as a result of his work on loneliness is that "Human services rules and regulations that contribute to the isolation of people must be changed immediately and replaced with designs, practices, and policies that support the building of social networks" (p.82). Benz & McAllister (1990) indicate that in order to design services that are appropriate for people with disabilities, we need

to be aware of the issues that have the greatest impact on their quality of life. They state that very little is known about the opinions of older adults with intellectual disabilities concerning how they envision their retirement years. This study is a step in that direction. The interviews provide excellent information about the lives and experiences of the participants. This study gives support to soliciting information about people with disabilities from people with disabilities. This research also illustrated that when interviewing individuals with intellectual disabilities, it is important to try and get at the information in different ways. In other words, asking direct questions does not always elicit complete answers, and you may get the information you are looking for from further discussions and questioning. If I hadn't visited with the women on more than one occasion, and persisted in trying to understand their experiences, I would not have as thorough an understanding of the realities of their lives.

There is clearly a need for leisure education. Bullock & Mahon (2000) define leisure education as "an individualized and contextualized educational process through which a person develops an understanding of self and leisure and identifies and learns the cluster of skills necessary to participate in freely chosen activities which lead to an optimally satisfying life" (p.332). The participants in this study experience a lack of activities. This lack of activities was not something that the participants necessarily recognized, but they have a very small repertoire of leisure that they participate in, and could not readily think of other things that they wanted to do. A leisure education program could expose them to a wider variety of opportunities, and allow them to explore their interests. Part of this education should also focus on social skill development. It was obvious that the participants in this study needed to learn how to maintain friendships

across diverse settings and situations. One of the goals of a leisure education program could be to teach an individual how to ask for someone's phone number, or how to plan to meet someone for coffee. Improved leisure education and opportunities could have a huge impact on the lives and life satisfaction of all of the participants.

The findings in relation to the friendships of the participants indicate that friendships tend to be context specific, and that the women have limited opportunities to develop friendships. Service providers need to be aware of this issue, and should look at ways to support individuals in a way that facilitates friendship development. Service providers should also be aware that when an individual is reluctant to make a change, for example, retire, it may be because the individual does not want to lose contact with their friends. In an ongoing research project by Mahon, Lutfiyya, Mactavish, Rodrigue, Strain, Studholme, & Bockstael (2000) which is focused on later life planning, the two older women involved are both very reluctant to consider retiring from their workshops. They never socialize with their friends outside of the workshop, and if their experiences are consistent with the participants in this study, they will lose these friends after they leave the workshop. This is an issue that service providers need to address.

Brown (1993) suggested that leisure activities should be encouraged from a much earlier age. Brown related this to the issues of choice, freedom of access to integrated environments, and exploration. "In other words, if we wish people to age more gently, then it is important that in their early years, and certainly in their young adult years, they have considerable opportunity to explore their environment, with decreasing structure and decreasing support, in order that they may learn to be independent and continue to be active in their aging years" (p.222). Based on what I have learned through my study, I

think this is an excellent recommendation. Bigby (1997) recommended that “rather than focusing on retirement, the focus must shift to how existing or alternative new services can provide optimal living environments, skill maintenance and development, stimulating leisure, recreational and social opportunities appropriate to each individual’s rate of aging” (p.106). Planning for the future should include preparing for a healthy leisure life.

REFERENCES

Amado, R. S. (1993). Loneliness: Effects and implications. In A. N. Amado (Ed.), Friendships and community connections between people with and without developmental disabilities (pp.67-84). Baltimore, MD: Paul H. Brookes Publishing Co.

Asch, A., & Fine, M. (1988). Introduction: Beyond Pedestals. In Fine & A. Asch (Eds.), Women with disabilities: Essays in psychology, culture, and politics. Philadelphia, PA: Temple University Press.

Ashman, A. F., & Suttie, J. N. (1996). The social and community involvement of older Australians with intellectual disabilities. Journal of Intellectual Disability Research, 40, 120-129.

Babbie, E. (1992). The Practice of Social Research. Belmont, CA: Wadsworth Publishing Company.

Bedini, L. A., & Henderson, K. A. (1994). Interdependence, social support, and leisure: Describing the experiences of women with physical disabilities. Annual in Therapeutic Recreation, 4, 96-105.

Benz, M. R., & McAllister, M. (1990). Occupational and leisure preferences of older adults with mental retardation. Australia and New Zealand Journal of Developmental Disabilities, 16(3), 233-244.

Bigby, C. Later life for adults with intellectual disability: A time of opportunity and vulnerability. Journal of Intellectual & Developmental Disability, 22(2), 97-108.

Blackwell-Stratton, M., Breslin, M. L., Mayerson, A. B., & Bailey, S. (1988). Smashing icons: Disabled women and the disability and women's movements. In M. Fine

& A. Asch (Eds.), Women with Disabilities: Essays in Psychology, Culture, and Politics, (pp. 306-332). Philadelphia, PA: Temple University Press.

Bogdan, R. C., & Biklen, S. K. (1992). Qualitative Research for Education: An Introduction to Theory and Methods. Needham Heights, MA: Allyn and Bacon.

Botuck, S., & Levy, J. M. (1995). A preliminary investigation of elderly individuals with mental retardation living in community residences. The British Journal of Developmental Disabilities, 41, 3-12.

Botuck, S., Levy, J. M., & Rimmerman, A. (1996). Gender-related differences in placement rates of young adults with mental retardation and severe learning disabilities. International Journal of Rehabilitation Research, 19, 259-263.

Boyd, R., & Tedrick, T. (1992). Aging adults with mental retardation and leisure. Parks and Recreation, 27(10), 20-27,86.

Boylan, E. (1991). Women and Disability. Zed Books Ltd: London, U.K.

Boyle, G. Rioux, M., Ticoll, F., & Felske, A. W. (1988). Women and disabilities: A national forum. Entourage, 3(4), 9-13.

Browder, D. M., & Cooper, K. J. (1994). Inclusion of older adults with mental retardation in leisure opportunities. Mental Retardation, 32(2), 91-99.

Brown, R. I. (1993). Quality of life issues in aging and intellectual disability. Australia and New Zealand Journal of Developmental Disabilities, 18(4), 219-227.

Brown, R. I. (1989). Aging, disability, and quality of life: A challenge for society. Canadian Psychology, 30(3), 551-559.

Bullock, C. C. & Mahon, M. J. (1997). Introduction to Recreation Services for People with Disabilities, A Person-Centered Approach. Champaign, IL: Sagamore Publishing.

Bullock, C. C. & Mahon, M. J. (2000). Introduction to Recreation Services for People with Disabilities, A Person-Centered Approach (2nd ed.). Champaign, IL: Sagamore Publishing.

Carter, M. J., & Foret, C. (1991). Therapeutic recreation programming for older adults with developmental disabilities. In M.J. Keller (Ed.), Activities with developmentally disabled elderly and older adults (pp.35-51). Binghamton, NY: Haworth Press.

Coleman, D. (1993). Leisure based social support, leisure dispositions and health. Journal of Leisure Research, 25(4), 350-361.

Danek, M. M. (1992). The status of women with disabilities revisited. Journal of Applied Rehabilitation Counseling, 23(4), 7-13.

Dawson, D. (1984). Phenomenological approaches to leisure research. Recreation Research Review, 18-23.

Deegan, M. J. (1981). Multiple minority groups: A case study of physically disabled women. Journal of Sociology and Social Welfare, 8(2), 274-297.

Denzin, N. K. (1992). Symbolic interactionism and cultural studies: The politics of interpretation. Cambridge, MA: Blackwell Publishers.

Edgerton, R. B. & Gaston, M. A. (Eds.) (1991). "I've Seen it All": Lives of Older Persons with Mental Retardation in the Community. Baltimore, MD: Paul H. Brookes Publishing Co.

Fine, M. F., & Asch, A. A. (1981). Disabled women: Sexism without the pedestal. Journal of Sociology and Social Welfare, 8(2), p.233-248.

Fisher, B. & Galler, R. (1988). Friendship and fairness: How disability affects friendship between women. In M. Fine & A. Asch (Eds.), Women with Disabilities: Essays in Psychology, Culture, and Politics (pp.172-194). Philadelphia, PA: Temple University Press.

Fowler, C., O'Rourke, B., Wadsworth, J. & Harper, D. (1992). Disability and feminism: Models for counselor exploration of personal values and beliefs. Journal of Applied Rehabilitation Counseling, 23(4), 14-19.

Fulton, S. A., & Sabornie, E. J. (1994). Evidence of employment inequality among females with disabilities. The Journal of Special Education, 28(2), 149-165.

Garwick, G. (1992). Old age, love, and hope for women with developmental disabilities. Journal on Developmental Disabilities, 1(2), 1-15.

Glausier, S. R., Whorton, J. E., & Knight, H. V. (1995). Recreation and leisure likes/dislikes of senior citizens with mental retardation. Activities, Adaptation, & Aging, 19(3), 43-54.

Grbich, C., & Sykes, S. (1990). A study of persons with severe intellectual disabilities: Gender, the home environment, schooling and outcomes. Australia and New Zealand Journal of Developmental Disabilities, 16(3), 259-273.

Hanna, W. J., & Rogovsky, E. (1991). Women and disabilities: Two handicaps plus. Disability, Handicap, & Society, 6(1), 49-63.

Harper, J., Mahon, M. J., Foreman, S., & Godbey, G. (1999). The use and benefits of local government parks and recreation services in Canada and the United States- A

perspective of people with disabilities [Abstract]. In P. Heintzman (Ed.), Proceedings of the Ninth Canadian Congress on Leisure Research (pp.113-116). Nova Scotia, CA: Acadia University Printing Services.

Hasazi, S. B., Johnson, R. E., Hasazi, J. E., Gordon, L. R., & Hull, M. (1989). Employment of youth with and without handicaps following high school: Outcomes and correlates. The Journal of Special Education, 23, 243-255.

Hawkins, B. A. (1993). An exploratory analysis of leisure and life satisfaction of aging adults with mental retardation. Therapeutic Recreation Journal, 27(2), 98-109.

Heller, T. (1997). Older adults with mental retardation and their families. International Review of Research in Mental Retardation, 20, 99-136.

Henderson, K. A., Bedini, L. A., & Hecht, L. (1994). "Not Just a Wheelchair, Not Just a Woman": Self-identity and leisure. Therapeutic Recreation Journal, 28(2), p.73-86.

Henderson, K. A., Bialeschki, M. D., Shaw, S. M., & Freysinger, V. J. (1989). A leisure of one's own. State College, PA: Venture Publishing, Inc.

Henderson, K. A., & Rannells, J. S. (1988). Farm women and the meaning of work and leisure: An oral history perspective. Leisure Sciences, 10, 41-50.

Heyne, L. A., Schleien, S. J., & McAvoy, L. H. (1994). Making friends; Using recreation activities to promote friendship between children with and without disabilities. Minneapolis, MN: Publications Office, Institute on Community Integration.

Hogg, J. (1997). Intellectual disability and aging: ecological perspectives from recent research. Journal of Intellectual Disability Research, 41, 136-143.

Hong, L. K., & Duff, R. W. (1994). Widows in retirement communities: The social context of subjective well-being. The Gerontologist, 34(3), 347-352.

Hoover, J., Wheeler, J., & Reetz, L. (1992). Development of a leisure satisfaction scale for use with adolescents and adults with mental retardation: initial findings.

Education and Training in Mental Retardation, 27, 153-160.

Horna, J. (1994). The study of leisure: An introduction. Toronto: Oxford University Press.

Howard, J. A., & Hollander, J. (1997). Gendered situations, gendered selves. Thousand Oaks, CA: Sage Publications, Inc.

Howe, (1985). Possibilities for using a qualitative research approach in the sociological study of leisure. Journal of Leisure Research, 17(3), 212-224.

Hutchinson, P. (1994). Work and leisure: paradoxes and dilemmas for people with developmental disabilities. Journal on Developmental Disabilities, 3, 1-15.

Hutchison, P., & McGill, J. (1992). Leisure, integration, and community. Concord, Ontario: Leisurability Publications, Inc.

Iso-Ahola, S. E. (1980). The social psychology of leisure and recreation. Dubuque, IA: William Brown.

Janicki, M. P. (1990). Growing old with dignity: On quality of life for older person with a lifelong disability. In R. L. Schalock & M. H. Begab (Eds.) Quality of Life: Perspectives and Issues.

Jurkowski, E., & Amado, A. N. (1993). Affection, love, intimacy, and sexual relationships. In A. N. Amado (Ed.), Friendships and community connections between people with and without developmental disabilities (pp.129-151). Baltimore, MD: Paul H. Brookes Publishing Co.

- Kelly, J. R., & Godbey, G. (1992). The sociology of leisure. State College, PA: Venture Press.
- Kutner, N. G. (1987). Social ties, social support, and perceived health status among chronically disabled people. Social Science Medicine, 25(1), 29-34.
- Landesman, S. (1986). Quality of life and personal life satisfaction: Definition and measurement issues. Mental Retardation, 24, 141-143.
- Levy, J. M., Botuck, S., Levy, P. H., Kramer, M. E., Murphy, B. S., & Rimmerman, A. (1994). Differences in job placements between men and women with mental retardation. Disability and Rehabilitation, 16(2), 53-57.
- Locke, L. F. (1989). Qualitative research as a form of scientific inquiry in sport and physical education. Research Quarterly for Exercise and Sport, 60(1), p.1-20.
- Mahon, M. J., & Bullock, C. C. (1993/94). An investigation of the social validity of a leisure education intervention. Annual in Therapeutic Recreation, 4, p.82-95.
- Mahon, M. J., Mactavish, J., & Bockstael, E. (in press). Social integration, leisure, and individuals with intellectual disability: Perspectives on connections.
- Mason, J. (1988). 'No peace for the wicked': older married women and leisure. In E. Wimbush & M. Talbot, (Eds.), Relative Freedoms, (pp. 75-86). Philadelphia, PA: Open University Press.
- McCarthy, M. (1998). Whose body is it anyway? Pressures and control for women with learning disabilities. Disability & Society, 13(4), 557-574.
- McGuire, F. A., Boyd, R. K., & Tedrick, R. E. (1999). Leisure and aging: Ulyssean living in later life. Champaign, IL: Sagamore Publishing.

Moss, S., & Patel, P. (1997). Dementia in older people with intellectual disability: symptoms of physical and mental illness, and levels of adaptive behaviour. Journal of Intellectual Disability Research, 41(1), 60-69.

Myers, F., Ager, A., Kerr, P., & Myles, S. (1998). Outside looking in? Studies of the community integration of people with learning disabilities. Disability & Society, 13(3), p. 389-413.

Neumayer, R., & Bleasdale, M. (1996). Personal lifestyle preferences of people with an intellectual disability. Journal of Intellectual and Developmental Disability, 21(2), 91-114.

Olney, M. F., & Kuper, E. V. (1998). The situation of women with developmental disabilities: Implications for practitioners in supported employment. Journal of Applied Rehabilitation Counseling, 29(2), 3-8.

Patton, M. Q. (1990). Qualitative Evaluation and Research Methods. Newberry Park, CA: Sage Publications, Inc.

Pedlar, A., Haworth, L., Hutchison, P., Taylor, A., & Dunn, P. (1999). A textured life: Empowerment and adults with developmental disabilities. Waterloo, ON: Wilfrid Laurier University Press.

Rehabilitation International, (1980). The special hardships of disabled women. Assignment Children, 49/50, 89-93.

Riddick, C. C. & Daniel, S. N. (1984). The relative contribution of leisure activities and other factors to the mental health of older women. Journal of Leisure Research, 16, 136-148.

Rousso, H. (1988). Daughters with disabilities: Defective women or minority women? In M. Fine & A. Asch (Eds.), Women with Disabilities: Essays in Psychology, Culture, and Politics (pp.172-194). Philadelphia, PA: Temple University Press.

Russo, N. F., & Jansen, M. A. (1988). Women, work, and disability: Opportunities and challenges. In M. Fine & A. Asch (Eds.), Women with Disabilities: Essays in Psychology, Culture, and Politics (pp.172-194). Philadelphia, PA: Temple University Press.

Salvatori, P., Tremblay, M., Sandys, J., & Marcaccio, D. (1998). Aging with an intellectual disability: A review of Canadian literature. Canadian Journal on Aging, 17(3), 249-271.

Sands, D. J., & Kozleski, E. B. (1994). Quality of life differences between adults with and without disabilities. Education and Training in Mental Retardation and Developmental Disabilities, 26, 90-101.

Scheerenberger, R. C. (1987). A history of mental retardation: A quarter century of promise. Baltimore, MD: Paul H. Brookes.

Seltzer, G. B. (1993). Psychological adjustment in midlife for persons with mental retardation. In E. Sutton, A.R. Factor, B.A. Hawkins, T. Heller, & G.B. Seltzer (Eds.), Older Adults with Developmental Disabilities, Optimizing Choice and Change (pp.157-184). Baltimore, MD: Paul H. Brookes Publishing Co.

Siegenthaler, K. L. (1996). Leisure and the elderly. Parks and Recreation, 31(1), 18-24.

Sinnott-Oswald, M., Gliner, J. A., & Spencer, K. C. (1991). Supported and sheltered employment: Quality of life issues among workers with disabilities. Education and Training in Mental Retardation, 26(4), 388-397.

Sison, G. F. P. & Cotten, P. D. (1989). The elderly mentally retarded person: current perspectives and future directions. The Journal of Applied Gerontology, 8(2), 151-167.

Stainback, S., & Stainback, W. (1988). Understanding and Conducting Qualitative Research. Dubuque, IW: Kendall/Hunt Publishing Company.

Taylor, S. J., & Bogdan, R. (1984). Introduction to Qualitative Research Methods: The Search for Meaning. New York, USA: John Wiley & Sons.

Tedrick, T. (1991). Aging, developmental disabilities and leisure: Policy and service delivery issues. Activities, Adaptation, and Aging, 15, p.141-152.

Thomas, J. R., & Nelson, J. K. (1996). Research Methods in Physical Activity. Champaign, IL: Human Kinetics.

Thompson, D. R. (1985). Anger. In S. E. Browne, D. Connors, & N. Stern (Eds.), With the Power of each Breath: A Disabled Women's Anthology, (pp.78-85). Pittsburgh, PA: Cleis Press.

Thompson, P. (1992). 'I don't feel old': Subjective ageing and the search for meaning in later life. Ageing and Society, 12, 23-47.

Traustadottir, R. (1990). Women with disabilities: Issues, resources, connections. Syracuse, NY: Syracuse University Center on Human Policy.

Traustadottir, R. (1992). Part 1 Obstacles to equality: The double discrimination of women with disabilities. Journal of Leisurability, 19(2), 4-9.

Traustadottir, R. (1992). Part 2 Obstacles to equality: The double discrimination of women with disabilities. Journal of Leisurability, 19(3), 3-14.

Traustadottir, R. (1993). The gendered context of friendships. In A. N. Amado (Ed.), Friendships and community connections between people with and without developmental disabilities (pp.109-127). Baltimore, MD: Paul H. Brookes Publishing Co.

Van Moorst, H. (1982). Leisure and social theory. Leisure Studies, 1, 157-169.

Wearing, B., & Wearing, S. (1988). 'All in a day's leisure': Gender and the concept of leisure. Leisure Studies, 7, 111-123.

Wehmeyer, M. L. (1993). Factor structure and construct validity of a locus of control scale with individuals with mental retardation. Education and Psychological Measurement, 53(4), 1055-1066.

Weinberg, N. (1976). The effect of physical disability on self-perception. Rehabilitation Counseling Bulletin (September), 15-20.

Whorton, J. E., Morgan, R. L., & Nisbet, S. (1994). A comparison of leisure and recreational activities for adults with and without mental retardation. In D. Montgomery (Ed.), Rural Partnerships: Working Together, (pp.178-185).

Wilhite, B. C., Sheldon, K., & Jekubovich-Fenton, N. (1994). Leisure in daily life: Older widows living alone. Journal of Park and Recreation Administration, 12(4), 64-78.

Wilkins, S. & Cott, C. (1993). Ageing, chronic illness and disability. In M. Nagler (Ed.) Perspectives on Disability (pp.363-377). Ontario: Health Market Research.

APPENDIX A

Interview Guide - Pilot

Age:

Living Situation:

1. Tell me about a typical day for you.

- work
- retired
- activities

2. What are some things that you do that make you feel good?

- Are these things important to you?
- Are there other things that are more important to you?

3. What are some things that you do for fun?

4. Do you like doing these things by yourself or with other people?

- Who do you do them with?

5. Would you like to more of these types of things?

- Are you happy with the amount of things that you do?
- Is there something that you would like to be doing that you aren't doing now?

6. What stops you from doing things for fun?

7. Are you happy with the way your life is?

- What are you happy/unhappy with?

8. If you could only do one thing in a whole day, anything that you want, what would you do?

9. Is there something that you would like to change about your life?

APPENDIX B

Final Interview Guide

Age:

Living Situation:

Explain the study - interested in what role leisure has in your life. Do you know what I mean by leisure?

Are you married/ Have you ever been married or in a long-term relationship? Any children?

1. Tell me about a typical day for you.

- work
- retired
- activities

2. What are some things that you do that make you feel good?

- Are these things important to you?

3. What are some things that you do for fun?

4. Do you like doing these things by yourself or with other people?

- Who do you do them with?
- Do you do them with your friends? What sorts of things do you do with your friends?

5. Would you like to more of these types of things?

- Are you happy with the amount of things that you do?
- Is there something that you would like to be doing that you aren't doing now?

Probes:

(tell them that it's ok if some of these questions have the same answer.)

- what are some things you do to be active, get exercise?
- what are some things that you do to relax?
- what are some things that you do when you want to be alone?
- what are some things that you do when you want to be with other people?
- what are some things that you do when you want to feel good about yourself?
- what are some things that you do when you are lonely?
- what are some things that you do when you are feeling really good?
- what are some things that you do with your family?
- what are some things that you do with your friends?

6. What stops you from doing things for fun?

7. Do you think that you have a disability?

8. Are you happy with the way your life is?

- What are you happy/unhappy with?

9. If you could only do one thing in a whole day, anything that you want, what would you do?

10. Is there something that you would like to change about your life?

11. What is the most important thing to you?

- What do you care about the most?

APPENDIX C

Interview GuideThird Interview

What role does leisure have in your life?

Why do you...

- Volunteer at the drop-in center
- visit your brothers and sisters
- go to volunteer dinners
- watch sports on TV
- go to bowling
- go shopping (etc...)

After each activity, ask...

How does it make you feel?

Do you think this is leisure?

After going through all the activities, ask...

How do you think you would feel if you didn't have all these things to do?

What do you think your life would be like?

Do you feel that you have enough money to do the things that you want to do?

Has not having money ever stopped you from doing things?

Are you happy with the amount of friends that you have?

Would you like to have more?

How do you usually meet your friends/make new friends?

Why do you get lonely sometimes (if they had said they get lonely)

What role does leisure have in your life?

APPENDIX D

CONSENT FORM

You are being asked to take part in three to four interviews during which you will be asked to answer questions about what leisure means to you. Your answers may help us to understand the role of leisure in the lives of older women with intellectual disabilities. The interviews are being conducted as part of a thesis research project. The investigators conducting this project are Erika Bockstael and Michael Mahon, Ph.D.

Before you make a decision about taking part in this project, we want to make sure that you fully understand your rights about this.

You should be aware that:

We will be asking you to answer questions during three to four interviews, which will each take about one hour to complete. You are completely free to stop answering any of the questions at any time. If you decide not to answer any or all of the questions, this will not affect you in any way.

With your permission, the interviews will be tape recorded. Answers you provide during the interviews will be kept private, and any information about who you are will be left out of the report that will be written about this project. This consent form will also be kept private.

The services you now receive will not be affected by your participation in this project. We do not believe that answering these questions will create any problems for you.

1) To be signed below by an individual who is able to read and understand the above and can write his or her signature.

I have read and I understand the above information, and I agree to answer the questions. A copy of this has been given to me.

(printed name)

(signature)

(date)

(substitute consent giver or
co-consent giver, if applicable)

(date)

(witness)

(date)

2) To be signed below when an individual cannot read and is unable to write his or her name in order to give consent, but is able to understand the information given above.

The above information has been read to the participant named below and I am satisfied that he or she understands it and has agreed to answer the questions. A copy of this agreement has been provided to the participant.

(printed name)

(signature)

(date)

(substitute consent giver or
co-consent giver, if applicable)

(date)

(witness)

(date)

3) To be signed below when the participant is able to understand the information above and write his or her own signature, but is unable to read.

I have received the above information and understand what it is about and agree to answer these questions. A copy of this agreement has been provided to me.

(printed name)

(signature)

(date)

(substitute consent giver or
co-consent giver, if applicable)

(date)

(witness)

(date)

I would attend another meeting about this research if I am asked. Please check your answer.

_____ Yes _____ No