

SELF-DETERMINATION AND
THE LEISURE EXPERIENCES
OF WOMEN WITH
INTELLECTUAL DISABILITIES
LIVING IN TWO GROUP HOMES

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Abstract

This phenomenological case study aimed to understand the leisure experiences of 5 women with intellectual disabilities (ages 44-60) living in a two group homes. The experiences of the 5 women (3 in one home, 2 in another) were captured using the phenomenological methods of participant observation, artifacts, and semi-structured and active interviewing. Staff members from each home were also interviewed to give further context to the women's leisure experiences. The nature of the women's leisure experiences were understood within the conceptual framework of self-determination. The leisure experiences were encapsulated under 3 main themes (*leisure at home, leisure in the community, leisure with family and friends*). However, the subthemes indicated that the nature of the leisure experiences and opportunities for input into leisure were different in each home. The essence of the women's leisure experiences were strongly influenced by their interactions with staff who determined opportunities (or lack thereof) for the women to provide input into their leisure experiences. In one group home, leisure was self-directed, even when staff support was required for the women (*independent self-directed leisure; staff supported self-directed*). In the same group home, leisure in the community was experienced independently (*independent outings*) even when staff were required to provide assistance in unfamiliar settings (*accompanied outings*). The women of this group home experienced leisure with family and friends when they initiated contact with loved ones (*connecting with others*). Conversely, many of the leisure experiences in the other group home were supervised even when the women chose the activity (*supervised, self-directed leisure; supervised directed leisure*). Community

outings were also supervised (*supervised outings*) and leisure with family and friends was experienced when important others initiated contact (*awaiting a connection with others*).

The women in one home experienced opportunities for input into spontaneous leisure at home as well as in the community. Even when staff support was required to engage in an activity, the type and amount of support was determined by the women. The leisure experiences for the women of the other home were defined, in large part, by planned and scheduled events in the home. The activities needed in the daily management of the group home appeared to take precedence over opportunities for leisure experiences and the women's input into the nature of their leisure experiences. The results draw attention to the environments of each home and the experiences of the women. The empowering effects of such a case study may elicit action on behalf of the reader through conscious raising of important issues (i.e., the importance of self-determination for people with disabilities). This study increases the awareness of the influence the context has on self-determination and has important implications for service providers in the field of disability.

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Dedication

To the women of

Cairn Home

and

Elm Home

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Chapter 1

1.1 Introduction

Prior to introducing the topic of my thesis, I would like to tell you a story. This story, like the other stories you will find throughout my thesis, will provide you with an idea of how I arrived at my area of interest. The narratives that I have included throughout my thesis paint a picture of the experiences I have shared with people with intellectual disabilities. These experiences have served as the driving passion behind my research.

In September of 1999 I was hired by an agency to manage a group home. A group home is a supported living environment for people with intellectual disabilities. Staff are hired to provide personal care, supervision, and support to 3 to 6 individuals (Saskatchewan Social Services, 2002). The home I was assigned to was established in the early 1970s and, similar to other group homes within the city in which I was currently residing, was located in a residential neighborhood. Within the home lived 5 women ranging in age from 40 to 55 years. Support was provided by 2 house managers who worked split shifts (2 days on, 2 days off), and one part-time staff person who assisted with recreation and leisure in the home and in the community. For over 25 years, the women of this house had been living together. Staff turnover occurred and the neighborhood had changed, but throughout it all, these women stayed together. During my time at the group home, I soon came to

realize that the women rarely did anything without one another. They all watched TV together, even though three of the five women had personal TV's in their rooms. They all went bowling together, even on weekends when one of them would have preferred to stay at home. They all went shopping together, even if only one of them needed to pick up something from the store. They even worked together in the same workshops and sat together on the same bus on the way to work! Every waking moment appeared to be spent together.

I also came to learn quickly that the women were dependent on others to make decisions for them. When they watched TV together, they asked me what they should watch. When they went bowling on the weekends, they asked me if they could have coffee at the bowling alley. When they went shopping, they followed me around the store, single file, and only stopped to 'shop' when I stopped. When I encouraged them to make their own decisions, they looked at me with a panicked look on their faces, unsure of what to do next.

I clearly recall an incident that occurred during one of the first evenings I worked at the group home. One of the women was hovering around the kitchen as I cleaned up after supper. I was aware of her presence because she followed me everywhere I went. I could tell that she was anxious to discuss something with me.

"What would you like?" I asked her.

"Nothing" she quickly responded.

"Okay" I said, as I continued with my cleaning. A few minutes passed and she was still hovering around the kitchen watching my every move.

"Are you sure you don't need something?" I asked.

"Brenda," she paused... "I'm thirsty."

"Oh?" I said. I was surprised. I wondered, 'Why would she tell me that she's thirsty?'

Silence. "Can... I have... a drink?" she asked reluctantly.

More silence. I was still surprised! Why, I thought, is she asking me if she could have a drink? I responded, "I don't know ...Can you?"

Silence. Seconds passed. "I don't know" she responded.

I was stunned. I clearly remember my thoughts at that moment. I was frustrated and surprised at the same time. I thought, 'Why are you asking me? This is your home...don't ask me if you can have a drink. You know where the fridge is; you should go get a drink.'

Still so surprised at her hesitation to quench her own thirst, I thought I should use this as a learning experience.

"What should you do if you are thirsty?" I asked her.

She paused, thought for a few seconds, and timidly responded, "Get...a...drink?"

"Yes! That's a great idea!"

I felt relieved that she knew that she should get a drink, but a wave of concern washed over me as I questioned why she did not feel comfortable to help herself to a drink. After all, house managers have come and gone, but these women had lived in this home for over 25 years. This house was *their* home. If anyone should be asking permission to have a drink, it should be me! I was a weekly guest in their home.

"Brenda..." I heard as I was thinking about what had just happened.

"Yes?" I replied.

Pause. "What should I have to drink?"

I will never forget that moment. I will never forget what I felt. Although still somewhat frustrated and surprised, I was more disappointed than anything. I was not disappointed in her for not knowing to get a drink. I was disappointed that, from what I perceived, these women could not make a simple choice. Why did no one teach these women how to make their own choices? Time had passed, the world had progressed, and yet it appeared that time stood still within this house. I felt sad for these women. I thought

about how I would feel if I felt I had to ask a relative stranger in my house if I could have a drink. I decided at that moment that I was going to try to provide these women with the tools and resources they needed to become more confident in their decision making.

After I became aware of the women's discomfort and unfamiliarity with decision making, I diligently worked with them, the staff, the executive board of the group home, and family members to increase their awareness about the right of personal choice for people with intellectual disabilities. Information was presented at meetings with the residents, staff, family members, and board members in attendance and I encouraged everyone to provide opportunities for the women to experience choice making. I discussed the history of choice making in the lives of people with intellectual disabilities and how the concepts of 'empowerment and self-determination' were influencing the field of disability issues. I was making remarkable progress with everyone, particularly the women who resided at the group home. They were able to make some decisions independently, such as what to eat for breakfast in the mornings, how to rearrange the furniture in their rooms and how to spend leisure time on weekends. We had come a long way from deciding when and what to drink, to contributing ideas for leisure time activities. But we had many challenges ahead. I recall one Sunday in February of 2000 in which the women were required to make a decision in order to avoid an uncomfortable situation.

This particular Sunday afternoon began as any other. A part-time support staff came into the home for 4 hours in the afternoon to assist with a community outing. Only four women were home that afternoon, as the fifth woman was spending the weekend with her mother as she always did. Discussion arose between the four women, the part-

time support staff, and myself as to what activities were available to partake in that particular afternoon. The role that the support staff and myself had during this discussion was to assist the women in identifying what activities were available to them. Once activity options were presented to the women, they chose what to do. We all sat at the table and looked through the weekend paper together. There was a large advertisement promoting the annual winter festival on the lake. One woman immediately pointed to the pictures of the snowmen and snowmobiles in the ad and said, "We could go to the lake! We could watch the snowmobile races. Do you want to go to the lake?" she asked the others. Each woman indicated, in her own way, that attending the festival would be a good idea. One woman responded, "Yes", another responded repeating the words, "Festival...Lake!" which was her way of indicating agreement. Another woman simply smiled, nodded her head 'Yes', and left the table, only to return a few seconds later with her winter-wear required for the afternoon. The women were quite excited to get to the lake, as they knew of friends from work who would be there as well. Little did I know at the time, this was the beginning of what was to become a very long and very cold afternoon.

The temperature was -22 Celsius and 10 degrees colder with the wind-chill. We all dressed appropriately in long johns, two pair of socks, scarves, mitts and toques. We were ready. We piled into the car and headed for the lake. Once we arrived, the 4 women immediately noticed several people they knew. After they spent some time visiting with friends and acquaintances, we all met back together to watch the snowmobile races.

The wind was blowing and it began to snow. Soon, we were all shivering and sporting a blue tinge on our lips. All four of the women stared at me for the longest time,

as though they were waiting for me to say something, waiting for me to do something to save us all from this freezing hell to which we were being subjected to. ‘My gawd,’ I thought, ‘I’m FREEZING! Why won’t they say they want to go to the car? I want to go to the car!’

I pride myself in recognizing and utilizing opportunities for teaching. I truly believed that these women needed to be confident making decisions and expressing them. ‘I’m going to let them decide when we should leave,’ I thought. I told them to let me know when they wanted to head back to the car. I thought to myself, ‘They decided to come to the lake; they can decide when we leave.’

Time passed. “You guys look cold. Are you cold?” I asked as we all sheltered our faces with our coats. They all replied with a resounding, “Yes!”

“Well,” I said through chattering teeth, “What should we do?”

Silence. They all looked at each other, and then stared blankly at me. It was painfully obvious that all of us were very uncomfortable. The part-time staff person and I periodically exchanged glances, both of us recognizing the ‘Gawd-I-hope-they-ask-to-leave-soon’ looks we had on our faces. Finally, when it felt like a hundred gales of wind whipped across our faces, one of the women spoke up.

“Should we go to the car, Brenda?”

‘Yes! Yes! Yes!’ I called out in my head! ‘YES!’

“Only if you’re sure” I attempted to respond indifferently.

We walked, well, okay, *ran* back to the car and drove to the nearest donut shop for a snack and a hot drink. We were glad to be warm!

Experiences such as this ignited a passion within me. Perhaps due to my sensitive nature and exposure to similar ongoing experiences with these women, I was driven to

learn more. I felt it was my responsibility to learn more about the leisure experiences of these women. Was that cold, snowy day on the lake an enjoyable experience for them? What, if anything, did they learn from that experience? What meaning will that experience hold for them over the course of their lives? Perhaps, with my awareness, I could inform and educate others about the importance of self-determination, choice, and decision making in leisure activities for women with intellectual disabilities. I continuously placed myself in their shoes asking, "How would I feel if this was happening to me? How would I feel if I could not make a simple choice?"

1.2 Review of Literature

1.2.1 Intellectual Disability

Over the past fifty years, in the field of disability, the definition of intellectual disability has changed significantly. The field has moved away from a person-centered definition in which personal deficits were emphasized, to a more ecologically based description that takes into account interactions with one's environment. A brief history of the transformation of the definition of intellectual disability is provided below to aid readers in understanding the context surrounding the development of and management of group home settings, the need for staff development, and resource allocation.

In the 1960s, the American Association of Mental Retardation (AAMR) defined intellectual disability as “subaverage general intellectual functioning which originates in the developmental period and is associated with impairment in adaptive behaviour” (Scheerenberger, 1987, p. 11). An individual was considered to have an intellectual disability if performance was greater than one standard deviation below the population mean, the performance deficits were thought to have begun between birth and 16 years of age, and motor and self-care skills, learning from experience, and social adjustment was delayed (Scheerenberger, 1987).

Sub-classifications were developed in recognition of the continuum of function evident in people with sub-average intellectual functioning (i.e., borderline, mild, moderate, severe, profound). A borderline intellectual disability was represented by an intelligence quotient (IQ) from 85-70, a mild disability was from 70-55, a moderate intellectual disability ranged from 55-40, a severe disability ranged from 40-25, and a profound disability was an IQ below 25 (AAMR, 2002). Some critics did not support the

notion that individuals with an IQ score between 85 and 70 should be classified as possessing borderline intellectual disability (Scheerenberger, 1987). Therefore, in 1973, the AAMR revised their previous definition to include the word significantly. “Mental retardation refers to *significantly* subaverage general intellectual functioning existing concurrently with deficits in adaptive behaviour and manifested during the developmental period” (Scheerenberger, 1987, p. 12). The developmental period referred to was increased two years from age 16 to 18 (AAMR, 2002). The levels of intellectual disability were revised to eliminate the classification of borderline IQ levels of intellectual disability which encompassed IQ scores from 70 to 25. This was now representative of two or more standard deviations below the mean (AAMR, 2002).

The inclusion of adaptive behaviour in the definition was significant as it acknowledged not only the outcome of the psychological testing, but people’s ability to interact with their environment. Diagnosis alone was found to be inadequate for predicting required services, level of care, or setting functional outcomes for the individual (WHO, 2002). Adaptive behaviour was defined by age and degree of intellectual disability (i.e., during infancy and early childhood, deficits would be reflected in sensorimotor skill development and communication skills). As the individual aged, self-help skills, socialization, academic skills, judgement ability, and vocational and social responsibilities became critically important.

The global definition of intellectual disability continued to be revised. New terms were developed to distinguish between mental retardation, emotional disorders (e.g., autism), brain damage (e.g., acquired brain injury), and intellectual disability (Baroff, 1991). In the 1990s, intellectual disability was defined as a severe and chronic disorder

involving an indefinite mental impairment originating before the age of 22 that causes substantial functional limitations in at least three of seven areas of major life activity, including self care, receptive and expressive language, learning, mobility, self-direction, capacity of independent living, and economic self-sufficiency (Baroff, 1991). This definition of intellectual disability, unlike definitions set out by the AAMR, takes a functional approach, rather than a categorical approach based on IQ. The evolving definitions of disability began to reflect the reciprocal interaction of the person, the tasks or activities of life, and the context of the environment.

Most recently, the World Health Organization (WHO) approved the International Classification of Functioning, Disability and Health, also known as the ICF. The ICF includes all aspects of human health and describes them in terms of health domains and health-related domains. The ICF defines disability by level of functioning of the individual. This new classification is contextual in nature and examines environmental factors that may affect one's ability to function within particular settings. The ICF organizes information in two parts. Part 1, Functioning and Disability, includes two classifications: one for functions of the Body Systems and Body Structures, and the second for Activities and Participation. Part 2 deals with Contextual Factors, which include a list of environmental and personal factors that may influence health and health related states of an individual (WHO, 2002). This international classification system "provides a framework to code a wide range of information about health and uses a standardized common language, which allows communication about health and health care across the world in various disciplines and sciences" (WHO, 2002, p. 3).

The ICF determines disability through bodily functions and structures (which includes, but is not limited to mental, sensory, cardiovascular and metabolic functioning and structure), environmental factors (which includes but is not limited to products and technology, support and relationships, services, systems, policies, and climate and terrain), activity and participation (which includes but is not limited to learning and applying knowledge, mobility, self-care, and community, social, and civic life), and personal factors (such as gender, age, background, education, profession, and past and current experiences) that can be described as positive or negative (WHO, 2002). A negative scale indicates the extent or magnitude of an impairment. For example, one's physiological functioning (e.g., cardiovascular, digestive, and neuromuscular systems) and psychological capacities (e.g., mental health, cognitive abilities) may be indicated to be negative if functioning is poor. This method of scaling is also used for body structures, which includes structures of the nervous system and structures involved with movement. The nature or changes of the structure (e.g., absence, position, or changes in the structure) may influence how one experiences a disability. The impact that bodily functioning and bodily structure has on disability can be lessened or intensified by the presence or lack of contextual factors, (referred to as barriers or facilitators), such as services, supports, technology, policies, and social attitudes.

The extent to which bodily functions and contextual factors exacerbate or facilitate functioning can be observed in the activities and participation patterns of the individual (e.g., activities of daily living such as self-care, mobility, domestic life, community involvement). Body Functions and Structures and Activities and Participation “replace the previous terms of impairment, disability, and handicap to extend the scope of

the classification to allow positive experiences to be described” (WHO, 2002, p. 3).

Disability is not emphasized in this classification system, as health and function have come to the forefront. Anyone at anytime can experience disability depending on their functioning in a particular context. For example, anyone who has experienced difficulty with daily living tasks when a limb or appendage has been sprained or broken has, by the ICF definition of disability, experienced a disability themselves. Thus, the ICF “mainstreams the experience of disability and recognises it as a universal human experience” (WHO, 2002, p. 3). This new definition opens the door for looking more closely at how the social context can facilitate or debilitate individual functioning and the tasks or activities of life.

In summary, intellectual disability is not simply a condition that someone has, nor is it a condition that solely indicates an individual is lacking in a particular area of human development. Rather, it is a state of functioning that an individual experiences within particular environments. The level of functioning the person will experience is an indication of the ‘fit’ between one’s abilities and immediate environment and is considered to be based on a continuum. Level of functioning is not thought to be a static state. Within one’s environment, the ability to function may be increased with the presence of contextual factors such as services, supports, technology, policies, and social attitudes.

1.2.2 Historic Disability Paradigms: Progression Towards Empowerment

With a change in our understanding of intellectual disability, service delivery models have also evolved. Four paradigms can be identified that reflect our understanding, practices, and assumptions of service provision for persons with

disabilities over time (Polloway, Smith, Patton, & Smith, 1996). The four paradigms are the facility-based paradigm, the service-based paradigm, the supports-based paradigm, and empowerment. The facility-based paradigm extended from the early to middle 1900's and resulted in large institutional settings and residential programs for people who were considered to have subaverage intellectual functioning. The goal of this period of service provision was to bring individuals who required special services together into one setting. The assumption was that the needs of this particular population could best be met if they were grouped together in the same environment (Polloway et al., 1996). The individuals residing in these facilities were permitted few personal possessions, family members were discouraged from visiting, there was little or no privacy, and schedules were strictly set and adhered to (Pringle, 1997). In essence, all aspects of the individual's life were subject to surveillance and scrutiny. Although well intentioned at its inception, overcrowding, poor staffing, involuntary sterilization, poor treatment and misconceptions about the impact of persons with disabilities on society resulted in calls for deinstitutionalization (Pringle, 1997).

The services-paradigm of the 1960s followed. Rather than bringing people to the services or institution, the services were brought to the people. The goal of this paradigm was to prepare individuals for integration into the community through skill upgrading and educational programming. Special education classes were taught in regular schools and training programs within sheltered workshops were established. Group homes were established as a means by which people with disabilities could progress towards more independent living. It was assumed that within these specially contained environments, individuals with intellectual disabilities would learn the skills and behaviors required to

succeed outside of their self-contained setting. Unfortunately, many of the participants never left these self-contained programs. Students remained in special classes and transitional workshops became permanent places of employment. Although no longer isolated in large facilities, individuals became permanent residents of group homes with little or no choice of living arrangements (Stainback & Stainback, 1996).

The supports-based paradigm reflects, in large part, the current service delivery ideology. It focuses on inclusion, or full participation in all aspects of family and community life. For individuals with disabilities to be successful in an inclusive setting, supports are required to achieve and maintain success. Supporters of this paradigm assume that with proper and adequate support, individuals will experience successful learning, work-related achievements, and positive encounters with community members (Polloway et al., 1996). Concerns surrounding the efficacy of this paradigm include cost effectiveness, availability of trained professionals, and the degree to which instructional models are supportive of persons with intellectual disabilities in inclusive contexts. These concerns have caused some to look towards the importance of personal agency by persons with disabilities in determining their own goals, desires, and aspirations.

The paradigm that is appearing on the horizon is personal empowerment. Empowerment, as Bandura (1998) suggests, is not simply a state that can be granted to someone. Personal empowerment is gained through a *process* in which one develops self-efficacy, self-esteem, a sense of personal control, a sense of belonging, and self-determination (Polloway et al., 1996). Rappaport (1981) suggests that empowerment can be used to enhance the possibility of people gaining control of their own lives. Arai (1997) highlights the multifaceted nature of empowerment. "Empowerment is defined as

an individual *process* by which one secures increased *control* over his/her life, and positive changes in the *capacities* or abilities of the individual occur in conjunction with *supportive* change within the community” (p. 4). Arai suggests four components that are required for empowerment to occur, those being *awareness, connecting and learning, mobilization, and contribution*.

For change to occur, the individual must be *aware* that a desire for change exists. The individual becomes aware of a personal desire to gain more control over one’s life and decision making. From this desire to change, the individual then seeks out *connections* with other individuals, agencies, or groups to learn the skills and acquire the information required to initiate the process of change. The individual needs to gather the knowledge and support to begin the change to take charge of one’s life. With information and support, the individual then mobilizes or takes *steps towards action* to achieve goals. The individual uses the newly acquired knowledge and supports to work towards reaching individualized goals that have been established for oneself. These goals are specific to the individual and focus on gaining more control over one’s life. The process of change becomes incorporated into the individual’s every day life activities. Empowerment is not complete without the contribution provided through community support. In other words, for one to be truly empowered a responsive environment that responds to decision making behaviors must exist. As Arai (1997) contends, individual empowerment will not be achieved if changes are not occurring within contributing factors (funding, community attitude, service provision). Thus, empowerment is a blending of external supports and mobilization making individual self-determination possible, which is the essential component of empowerment.

1.2.3 Self-determination as the Conceptual Framework

In the previous section, it was identified that self-determination is essential for the development of empowerment. Conversely, an environment that supports empowerment is fundamental for self-determination to occur. Self-determination is a life-long developmental process that means "... to act as the primary causal agent in one's life, and to make choices and decisions regarding one's quality of life free from undue external influence or interference" (Wehmeyer & Sands, 1996, p.24). Simply stated, it refers to, "both the right and capacity of individuals to exert control over and direct their lives" (Wehmeyer, 2004). To have control over one's life requires a supportive and accessible environment. It is through the process of self-determination that one becomes empowered.

According to Wehmeyer and Sands (1996) four characteristics must be met for behaviour to be considered self-determined: (a) the individual acted autonomously, (b) the behaviours were self-regulated, (c) the person initiated the events/behaviour in a psychologically empowered manner, and (d) the person acted in a self-realizing manner (see Figure 1.1).

An explanation of the four characteristics is required to fully understand the meaning of self-determination. *Autonomy*, of Greek origin, *autos* (meaning self) and *nomos* (meaning rule), literally translated means 'self-ruling'. This means that a person is able and free to make decisions without coercion. *Self-regulated behaviour* enables individuals to evaluate their environments and their options of response for coping within their environments and deciding how to act, respond, and change plans as necessary. *Psychological empowerment* means that one believes personal control is possible over

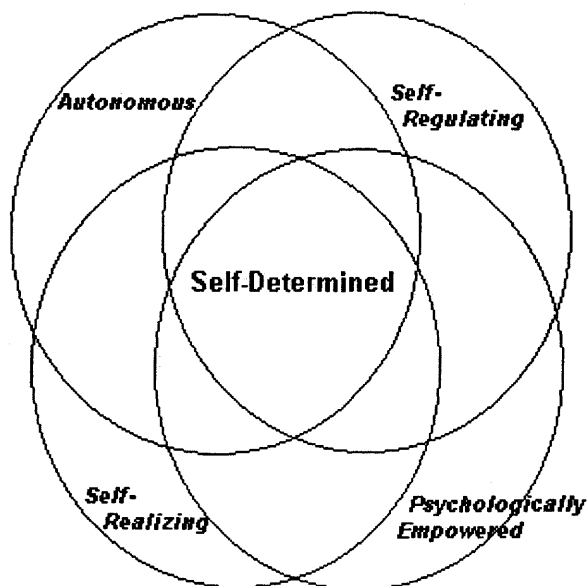


Figure 1.1 The essential characteristics of self-determination (from Wehmeyer & Sands, 1996, p. 25).

circumstances that are personally important and possess the skills to reach the desired outcome(s) if the skills are executed. *Self-realized* people use the knowledge of themselves, their strengths and weaknesses to reach a desired outcome. This set of attitudes (psychological empowerment and self-realization) and abilities (behavioural autonomy and self-regulation) must be present for an individual to be self-determined (Wehmeyer & Sands, 1996).

For self-determined behaviour to be expressed, Wehmeyer and Sands (1996) suggest the following skills are essential: choice making, decision making, problem solving, goal setting and attainment, self-observation, evaluation and reinforcement, internal locus of control, positive attributions of efficacy and outcome expectancy, self-awareness and self-knowledge. Thus, environments that are supportive of the development of these skills are ones in which self-determination is possible. Historically, people with disabilities were not provided with the opportunity to exercise self-determination. The facility-based paradigm, the services-based paradigm, and, to some

extent, the current supports-based paradigm that exist today were and are strongly influenced by the decision making of others (Polloway et al., 1996). Only with a move towards empowerment, which promotes a responsive environment for individual choice and decision making, will people with disabilities be provided with the opportunity to exercise self-determination.

Choice making is fundamental to self-determination (Wehmeyer & Sands, 1996). Presenting options and teaching choice making in the decision making process is a necessary prerequisite for self-determination among individuals with intellectual disabilities (Davis & Burton, 1991). Research has indicated that when given choices, students with intellectual disabilities are more productive, more active and attentive, and more self-confident and self-directed (Burton & Davis, 1996).

However, historically, the ability of persons with intellectual disabilities to make informed choices has been questioned (Polloway et al., 1996). Research has demonstrated that people with intellectual disabilities are capable of making choice in many contextual settings. For example, Realon, Favell, and Lowerre (1990) determined that 2 male participants who had profound multiple disabilities were able to make choices and indicate preference of leisure activities by pulling a lever attached to their preferred activity. Further, when participants with severe intellectual disabilities were allowed to choose their own work assignments, Parsons, Reid, Reynolds, and Bumgarner (1990) found the workers were twice as attentive when they were assigned to a non-preferred task. A study by Parsons and Reid (1990) determined that adult participants could successfully make choices regarding meal options. Of particular note from this study, it

was found that when service providers were questioned about client preferences, they did not accurately predict client choices.

Wall and Dattilo (1995) summarized seven strategies aimed at engaging adults with intellectual disabilities in self-determined leisure related behaviours. The strategies were (a) include self-determination goals in individual program plans (i.e., plans developed to identify goals and monitor progress in the areas of leisure, vocation, and daily living skills), (b) implement a 'team-approach' when encouraging self-determination (e.g., service providers, adapted physical activity specialists, and the person with a disability), (c) assess individual preferences, (d) create a responsive environment, (e) provide opportunities for the expression of self-determined behaviour (which requires service providers to be aware and accepting of a variety of communication methods), (f) respond positively to self-determined behaviour, and (g) teach skills for self-determination.

1.2.4 Leisure

Life satisfaction relates to leisure activity (Hawkins, 1993). For adults with intellectual disability, the relationship between life satisfaction, choice, and leisure activity has yet to be thoroughly examined. Previous literature that has examined the frequency, success, and importance of choice making of leisure activity has indicated that individuals with intellectual disabilities can in fact be successful in choice making, and desire increased opportunities for choice making and leisure activities (Benz & McAllister, 1990; Parsons, Reid, Reynolds & Bumgarner, 1990; & Realon, Favell & Lowerre, 1990). By utilizing the conceptual framework of self-determination to understand and interpret the leisure experiences of women with intellectual disabilities,

this study increases our understanding of the meanings ascribed to opportunities for choice in leisure participation.

The term leisure has taken on several meanings and interpretations. It can mean free time, time away from work, or time taken to relax (Pavelka, 2000). Arnold (1978) describes leisure as time when there is opportunity for choice and the purpose is threefold: relaxation, entertainment, and personal development. He further states, “Leisure is activity apart from obligations of work, family, and society to which the individual turns at will, for either relaxation, diversion, or broadening his knowledge and his spontaneous social participation, the free exercise of his creative capacity” (Arnold, 1978, p. 38). Arnold’s (1978) use of terms such as ‘choice’, ‘at will’ and ‘spontaneous’ suggest that self-determination is a key factor when one is experiencing leisure. The individual is experiencing leisure through self-direction. Leisure is choice driven.

At times, the terms leisure and recreation are used interchangeably (Karlis, 2004). Karlis (2004) suggests that recreation is structured and has rules that guide activities and is “the experience of activities defined by society” (p. 37). He distinguishes leisure from recreation by suggesting that leisure is any activity that is freely driven or happens spontaneously. Thus, there is a societal influence on the activities that one experiences during recreation while leisure is personally driven. In support of the notions presented by Karlis (2004), Parker (1981) also recognizes that recreation is a system of social control. He adds that recreation consists of activities that are pre-planned which abandon the notion spontaneity (Parker, 1981). Thus, when individuals participate in pre-planned activities, the experience is that of recreation, whereas leisure is determined by individual choice and control, or self-determination.

Parker (1981) identified four concepts when capturing the meaning of leisure; flexibility, spontaneity, self-determination, and choice. Flexibility is important to leisure, because having the opportunity to do what you want when you want is imperative to the leisure experience. Spontaneity, or the ability to do things of one's own choice on the spur of the moment, is another theme essential to understanding the meaning of leisure. Parker (1981) argued that the most enjoyable leisure experiences result from the impulsiveness of one's choices and actions. A third concept essential in understanding the meaning of leisure is self-determination. According to Parker, it is important that an individual is able to determine when, where, and how leisure is experienced. Lastly, the concept of choice is essential to understanding the meaning of leisure experiences. "Leisure is a time to be used according to our own judgement or choice; it is the whole of non-work where individuals are free to choose; or it is simply freely chosen activity" (Parker, 1981, p. 323). Parker's four concepts of leisure echo the notion of self-determination suggesting that leisure is choice driven and self-directed.

1.3 Leisure and People with Disabilities

Leisure is an important facet in one's quality of life and people with intellectual disabilities are no exception to this. We cannot assume that providing the basic needs, such as food, shelter, and clothing for people with disabilities is sufficient for an acceptable quality of life. Companionship, physical and emotional comforts, recreation and leisure opportunities are essential for a satisfactory quality of life for anyone (Dupuis & Smale, 1995). For individuals with intellectual disabilities, leisure has been described as "grey, monotonous, and confined without much sense of freedom" (Nirje, 1972, p. 18). Perhaps this is because individuals with intellectual disabilities spend much of their

leisure time with peers who also have disabilities and are under supervision of staff personnel (Glausier, Whorton, & Knight 1995; Hayden, Soulen, Schleien, & Tabourne, 1996; Mahon & Martens, 1996). Thus, opportunities for spontaneous or varied leisure activities may be limited.

Leisure activities for people with intellectual disabilities are reflective of societal beliefs (Hawkins, 1993). If people with intellectual disabilities are not accepted by society as equal contributing members, a responsive environment may not emerge in which these individuals can develop and gain confidence in demonstrating self-determined leisure related behaviors. Leisure is a way to develop and maintain relationships with the community and society as a whole.

1.3.1 The Frequency of Leisure Participation for People with Disabilities

Several studies have examined the frequency (e.g., Benz & McAllister, 1990; Hoge & Dattilo, 1995; Kishi, Teelucksingh, Zollers, Park-Lee & Meyer, 1988) type (Glausier et al., 1995), and leisure participation interests (Dattilo & Rusch, 1985) of people with intellectual disabilities. Benz and McAllister (1990) interviewed 286 adults (aged 35 to 55) with mild to moderate intellectual disabilities. Participants answered questions regarding occupational activities (jobs, programs) and leisure activities (crafts, hobbies). The results indicated that all participants had a desire to continue engaging in both occupational and leisure activities that were personally meaningful. The participants also had a strong desire for greater frequencies, increased choice, and more variety within these activities.

Another study examining leisure preferences and participation frequencies of 46 adults (over the age of 50) with intellectual disabilities found that participants spent most

of their time in passive activities such as watching TV or listening to records, generally with people from their immediate environment (i.e., group home setting) (Glausier et al., 1995; Stainback & Stainback, 1996). In addition, using structured in-depth interviews to determine frequency and type of leisure participation, Hoge and Dattilo (1995) investigated the leisure patterns of 100 adults with intellectual disability compared to 100 adults without disabilities. They found that adults with and without intellectual disabilities enjoy similar leisure activities, but adults with disabilities have lower participation frequencies than those without disabilities.

1.3.2 Residential Influences on Decision-Making

Polloway et al. (1996) suggested that, although individuals with mild to severe intellectual disabilities are capable of making personal choices regarding leisure and other aspects of their lives, their opportunities to do so are limited. Persons with intellectual disabilities are often not allowed to make choices in many aspects of their lives, including school, work, home, and leisure (Mahon, 1995). Kishi et al., (1988) examined the life choices of previously institutionalized persons currently residing in a group home setting. Participants with mild to severe intellectual disabilities were interviewed, along with group home staff. All were interviewed about the extent and occurrence of opportunities that individuals had to make choices. Forty-two adults without disabilities were asked the same questions and the answers were compared to those of the 24 adults with intellectual disabilities. Kishi et al. (1988) discovered that the adults with intellectual disabilities had significantly fewer opportunities to make choices than the participants without disabilities. Interestingly, as cognitive functioning decreased, so did opportunities for choice making. Group home staff supported this

finding by suggesting that individuals with lower cognitive functioning had limited ability to indicate preference.

Duvdevany, Ben-Zur, and Ambar (2002) found that individuals with intellectual disabilities who lived in a group home setting displayed low self-determination compared to those individuals who still resided with their parents. Kishi et al. (1988) and Hoge and Dattilo (1995) found that there are limited opportunities to develop and practice leisure skills within supervised group home environments.

In addition, individuals with intellectual disability may be limited in their opportunities to make choices because there is not enough staff to accommodate individual preferences (Pedlar, Haworth, Hutchinson, Taylor, & Dunn, 1999). One individual may want to attend a movie, while another wishes to go shopping at the mall. It is seldom there is a staff person for each person in a group home, thus either both people have to attend the movie or both have to go to the mall. For this reason, much of the free time spent by people with intellectual disabilities is spent with others who also have disabilities (Glausier et al., 1995; Hayden, Soulen, Schleien, & Tabourne, 1996; Mahon & Martens, 1996).

Stancliffe (1997) suggests that there are several living-environmental characteristics, including residence size, staffing arrangements, and program type, that influence one's experience in a residential setting. He found that residents in a small supported living setting (comprised of only 1 or 2 people) exercised choice making more often than residents in a large supported living setting (4 or 5 people). Also, Stancliffe (1997) determined that in residential settings in which staff were absent for long periods, opportunities for choice making increased. Because staff were unavailable to supervise or

'manage' decision making, people with disabilities were, to a certain extent, forced to be self-determined. When one considers the range and depth of barriers that are experienced in living situations common to people with disabilities a multileveled approach would be required to address these barriers.

1.3.3 Staff Influence on Decision-Making

Service providers often determine the daily routines of individuals with intellectual disabilities, including work and leisure activities (Duvdevany, Ben-Zur, & Ambar, 2002). Individuals who live in a group home setting, which is a fully supervised environment, are assumed to require 24-hour support. Because of this assumption, support staff are hired to assist the residents with everyday activities, including making choices about leisure and recreation. But due to the continuous presence of staff, opportunities for choice making by residents is inhibited as some staff become more 'outcome' focused rather than 'choice' focused (Stancliffe, 1997). For example, some staff feel a need to keep people busy through planned activities, or 'program' the days events so as to avoid down time in which the people they support may become bored. Thus, how the staff perceive the 'productiveness' of those in the home can affect opportunities for choice in how personal leisure time of adults with intellectual disabilities is spent.

Furthermore, service providers may support the notion that individuals with severe intellectual disabilities are incapable of indicating preference and thus do not provide opportunities for choice-making (Kishi et al., 1988). Furthermore, Kishi et al. (1998) suggested that if service providers hold assumptions that people with disabilities are unable to learn or comprehend the required skills for choice making and decision

making, opportunities to practice choice making and decision making skills are lost. A lack of awareness and understanding by service providers of the skills required to achieve empowerment and self-determination prevents people with disabilities from achieving self-determination (Kishi et al., 1998). Smith, Polloway, Patton, Dowdy, and Heath (2001) added to this suggesting that even when there is awareness on behalf of support staff of the importance of choice making for persons with intellectual disabilities, there is a lack of creativity, awareness and patience from support staff when attending to choice making behaviors.

Staff perceptions may also inhibit successful facilitation of social relationships away from the group home (Pedlar et al., 1999) which can affect community leisure involvement. Leisure participation can also be affected by organization and agency administration (Kishi et al., 1988; Neumayer & Bleasdale, 1996). In a study of 30 adults with intellectual disabilities, semi-structured interviews were used to gain an understanding of their preferences, viewpoints and values of home, work, leisure, and relationships. Neumayer and Bleasdale (1996) found that although the participants were able to clearly express a wide variety of leisure activity interests, just over half independently carried out their chosen leisure activities with staff often present during those activities.

1.3.4 The Workplace and Community

An entity of the services-based paradigm of the 1960s (Polloway et al., 1996), which exists today are supported employment or sheltered workshop settings (Sutton, Sterns, & Schwartz-Park, 1993). The workplace becomes a major source of life satisfaction with friendships and social interactions centered around the people

encountered at the workplace (Sutton et al., 1993). Few people with intellectual disabilities spend leisure time within the community or with people outside of their social circle from work or the group home setting (Glausier et al., 1995; Mahon & Martens, 1996). In fact, Stroud, Roberts, and Murphy (1986) reported that older adults with intellectual disabilities were dissatisfied with their leisure time and preferred the structured time found in the workplace as it brought them in contact with their peers because the workers had little or no social contact with others beyond work.

Another study examining community leisure involvement of adults with intellectual disabilities found that, when placed in supported employment programs, people with disabilities did not generally engage in community recreational activities (Mahon & Martens, 1996). This study lends support to Stroud, Roberts, and Murphy's study (1986) suggesting that people with disabilities engage in the social interactions primarily with those with whom they work. The researchers implemented a leisure education program during which time 10 participants learned about leisure options, developed decision making skills, participated in personal planning, and developed a personal leisure plan. At the conclusion of the leisure education program, all 10 participants showed enhanced leisure satisfaction and met the majority of the objectives outlined in the program. This study not only provided support for the need to educate working adults with intellectual disabilities about leisure and community activities, but also provided evidence that leisure educational supports are needed.

1.3.5 Retirement

Just as the general population ages and experiences life changes including declining health, changing roles, and retirement, so do older adults with intellectual

disabilities (Heller, Miller, Hsieh, & Sterns, 2000). Successful aging (i.e., mental health, physical health, and intellectual performance) is positively related to recreational participation (Iso-Ahola & Weissinger, 1984). But adults with intellectual disabilities who are not self-determined in their leisure may be ill prepared for their newly found free time when they face the reality of retirement. The idea of retirement may not be viewed as a time of opportunity for older adults with intellectual disabilities, but rather a time of loss.

Unfortunately, just as with many aspects of their lives, staff tend to make decisions regarding retirement plans for individuals with intellectual disabilities, based on their perceptions of the person's health, functioning, energy level, and interest in work, often without consulting the individual themselves (Heller et al., 2000). Also, funding, staff limitations, and the need for work placements of new participants can take priority over the preferences and opinions available to older adults (Sutton et al., 1993). Heller et al., (2000) determined that a person-centered later-life planning training program in which participants were educated about later-life issues and options, individual choice and participation in life-changing decision making, setting realistic goals, and increasing one's life satisfaction, produced participants who were more capable of making choices and reaching goals than those in the control group. Having control over one's life to exercise the skills and characteristics required for self-determination resulted in a greater ability of participants to execute the required skills and characteristics.

Active lifestyles produce more pleasure and reduce loneliness, depression and anxiety of isolation (Iso-Ahola & Weissinger, 1984). Mahon and Goatcher (1999) found that individuals with intellectual disabilities who were involved in leisure activities

during retirement experienced greater life satisfaction. Providing adults with the opportunity to take part in preferred leisure activities will increase their involvement and promote active living (Heller et al., 2000). However, people with disabilities who have not developed leisure skills in preparation for retirement may not experience the same quality of life as those who have developed the necessary skills.

1.4 Purpose of the Study

After compiling and developing my literature review and reflecting on my personal experiences working in the field, I realized that the leisure experiences of people with disabilities are influenced and, at times, defined by several factors (e.g., available opportunities to be self-determined in leisure, assumptions held by support staff that may prevent self-determined leisure experience, administrative and organizational structure). Once again, I began to reflect on my experiences working with people with disabilities and I recalled several encounters I had with the participants of an activity centre at which I worked. Interactions I experienced with some of the participants lead me to further question the factors that contributed to, or prevented, a true leisure experience.

I returned to the work force after two intense years dedicated solely to graduate school studies. I thought it would be beneficial to my research project and future career development if I returned to a 'hands-on' environment. I worked a couple of days a week in a sheltered workshop for people with intellectual disabilities. It reminded me of why I love working in this field and kept the fires of passion burning for my research.

My responsibility at the workshop was to ensure that the participants I worked with were working on projects they enjoyed while providing opportunities for personal growth (i.e., decision making skills, social skill development, vocational training). I

sought opportunities to interact with the participants and engaged in conversation with them. Undoubtedly, one of the questions that the participants always asked me Monday morning was “What did you do this weekend?” I always responded with a list of activities I was involved in, even as specific as, “I went to Safeway at the Southland Mall to buy groceries for supper.” (If I had simply stated that I went to the mall, I guarantee that I would have been asked, “Which mall? or “What did you go to the mall for?”) To reciprocate, I then asked the participants “What did *you* do this weekend?” I would estimate that 4 out of 5 individuals responded by saying, “Nothing”. I would probe a little and ask specifics such as “Did you leave the house? Did you watch television? What did you do Saturday night?” Responses would range from “No,” to “Nothing,” to complete silence. Week after week I encountered this phenomena; a group of individuals who did *absolutely nothing* on the weekend. I wondered “What does doing ‘nothing’ look like? How does it feel?” Perhaps my questions were not clearly understood, or, due to some communication barrier, the answers just did not “get out”. Nevertheless, I was left wondering about the leisure experiences of these individuals. My academic reading, my time spent in professional practice, and my passion for maximizing opportunities to increase the quality of life of persons with disabilities reaffirmed the importance of my research question.

The purpose of this descriptive study was to learn more about the leisure experiences of women with intellectual disabilities who live in group homes and to more fully understand their opportunities for input into personal leisure experiences. A study of the meaningfulness of leisure provides valuable insights into the lives of people who,

historically, have been protected from independent decision making (Polloway et al., 1996). More specifically, this study aimed to understand:

1. How women with intellectual disabilities experience leisure?
2. What opportunities they have to provide input into the nature of their leisure experiences?
3. What meanings women with intellectual disabilities ascribe to their leisure experiences?

For the purpose of this study, the parameters of leisure set out by Parker (1981) served as the definition for leisure. Thus, leisure was defined as ‘time away from work that one is able to choose how to spend time and no activity has been pre-planned.’

Chapter 2

2.1 Research Approach

To examine the leisure experiences of women with intellectual disabilities, a hermeneutic phenomenological comparative case study approach was undertaken. This form of inquiry is interpretive and naturalistic in nature. The researcher attempts to make sense of, or interpret, phenomena and come to an understanding of the meanings ascribed to the participants' day to day experiences (Creswell, 1998; Denzin, 1994). Simply stated, the goal of hermeneutic phenomenology is to gain an understanding of the essential meaning of something (Creswell, 1998). The phenomenon of leisure was examined within the parameters of a phenomenological case study with 2 group homes being the focus of the study.

Case Study

Geertz (1973) believes a case study is a fitting approach to provide the detailed description required to understand the context and circumstances of phenomena. Creswell (1998) describes a case study as an "exploration of a bounded system or a case over time through detailed, in-depth data collection involving multiple sources of information rich in context" (p. 61). In this study, women with intellectual disabilities were studied in 2 particular group homes (the cases) during a specific time period. Creswell (1998) advises that the case is best examined within its physical and social setting, just as the cases for this study were examined within their natural neighborhoods and the activities that naturally occurred within and

around them. Because the cases for this study were examined due to their uniqueness, they can be referred to as *intrinsic case studies* (Creswell, 1998). The two environments were unique in that each home was governed by a separate agency, both existed in distinct neighbourhoods, and both employed separate staff to provide support to a distinct, separate group of individuals within that particular environment.

The data collected for a case study comes from multiple sources and it is recommended that these sources include documentation, archival records, interviews, direct observations, participant observation, and physical artifacts (Creswell, 1998), all of which were gathered for this study and will be discussed in more detail in this chapter.

Through rich descriptions of the case, the researcher and the audience may come to better understand the experiences being considered. Lincoln and Guba (1990) believe a case study must have empowerment quality to be considered of value. The case study should have “the ability to evoke and facilitate action on the part of the reader” (Lincoln & Guba, 1990, p. 57). The reader’s conviction will compel personal action in the environment of focus to enhance the experiences of those participants. As Lincoln and Guba (1990) state, this empowerment “implies consciousness-raising” (p. 57).

On a personal note, completing this research had a profound effect on me. I became more determined than ever to make positive changes in the lives of the people with whom I work. Although I was already aware of the importance of providing choice to people with disabilities, particularly in regard to their leisure experiences, I became more determined to educate other professionals about the empowerment paradigm that is

on the horizon in the field of disability. This was very important to me because, as it was earlier identified, empowerment and self-determination demand a reciprocal relationship, for the advancement of one cannot exist without the other. Thus, for progress to occur, service providers and people with disabilities must work together for positive change.

Phenomenology

Phenomenology asks, “What is the nature of this lived experience” (Morse & Field, 1995, p. 42)? As a person cannot reflect on an experience while they are going through it, phenomenological reflection is retrospective and recollective; it is a reflection of an experience that has already occurred or been lived through (Creswell, 1998). Phenomenology is concerned with experience as it is lived. Phenomenological inquiry is hermeneutic when the lived experiences of the participants are interpreted so as to gain a common understanding of the meaning assigned to everyday experiences (Morse & Field, 1995). Phenomenology is concerned with the qualities, values, and impressions of experiences rather than the what, when and why which quantifies experiences. Phenomenology aims to describe and interpret lived meanings that occur in everyday life. “Phenomenology is the study of the lifeworld...as we immediately experience it...”(van Manen, 1990, p. 9). van Manen believes that investigating experience requires the researcher to “become full of the world, full of the lived experience” and to “stand in the fullness of life, in the midst of the world of living relations and shared situations (van Manen, 1990, p. 32).

2.1.1 Description of a Group Home

Within most urban centres, there are a number of agencies that oversee the management, staffing, and operations of community-based residential environments for

adults with intellectual disabilities. The role of these agencies is to provide supported living environments in neighbourhoods throughout the city. Each agency is typically responsible for 2 to 6 “group homes”. Group homes often have 24-hour staff support (referred to as ‘house managers’) for 3 to 6 individuals with intellectual disabilities. A group home resembles a family dwelling in that each person has a bedroom and shares common living areas of the home such as the kitchen, dining room, living room, washroom and yard. Group homes are government-funded, not-for-profit entities and their operations are shaped by a detailed annual budget which specifies how the allotted funding should be spent (i.e., staffing, staff and board member training, home maintenance, groceries, electrical, power, and water).

Each group home has a volunteer board of directors, usually comprised of community members and family members of residents, who work to “establish direction of the agency and formulate policy to allow the agency to carry out its mandate” (RRRC, 2002, Policy No. 2.001). Revision of policies, monitoring of programs, admission and review of new applicants, and budget reviews are a few of the responsibilities of a board of directors. The Executive Director, who is directly accountable to the board of directors, is responsible for the day to day operation of the group home (see Figure 2.1). The Executive Director acts as a liaison between the board of directors and staff personnel, implements policies outlined by the board, monitors the annual budget, and ensures proper practices are applied in the care and support of the residents.

Many group homes have a program coordinator who takes direction from the Executive Director and ensures the implementation and development of Individual Program Plans (RRRC, 2002, Policy No. 3000). The individual plans are developed to

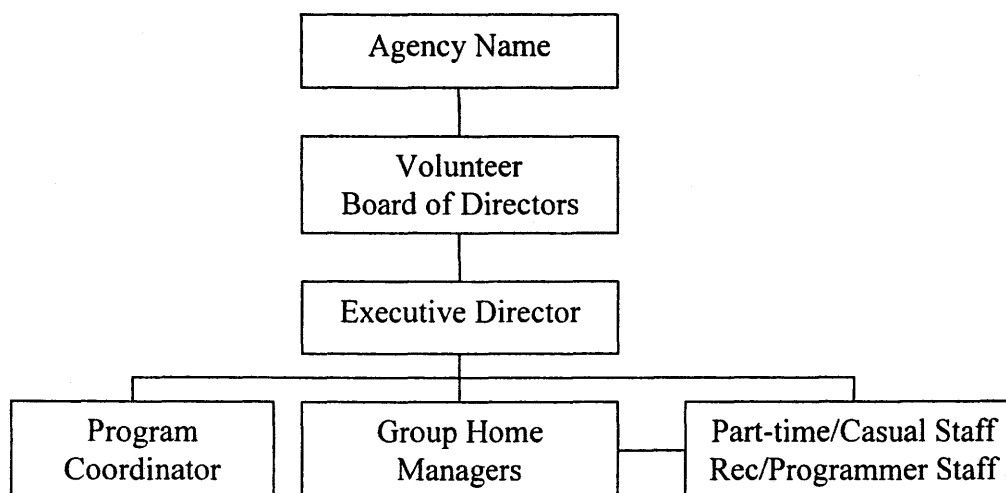


Figure 2.1 Organizational structure of the group home agencies.

ensure resident needs are being met in the allocation and dissemination of support services provided by the agency. The Individual Program Plans include, but are not limited to, leisure and recreation goals and the steps required to achieve them. The ‘focus person’ of this plan (i.e., a resident of the home) may or may not be involved in the development of this plan. Group Home Managers, who are also directly responsible to the Executive Director, are required to provide an environment within the home that is “conducive to the physical and emotional well-being of the residents and to ensure smooth day-to-day operations of the home” (RRRC, 2002, Policy No. 3000). This requires supervision of part time and casual staff, record keeping (e.g., resident history, petty cash, medication sheets), housekeeping, and maintenance. Part time and casual staff (those who work less than 40 hours per week) assist the group home manager in creating and maintaining the appropriate environment as outlined earlier. A part-time staff person is also often hired to assist with activities within the home and community outings, often referred to as a “Rec Worker” or “Programmer.”

The leisure experiences of the women in the two homes examined were influenced by parameters common to many group homes. Due to funding, it can be fiscally impossible to employ enough staff to provide the support required for each resident in the home to take part in individual activities of one's own choosing because of supervision requirements (i.e., it is assumed that individuals who reside in group homes require 24 hour support). For example, one individual may choose to go to a movie while another may indicate a preference for bowling. While an attempt to meet each individual choice is made, it is impossible for a staff person to be in two places at once. As a result, one of the individuals must agree to go to a movie while the other waits for another opportunity to go bowling. Thus, group outings are necessary within this specific context. In a group home, the staff to resident ratio seldom exceeds one staff person to five residents or 'housemates'.

Access to transportation also affects opportunities for leisure experiences. When transportation is not readily available, it is difficult for housemates to experience spontaneous leisure. Not all staff personnel drive or have a car available to transport housemates to and from their leisure destinations. Paratransit, a public transportation system, is available but bookings must be made in advance via telephone.

Weather and time of day impact leisure experiences as well. When winter conditions are present, the uncomfortable cold is avoided and walking becomes unsafe due to icy conditions. In the summer months, hot temperatures deter outings to offset the risk of experiencing heatstroke and sunburn. Furthermore, evening activities are less likely to be engaged in than daytime activities due to the lack of light and possible safety risks.

The two group homes, or 'cases', for this study were Elm Home and Cairn Home (pseudonyms). Elm Home was established in 1985. It was a split-level house (there were stairs ascending to the front entrance of the home and part of the living space was in the basement). There were three bedrooms upstairs, and three bedrooms downstairs. The upstairs also consisted of a sitting area with a TV, a kitchen, and a washroom. Downstairs included a sitting area, with a washroom, laundry and storage area nearby. There was no backyard. Five residents lived in Elm Home, three women and two men.

Cairn Home was opened in 1977. The home itself was once a duplex (i.e., a dwelling consisting of two separate suites yet structurally joined together) but was renovated so the structure could become one large unit. The wall separating the two suites was knocked out and the extra living room was converted into a dining area. Upstairs, three bedrooms and one washroom could be located on each 'side' (i.e., duplex side). Downstairs consisted of a bedroom (only used by guests), a sitting area with a television and VCR, a rumpus room large enough to accommodate a ping-pong table, and laundry facilities. Outside, a large backyard housed a barbeque, lawn furniture, and a garage which was only used for storage. All five individuals who lived in Elm Home were women.

2.1.2 Criteria and Recruitment

A criterion sampling strategy was utilized for this study, meaning that each case (i.e., group home) must be specific and meet outlined criteria (Lincoln & Guba, 1985; Miles & Huberman, 1994). Two cases (i.e., group homes) were chosen for this particular study. The decision to investigate two group homes was made for three reasons: (a) to gain a wider perspective of leisure experiences of women with intellectual disabilities, (b)

to avoid limiting the study by investigating only one group home of one agency and (c) to further investigate the leisure experiences of a group home I was already familiar with. To clarify, previous to this study I was employed as a house manager for two years by the agency responsible for one of the homes. A sense of trust had long been established and I maintained a strong rapport with the housemates, staff members, and board of directors.

The cases (i.e., group homes) matched the following criteria:

1. The “cases” (i.e., group homes) met the definition provided by Saskatchewan Social Services (2002) as “a home within a residential neighborhood which is staffed to provide personal care, supervision and support to usually three to six adults with intellectual disabilities,”
2. The group home structure provided opportunities for leisure each week,
3. The group home staffed a ‘Rec Worker’ or ‘Programmer’,
4. The group home had permanent, established residents (i.e., the housemates lived together in the home for a minimum of 5 years),
5. The group home had female residents,
6. The group home did not provide day programs to the housemates (i.e., all were active in vocational programs away from the group home during weekdays),
7. Communication in the home was primarily verbal (i.e., augmented communication systems between the staff and the housemates were not used),
8. The staff members and housemates of the group home agreed to participate in the study, and
9. The staff personnel were paid staff of the group home (not volunteers) and had a minimum of 2 years experience working with people with intellectual disabilities.

Women were specifically chosen to participate in this study. We cannot assume that men and women would have the same leisure experiences. Studies have shown that the leisure participation patterns of women differ from those of men due to personal preference, opportunities available, societal approval, household duties and child care responsibilities, past experiences, and perceptions of leisure (Searle & Brayley, 2000). “The most important outcome of this research over the past ten years has been to make explicit the understanding that for women leisure is experienced differently, perceived differently, and constrained differently...” (Searle & Brayley, 2000, p. 64). Thus, the meaning ascribed to these experiences would be specific to each gender.

To gain an in-depth understanding of the lived leisure experiences of the women within the group homes, information from multiple perspectives was gathered from each case. One perspective was provided by the women with intellectual disabilities who resided in the homes (hereafter referred to as “the women”) and offered personal accounts of their leisure experiences. The second perspective was provided by the support staff of the homes which afforded context for the leisure opportunities. A more in depth description of the participants of the study is provided later within this section.

Two agencies were originally contacted via formal letters of invitation to participate in the study. Both agencies responded within a 2-week period upon receiving the letter. The executive director overseeing Cairn Home invited me to contact the group home staff and women to set up an initial meeting to discuss the study. The program coordinator of Elm Home, under the direction of the executive director, encouraged me to contact the staff and women of Elm Home to set up an initial meeting to discuss the study.

I contacted the group home staff of both homes to set up an initial meeting with them and the women. A meeting with all women and both full-time staff of Cairn Home was held at the home during afternoon coffee when the women had returned from their vocational programs. Later in the week, an early evening meeting was scheduled with the women and full-time staff of Elm Home. The meetings allowed me to address the purpose of the research, the commitment required of the women and staff, the benefits of participation, the importance of the research, as well as confidentiality and anonymity protocol using simple, non-complicated terms. For example, I explained that I was a 'student' and was working on a 'school project' for my 'teacher'. I asked the housemates and staff if it would be okay to "spend some time with them after work and on weekends to see what they do in their free time". They were informed that I would be spending approximately 5 hours per week in each home. I indicated that I would spend a weekday evening and a weekend afternoon with the women each week for the next 10 weeks observing 'activities of free time' at home and in the community as well as conducting interviews with the women and staff of the home. I further explained that all participants would be interviewed and that approximately half-way through the study the women could take photos of their leisure time with one-time use cameras I provided. It was made clear to the staff in each group home that routines would not be disrupted and I would be available to provide support during outings if required.

In Cairn Home, upon reviewing the participant criteria and recommendation of staff, it was determined that 3 of the 5 women who lived at the home would be interested, willing, and suitable to participate in the study. The staff recommendations were based on their previous experiences with the women and their perceptions of the women's

cooperative nature, comprehension and communication ability. Cairn Home staff were instrumental in explaining to the participants, in simple terms, the purpose of the research. The women were asked to state, in their own words, what they interpreted the purpose of the study and my role to be. They were asked to explain “Why is Brenda spending time with you and what does she want to learn about you?” and “What are you going to be doing with Brenda?” At this point, I, or the staff, clarified any inconsistencies, and participants were asked to pose any questions they had. Once all questions were answered and the staff and I felt that the women could provide informed consent, The Agreement to Participate form (see Appendix A) was read to the participants and the three women verbally agreed to participate in the study. The Agreement to Participate form was then signed, dated, and witnessed by the staff person. At this time, I also gained permission from the staff and women to take photographs of artifacts in the home and of leisure activities they engaged in.

At the initial meeting with participants from Elm Home, I addressed the participants and the one staff person who was currently on duty. Once again, upon review of the outlined criteria, the staff person and I determined that 2 of the 5 individuals residing in the home were suitable to participate in the study. To achieve informed consent, the same process was used with the participants from Elm Home as was used for the participants of Cairn Home. Simple terms were used to explain the purpose of the research and my role to the women. Once again, the participants were asked to state, in their own words, what they interpreted the purpose of the study and my role to be. They were asked to explain “Why is Brenda spending time with you and what does she want to learn about you?” and “What are you going to be doing with Brenda?” Due to lack of

participant response to the questions and inaccurate understanding of the purpose of the study, the staff person and I did not feel that the women could provide informed consent at that time. The staff person recommended that I visit the women later in the week to discuss the study again.

I followed up on the recommendation to revisit the women and met with them again later in the week. At this visit, the other full-time house manager was on duty. At this meeting, the staff person helped explain the purpose of the study to the women. Again, I explained my role to the participants. The staff person patiently observed and supported the women only when necessary as they asked questions. Upon reviewing the purpose of the research and my role to the women and staff (using the same process that had been used before), it was determined, upon recommendation by the staff, that the women could make an informed decision to participate in the study at that point. The Agreement to Participate form was read to the participants and both women verbally agreed to participate in the study. The Agreement to Participate form was then signed, dated, and witnessed by the staff person. Permission to take photos of artifacts and leisure experiences in the home and community was also obtained from the staff and women at this time.

Background information for each woman was collected with the assistance of the woman herself, the staff, and Executive Directors of each agency. The historical sketch outlined information such as family proximity, frequency of family interaction, residential history (e.g., length of time in a staff supported living environment, past living circumstances), and history of choice making opportunities (e.g. choosing what clothes to wear, what movie to watch, what items to pack for lunch). Also, relevant information was

gathered in regards to leisure interests, use of leisure time, and interest for leisure participation (see Appendix B for Sample Historical Sketch Form).

Common to both cases (i.e., group homes), was that all of the women attended vocational programs during the day, leaving home at 7:30 a.m. and returning just after 3:00 p.m. All women regularly spent time with family who lived in the city (at least one meeting per month). All participants had a history of choice making in regards to daily living activities. Based on this, it was assumed that the women from both homes were of equal functioning (i.e., lived in similar contexts, attended similar day programs, communicated using similar vocabulary and phrases, engaged in similar activities).

A description of the participants from each case follows. Please note that just as in the names of the cases (group homes) the names of all the participants (women and staff) are pseudonyms to protect anonymity and confidentiality.

2.1.3 Description of Participants

Elm home. The participants from Elm Home consisted of two women with intellectual disabilities, Brie and Daria. Brie, 44 years old, moved into Elm Home when she was 25 years old and had resided there for 19 years. Previous to her time in Elm Home she resided in another group home (governed by the same agency) for 9 years. Brie spent time with her family (mother and sister) once a month during weekend visits to their homes. Daria, a 45 year old woman, resided in Elm Home for 7 years at the time of data collection. Prior to her move into the home she lived with her mother. Since her move to the home, Daria stayed with her mother at least one weekend per month.

The two staff from Elm Home included one full-time staff and a part-time recreation support staff who was referred to as a 'programmer'. Mike was a 32 year old

male who had been employed at the home for 10 years. During his time in the home, he worked in various capacities (e.g., casual, part-time, full-time). Mike completed his Grade 12 education and Level I and II training of Saskatchewan Social Services, Community Living Division (this training provides information on the philosophy outlining support strategies, behaviour management, and supervision of support staff in the field). Natasha, a 22 year old university student who worked part-time at the home for two and one half years, had the role of programming recreational activities and outings for all individuals in the home each week.

Cairn home. The 3 participants from Cairn Home were Beth, Ina, and Jackie. All of the women moved into the group home when it opened in 1977 and thus had lived together for 26 years at the time of data collection. Prior to residing in Cairn Home, the women resided with family members. At the time of data collection, Beth was 60 years old, Ina was 55 years old, and Jackie was 50 years old. Both Ina and Beth had weekly contact with family members who resided in the same city (telephone and/or face-to-face visits) while Jackie had contact with a family member, who resided out of town, on a monthly basis.

Three staff personnel participated from Cairn Home; two full-time house managers and one recreation worker. Mitzy, a 37 year old, full-time house manager at the time of the study, had been employed by Cairn Home for two and one half years. She had been working in the field for 15 years and possessed a Rehabilitation Worker Certificate and a university degree. Over the past 10 years, Mitzy had also completed her Supported Decision Making (Bodnar & Coflin, 2001) Instructor Certification (qualifications to instruct supported decision making strategies for persons with intellectual disabilities to

care providers), Stress Management Course, and Levels I, II, and III Training from Saskatchewan Social Services, Community Living Division. She was also an instructor for the Basic Skills Training course, a course designed to educate professionals new to the field on the history of treatment towards individuals with intellectual disability, communication techniques, instructional strategies, personal care, and attitudinal awareness.

Bella, a 51 year old, full-time house manager, had been working at the home for 6 years. Bella completed her grade 12 education, had her Basic Skills Training, and PATH training-Planning Alternative Tomorrow's with Hope, (a method of personal planning to achieve future goals and dreams). Previous to Bella's experience working in Cairn Home she had been a foster parent for nearly 20 years.

Shannon, a 27 year old recreation worker had been a part-time employee of the home for 4 years. Previous to her employment with the agency, she had worked in a vocational training program for people with disabilities for one year. During her time at Cairn Home, she worked a 4 hour shift each week providing support to the women in achieving their leisure and recreation interests. On occasion, she would cover a manager's shift, providing 24 hour support to the women. Shannon had a university degree as well as Basic Skills Training and Supported Decision Making (Bodnar & Coflin, 2001).

In summary, there were five women with intellectual disabilities from two group homes, 2 women from Elm Home and 3 women from Cairn Home, who took part in this study. Five staff personnel participated in this study, 2 staff from Elm Home and 3 staff from Cairn Home.

2.2 Data Collection

In addition to gathering information from the women with intellectual disabilities and group home staff (i.e., multiple data sources) multiple methods were used to enrich the study and provide as much insight into the research question as possible (Meadows & Morse, 2001). Interviews, observations, artifacts, and photographic images were all gathered.

It is also important to note at this time that while not all residents in each home were suitable to participate in the study (if the individual was non-verbal, for example) 'non-participants' in the homes were never excluded from activities in the home or community. However, I focused my attention on the behaviours, interactions, and conversations of the participants without jeopardizing the sense of 'belonging to a group' that all of the residents experienced.

2.2.1 Interviews

Two interview techniques were used in the study, semi-structured interviews and active interviewing. Interviews took place throughout the 10 weeks I spent in the group homes. Audiotaped interviews were conducted at the group home or in the community. The participants determined the location and time of interviews. Each of the women were interviewed a minimum of 3 times using the interview guide (see Appendix C). Depending on the motivation, fatigue, and comfort levels, each interview lasted 15 minutes to 30 minutes. Participants who were unable to answer the guide questions in three interviews (due to fatigue or time constraints) were interviewed a fourth time. In total, for each woman, cumulated interview time was approximately 45 to 90 minutes. All interviews were audio taped and transcribed verbatim.

Active interviewing is similar to semi-structured interviewing in the sense that the researcher follows up on participant responses (Holstein & Gubriem, 1997). It is improvisational in that the conversation is spontaneous yet directed by the researcher within the loose parameters set out by the purpose of the study. The goal of using active interviewing was to provide an environment in which the participants could comfortably express experiences, thoughts and feelings and not be limited by predetermined questions by the researcher (Holstein & Gubreim, 1997). The main advantage of active interviewing is that participants provide information within the immediate context of the situation eliminating a dependency on recall to discuss experiences later. In this study, the tape recorder was always readily available. At times, the tape recorder was left on in 'high-traffic areas', (e.g., areas of the home where group gatherings often took place such as the living room or dining room), and interactions were recorded as participants entered and departed the room. I would pose questions to the participants that were relevant to the current state of the environment such as, "What are you watching on TV? Where are you going today? What did you do last night?" The participants were also encouraged to ask me to record when they had "something important to say." This suggestion worked well, as two of the women would often ask, "Can you record this? I'm going to say something." Active interviews were extremely beneficial to the nature of this study as I could ask questions of the participants in an attempt to understand the meanings that were immediately ascribed to their experiences. For example, if a participant appeared to be particularly excited during an event or outing, questions could be asked surrounding its importance and its emotional connection. If a particular event or outing appeared to be

inconsequential to a participant, thoughts surrounding their indifference towards the situation could be immediately recorded.

Staff also participated in audiotaped semi-structured one-on-one format interviews ranging from 60 to 90 minutes (see Appendix D for interview guide). The staff participants were purposely interviewed after the women. This was done in order to prevent bias (i.e., I did not want information obtained from staff to lead the interviews with the women). Once again, location and time of interviews were determined by the participants. All interviews were audio taped and transcribed verbatim.

2.2.2 Participant Observation and Fieldnotes

Due to the nature of the women's interview responses, participant observation was beneficial in coming to understand the women's leisure experiences. The women's interviews did not provide long narrative responses to the questions asked of them. Their vocabulary, although descriptive of their experiences, was limited and their responses were often short and direct. To give context and greater understanding to the women's responses, it was necessary to focus on the participant observations and carefully recorded field notes. In most cases, the themes and subthemes that emerged from the analysis are illustrated via participant observations and field notes, including photographs. Throughout the results, the women's interview data is inserted where appropriate. In addition, the interview data from the staff appears secondary to participant observations and field notes when their interview data provided the best illustration of a subtheme. In an effort to avoid a misunderstanding regarding the women's leisure experiences, much of the data for this study was collected during participant observation.

Participant observation was also used to gain an understanding of the lived leisure experiences of the women. Participant observation calls for the investigator to enter as fully and naturally as possible into the lives of the participants, listening to what they say in the course of everyday life, observe what they do, ask questions if and when appropriate, and participate in routine or special activities when it is acceptable (Kernan & Sabsay, 1989). Observations of the women and staff provided context for the interview data and eliminated potential marginalization of myself in the activities of the group home (Creswell, 1998). Observations were recorded via two methods: (a) verbal audio recording which were transcribed into field notes, and (b) written field notes. I recorded observations verbally during the women's leisure experiences. Also, at the end of the day, I made detailed field notes recalling and reflecting on the activities and happenings that had been observed. The field notes included a summary of the day's events, overall impressions, and significant happenings or reactions of participants and staff. For example, a field note would include my time of arrival and departure time, activities for the day and how it was decided that those particular activities would be engaged in (i.e., staff decision, woman's decision, or cooperative decision), perceived responses of the women to the activity (i.e., excitement, indifference, boredom) and any significant happenings (i.e., positive or negative interactions with other women, staff, or community members).

I was able to spend time observing the participants in the home and community during non-work time. The observations occurred during the week when participants returned home from day programs or vocational responsibilities, but most observation time occurred on weekends when participants had more opportunity to experience leisure.

Often, I would spend a weekday evening and a weekend afternoon in each home, totalling approximately five hours per week for 10 weeks in each group home. Scheduling of time at the group homes was always determined according to the convenience of participant and staff timetables. Routines within the homes were not disturbed. Observations took place within the residence to gain a sense of the choice making capabilities of each participant and how each participant was involved in determining how leisure time would be spent. Observations also took place in the community to observe participation in leisure activities. I acted as a volunteer under staff leadership during leisure activities by assisting on outings and group home duties.

2.2.3 Artifacts

Examining artifacts is an unobtrusive method by which to collect relevant information and can provide background information and context relevant to the research questions (Denzin & Lincoln, 1994). Written artifacts which included notes from the daily log book from each home were gathered and examined with permission of the staff and women for the purpose of learning about commonly occurring events in and out of the home. Other artifacts included photographs and personal items of the women which were used to elicit discussion and reflection of past leisure experiences. By using personal artifacts to gain the women's perspectives, to access thoughts and feelings, and to understand their meaning of leisure, a greater understanding of their experiences could be gained.

Daily log books. Notes from the daily log book from each group home were collected over the 10-week period spent in the home. The purpose of the daily log book in a group home setting is to provide detailed information on daily happenings within the

home, community outings, planned activities, future activities, and general state or significant behaviours of those residing in the group home. It is a form of communication and record keeping between staff working separate shifts. The log book for each group home was kept on the staff desk and notes were made by staff throughout the day and at the end of a shift. The log book was beneficial to this study for two main reasons. Firstly, the log book provided me with information on events and happenings that occurred when I was not present (e.g., “Ina and Beth went out for a donut and coffee” or “Watched TV in evening”). Secondly, the log book provided information on the actions and behaviours of the women relevant to leisure time, (e.g., “Ina upset she did not have money to go out for coffee”). The log book provided contextual information regarding the routines and culture of the two group homes beyond that which was obtainable through observations and interviews.

Photographs. During data collection, I took several photos of the women engaged in activities in the home and the community. These photos were used as fieldnotes in addition to the written notes I made. During week 6 of the study, each participant was provided with one-time-use cameras (12 exposures) and were encouraged to take photos of their leisure experiences in the community and at home. The photos provided another avenue in which participants could share their experiences as they also provided a stimulus for conversation. I provided a ‘tutorial’ for both the women and staff on how to use the cameras. Each woman was asked if she could “think of anything to take a picture of that showed what she did in her free time.” I provided examples as to what I do in my free time. For example, I said, “I have a dog. I walk him in my free time. I could take a picture of my dog.” Staff were instructed that any photos were to be taken by the women

and to encourage them to take photos on days between researcher contact. During a 2-week period, the women had use of the cameras. Participant access to the cameras varied between group homes. Unlike the women of Cairn Home, who were allowed to keep their camera in their possession at all times, the women of Elm Home were required to keep their cameras in the staff room. The cameras were only available by asking a staff person for them.

After the two weeks, I developed the films and ordered 2 sets of prints; one set of prints for research use and one for the participant. However, several of the photos the women took did not turn out (e.g., too dark, unrecognizable features). In an attempt to understand the significance of the photos taken by the women, each woman was asked to describe the photos she took. Questions were asked regarding the content of the photos and the importance of the photo. For example, questions such as, “Where did you take this? What do you like in this picture? Why did you take this picture?” were asked to gather information of the photos. Interviews were recorded on audiotape, transcribed verbatim, and became part of the interview transcript text.

Personal items. During active interview sessions, the women were asked to discuss personal items that were important to them. These items were often located in their bedrooms and included such things as pictures, videos, clothing, furniture, wall hangings and stuffed animals. Participants were asked, “What can you show me in your bedroom that will tell me about what you like?” or “What is your favourite thing in your bedroom?” Personal items were used to elicit conversation to determine what items appeared to be meaningful, what ‘story’ was attached to the item, and the meaningfulness of the item. Gathering this information was useful in coming to understand the

importance of personal property and the role it played in opportunities for choice, personal expression, and leisure.

2.3 The Researcher as the Instrument

When conducting qualitative research, the researcher is the primary instrument of data collection (Silverman, 2000). A 'subjective bias' that a qualitative researcher may bring to a study is beneficial in that previous experiences within the field of interest bring credibility to the research question. It enables the researcher to see, hear, and take into careful consideration the events and actions witnessed within a particular environment (Strauss & Corbin, 1998). I drew upon my professional experience and applied knowledge to bring sensitivity and insight to the research questions and information gathering procedures. The comprehensive knowledge I have acquired while working with people with disabilities regarding group home living, experiences of those living in the homes, and staff roles in the home allowed me to develop a heightened awareness of the context in which I conducted my research.

Over the past seven years, I worked closely with people with disabilities providing advocacy and daily living support. This support was provided in many environments such as group homes, vocational programs, and community settings. Within a group home setting, my responsibilities included, but were not limited to:

- Providing daily living support (e.g., meal planning, personal shopping, hygiene, finances) for adults with intellectual disabilities, and
- Counselling people with disabilities about self-advocacy, maintaining and enhancing personal relationships, vocational goals, leisure opportunities, finances, problems solving, and opportunities to enhance quality of life.

Within the community, my responsibilities included, but were not limited to:

- Programming recreational outings,
- Enhancing leisure skills and social skill development,
- Providing alternative learning opportunities for leisure skill development,
- Advocating for residents' right to choose recreational and leisure activities, and
- Providing support for older adults with intellectual disabilities to take part in mainstream community programs.

As an active member of the disability community, I have attended several workshops to enhance personal awareness of current strategies to support individuals with intellectual disabilities, (e.g., Gentle Teaching-Communicating with People with Intellectual disabilities; Supported Decision Making for People with Intellectual Disabilities).

2.4 Trustworthiness

Trustworthiness refers to the quality of an investigation and its findings that make it noteworthy to its audiences (Schwandt, 1997). It is the ability of a naturalistic researcher to support the findings through verification, transferability, validation, and confirmability (Lincoln & Guba, 1985). Lincoln and Guba (1985) operationalize these four notions by posing four questions: (a) What is the truth-value of the findings? (b) How applicable are the findings to other contexts and other participants? (c) Are the results of the study consistent with the research question asked? and (d) Are the results determined by the participants and not by the biases and judgements of the researcher? Strategies such as prolonged engagement in the field (learning the culture, building trust with participants), observation (exposure to the characteristics and elements within the

situation that are most relevant to the question), and triangulation (the use of multiple methods, sources and investigators) bring trustworthiness to the findings of a naturalistic inquiry (Lincoln & Guba 1985).

“The foundation for interpretation rests on triangulated empirical materials that are trustworthy” (Denzin, 1994, p. 508). To appreciate this statement fully, the terms triangulation and trustworthy must be understood. “Triangulation is the attempt to get a ‘true’ fix on a situation by combining different ways of looking at it or different findings” (Silverman, 2000, p. 177). Empirical evidence is triangulated when the researcher makes use of multiple and different methods, sources, investigators, and theories to provide supporting evidence for a theme or perspective (Creswell, 1998). Triangulation is a way of tying together all of the data allowing the researcher to crosscheck findings and verify the authenticity of the interpretation of the results (Gorden, 1987).

Strategies to enhance verification and the credibility of the findings ensure that the best and most appropriate methods are being applied given the phenomenon that is being studied. Techniques used to achieve verification in this study included clearly defining the cases (i.e., the group homes), using multiple data sources (women and staff) developing a clearly articulated research design that was consistent with the case study approach, ensuring the research question was well situated within the current literature, and reaching data saturation, which was achieved at the close of the 10 weeks of data collection.

Dependability, or validation, provides assurance to the reader that the study is sound and there can be confidence in the results and the findings should not be doubted (Meadows and Morse, 2001). Member checking is one strategy used to address

dependability. Member checking provides the participants with the opportunity to “test the credibility of the inquiry report as a whole” (Lincoln & Guba, 1985, p. 373). Lincoln and Guba (1985) suggest that the participants who are involved in the member check “should be representative of as many of the stakeholding groups involved as possible” (p. 374). Once data analysis was completed and themes were developed, member checking was carried out. Member checking with the staff was carried out twofold: (a) staff were asked to read through their interview transcript and sign the transcript release form (see Appendix E) upon agreement that the document was an accurate reflection of the information they shared during their interview and (b) staff, as well as the women, were informed of the results of the study and asked to provide feedback regarding the accuracy of the findings.

As indicated, both staff and women were included in the member checking process. At the conclusion of data analysis, both the women and the staff of the homes were contacted to set up a meeting to discuss the findings of the research. At Cairn Home, I met with both the housemates and staff at the home one morning to discuss the themes that emerged from the data. One theme was discussed at a time, and the women and staff were invited to ask questions regarding the material presented. Also, I asked the women and staff if they could recognize and agree with the findings as they were presented to them. The women and staff agreed that the findings were an accurate reflection of the experiences in the home. When provided with the opportunity to change, add, or delete information, no one provided further comments.

At Elm Home, the same procedure was used to member check with the women, although the staff of the home had since resigned from their positions. Therefore, I did

not meet with the women and staff together. I was unable to contact Mike for member checking, for his contact information had changed since the data collection phase.

Natasha was contacted, via postal mail, and was asked to review the themes that were developed from the analysis of the data. She was invited to contact me if she had any questions and was encouraged to change, add, delete information as she saw fit. She provided additional comments to one theme in particular, which were included in the results section. Overall, she agreed that the themes were an accurate reflection of the experiences in the home. I met with the women at Elm Home to discuss the findings of the research. One theme was discussed at a time and the women were asked to pose questions regarding the findings of the study. They were also asked if they could see their experiences in the results as they were presented, and they women agreed. They were then invited to change, add, or delete any information they felt fit, but did not provide further comment.

It should be noted that although I carried out member checking with both the staff and women, and every effort was made to ensure and confirm understanding, I cannot guarantee that the participants with intellectual disabilities completely identified with the results (themes) as they were presented to them. I asked questions to explore their understanding (“Does that sound like what you do in your free time? Is there anything else you would like to add? Is there anything else my teacher should know about what you do in your free time?”). However, due to the lack of response, I can only assume that the women had an understanding of the results as they were presented to them.

Other strategies used to address dependability included coder checks (the supervisor and myself coded the same data to confirm meanings seen in the data), audit

trails (a documentation of my decisions, choices, and insights during the research process), and the use of multiple methods (interviews, artifacts, participant observation) and data sources (women with intellectual disabilities and staff personnel) to assure dependability (Meadows & Morse, 2001). Finally, peer defriefing was undertaken with my supervisor throughout the research process (Brantlinger, Jimenez, Klinger, Pugach, & Richardson, 2005).

Confirmability ensures that the information collected is a representation of the participants' experiences and not researcher imposed biases (Lincoln & Guba, 1985). Two perspectives, those of the women and staff, provided information regarding the leisure experiences of the women contributed to confirmability. Also, the study was overseen by me and my thesis committee which assisted in confirming the meanings discovered within the data.

Transferability asks whether or not the findings of a study can be applied to another group in a similar context (Denzin, 1994). Within the naturalistic paradigm, the findings of a study cannot always be generalized to other groups. While the positivist researcher makes precise statements about external validity, the naturalist researcher develops a working hypothesis with a description of the time and context in which the results were found (Lincoln & Guba, 1985). The participants' experiences are very specific and individualized. Thus, for results to be applied to other groups, rich and thick descriptions of the participants and the context within which the data was collected must be made available. For example, detailed descriptions of the participants of this study (women with intellectual disabilities, participant ages, residential history, staff education) and the environment in which they live (group home) provides information that assists

others to determine the transferability of these findings to their own context. The findings of this study could be applied (at the discretion of the reader) to other contexts given similarities in environments, participants, and circumstances. See Table 2.1 for a summary of trustworthiness strategies.

Having a previously established relationship in one of the homes was beneficial in that rapport and trust which already existed between the participants and I allowed them to feel at ease with me. Also, I was familiar with the routine within the home which allowed everyone to be more at ease in the environment during the data collection phase of the study. However, steps had to be taken to ensure that researcher bias was not clouded by the familiarity of the participants and environment in either group home. Prior to approaching Cairn Home with a formal letter of invitation to participate in the study, I met with the executive director to discuss my interest in conducting research in the home and informed her that my prior professional experience with the women was the driving force behind my research. In addition, my supervisor was aware of my prior relationship with the women and we discussed concerns and potential challenges that my prior experience in the home could present.

Steps taken to keep preconceived perceptions in check included utilizing the same techniques and tools for data collection for both cases, (i.e., consistent recording of field notes, use of same interview guide between the two homes, similar interview probes), and making a conscious effort not to take the experiences of the women for granted (i.e., asking questions surrounding their experiences as though I was seeing it for the 'first' time). Constant dialogue and data analysis code checking with the thesis supervisor was

Table 2.1

Summary of Trustworthiness Strategies

Strategy	Purpose	Techniques Used
Verification (Credibility)	Ensures that the proper techniques and methods are being used to effectively and correctly answer the research question.	a) Purposive sampling b) Clearly outlined research approach c) Research question within the current literature d) Multiple data sources e) Data saturation
Transferability	Asks whether the findings of a study can be applied to another group in a similar context.	a) Rich descriptions b) Detailed descriptions of participants
Validation (Dependability)	Provides assurance that there is little or no reason to doubt the truth of the findings.	a) Member checks b) Coder checks c) Audit trail d) Multiple methods e) Carefully formulate interview guide f) Careful presentation of interview questions g) Probe to clarify participant responses
Confirmability (Neutrality)	Assures that the information collected reflects the views of the participants and is free from bias.	a) Investigator triangulation b) Peer debriefing

also helpful in keeping perceptions gained through my previous interactions with Cairn

Home in check.

2.5 Data Analysis

2.5.1 Interview Transcripts and Participant Observation Fieldnotes

To identify common threads that extend throughout the data, an inductive thematic analysis typical of phenomenology was conducted (Creswell, 1998). To isolate the emerging thematic statements, a line-by-line analysis was carried out in which codes were assigned to phrases or sentences within the interview transcripts and participant observation field notes. This process required reading and rereading the transcripts and field notes. Particularly revealing phrases were highlighted and coded with meaningful labels. This ongoing process entailed constant comparisons between phrases to determine whether they should be classified separately or whether they belong to an existing code (Wolcott, 1994). The essential or invariant themes, or those that give fundamental meaning to the phenomenon, were then determined (Wolcott, 1994).

Morse (1994) suggests that there are four cognitive processes that a qualitative researcher must go through when analyzing qualitative data. The four processes are *comprehending*, *synthesizing*, *theorizing*, and *recontextualizing*. *Comprehending* requires the researcher to learn anything and everything about the setting, the phenomena of interest, and the experiences of the participants. The researcher must be able to view the experiences from the participants' perspective, maintain maximal awareness, and recognize new and exciting events with minimal intrusion to the lives of the participants. Comprehension was achieved through descriptive, complete field notes, and gaining and maintaining the trust of participants by spending time with them over a 10 week period. I arrived at the point of saturation, the point at which new information becomes redundant

because it has been ‘heard’ before (Creswell, 1998) as the events and happenings within the cases became predictable at the end of the ten weeks in the field. Coding aided in the facilitation of comprehension and emerging themes resulted as the line-by-line analysis was carried out (Morse, 1994).

The next stage in the cognitive process of qualitative analysis is *synthesizing*. This stage is “the merging of several stories, experiences, or cases to describe a typical, composite pattern of behaviour or response” (Morse, 1994, p. 30). The researcher sorts the significant from the insignificant, merges them together, and describes typical patterns and behaviours of the group (Morse, 1994). Synthesis was achieved when I was able to provide detailed descriptions of participants and their experiences.

The patterns and experience within each group home were discovered by thoroughly examining the information gathered in interview texts and field notes, artifacts, and participant observation. The information from these sources were synthesized to provide a detailed description of each home and the women and staff within each case. This wealth of rich, information gathered during the 10 weeks in the field enabled me to become aware of general, predictable patterns of behaviour and responses.

Once synthesis was completed, theorizing began. In theorizing, I returned to the literature and conceptual framework of self-determination theory to find the meaning behind the experiences of the women. Self-determination theory provided structure to analyze the data and share the experiences of the women. Also, the theory allowed interpretation of the lived experiences of the women for others to find their own meaning, including myself, service providers, and the women themselves.

Recontextualizing, which refers to the applicability of the research findings to other contexts and populations, is achieved by telling the story through writing about the experiences of others for others. The rich descriptions of the cases assist in applicability. The participant observation field notes provided the primary information for the study and the interviews and artifacts were used to bring further context to the analysis and interpretation of the findings. They also provided an additional source of data thereby adding to the depth of understanding of the women's experiences.

2.5.2 Artifacts

Artifacts from the group home setting included daily log notes that were recorded by each staff person during their shift, participant photographs, and personal items. Daily log notes on previous outings, planned activities and future activities were included in the data for the purpose of learning about commonly occurring events in and out of the home. Photographic images were used to provide another avenue for the participants to share the meaningfulness of their leisure experiences. The personal items (e.g., pictures, videos, clothing, wall hangings, stuffed animals) of the women were examined in an attempt to learn about who the women were, as these items were thought to reflect their individuality with respect to leisure and choice.

Daily log book. Notes from the daily log book provided me with more context in which to examine the experiences of the women. Notes from the daily log book were read to gain an understanding of common events within the home and the lives of the women. Significant occurrences in the home and community were highlighted. Significant events in the home included phone calls made to family and friends, guests who came to visit, and what activities the women were involved in during the course of a day (i.e., cleaning,

making crafts). Significant occurrences in the community included going shopping, going out to visit family or friends, or going out for coffee. The daily log book provided an additional perspective of the experiences of the women to complement and contrast to the interview transcripts.

Photographs. The main purpose of the photos was to provide additional opportunities for the participants to share their experiences as well as provide a stimulus for conversation. The transcripts resulting from the audiotape recorded interviews surrounding these particular artifacts were included as part of the text when data analysis occurred and were included in the themes as they emerged. The transcripts from these conversations were used to provide supporting evidence for the themes that emerged from the thematic analysis and are presented in the results section.

However, it is important to note that although the main intent was to use the photographs to stimulate conversation, the photos also support the themes and subthemes that emerged from the data. In some cases, I used photos that I had taken myself to aid in the illustration of the leisure experiences of the women in the two group homes. I indicated which photos I took in the results section. In all photos, the identity of the participants is concealed (i.e., faces are digitally blurred to ensure anonymity).

It should be noted that although I received consent from the women and staff to take photos of their leisure experiences, I did question the ethics of the photos as they reveal the women's 'true' identity. However, after discussions with my supervisor, we determined that the photos included in the results section 'tell a story' and strongly support the findings of the research.

2.6 Recalling Personal Experiences for People with Intellectual Disabilities

When collaborating with people with intellectual disabilities on the nature of their life experiences, several considerations must be taken into account. These considerations include acquiescence (Heal & Sigelman, 1995; Matikka & Vesala, 1997), understanding abstract constructs (Antaki & Rapley, 1996; Morris, Niederbuhl, & Mahr, 1993; Sigelman, Budd, Winer, Schoenrock, & Martin, 1982), recalling personal experiences (Michel, Gordon, Ornstein, & Simpson, 2000), communicating meaning about what they are thinking and feeling (Kernan & Sabsay, 1989), and giving informed consent (Knox, Mok, & Parmenteer, 2000). Due to the nature of the participants and the data collected (i.e., interviews, artifacts, and participant observations), several strategies were implemented to address these considerations.

2.6.1 Acquiescence

“Acquiescence is the tendency to answer a question affirmatively, regardless of its content” (Matikka & Vesala, 1997, p. 75). People with intellectual disabilities have been found to respond “yes” or acquiesce to questions that they do not understand to avoid responses that may be seen as negative or rebellious (Matikka & Vesala, 1997). Notably, women who lived in group homes were most acquiescent when the interviewer was female (Matikka & Vesala, 1997). The dependability of research findings can therefore be affected. Wanting to please the interviewer or biased responses from research participants can result in the meanings ascribed to experiences being inaccurate and relationships between experiences can be wrongly established (Matikka & Vesala, 1997).

To address the concerns of acquiescence in this study:

1. Semi-structured interviews were utilized thereby eliminating yes/no answers from the participant responses,
2. The questions were presented one idea at a time,
3. Participants were reminded that there were no right or wrong answers, and
4. Multiple probes were used to clarify the participants' answers, particularly if conflicting responses were given.

2.6.2 Understanding Abstract Concepts

Due to limitations in cognitive function, it has been suggested that individuals with intellectual disabilities may have difficulty understanding abstract leisure concepts (Antaki & Rapley, 1996; Morris et al., 1993; Sigelman et al., 1982). All possible steps were taken to provide the participants with concrete examples from their own environments to clarify meaning. For example, short questions with simple, concrete vocabulary were used during interviews and terminology appropriate to the participant's context and experiences (e.g., Do you enjoy "Special O"; What are you doing for "rec" this weekend?). The term *free time* was introduced to the participants as a means of coming to understand the participants' interpretation of time away from scheduled work and house obligations. If needed, questions were rephrased and reasked when participant responses were incoherent or contradictory to one and other. Or, I moved on to the next question and returned to the misunderstood question during the next semi-structured interview time or active interviewing opportunity.

2.6.3 Recalling Past Experiences

Research indicates that individuals with intellectual disability are capable of successfully recalling and reporting past experiences and do so more accurately when the

questions are open-ended, as is the case of semi-structured interviews. (Michel, Gordon, Ornstein, & Simpson, 2000). To enhance the ability of recall, for the purpose of this research project, participants were interviewed in the immediate setting of the leisure environment, during leisure activities, and as immediately after the leisure event as possible. Specific cues from the context were used during interviews to enhance recall ability. If a participant was asked to recall events that had passed weeks or months ago, specific cues and prompts familiar to the participant were used to assist with recall. For example, “What did you do last Saturday when Natasha was working?” was a more effective question than, “What did you do last weekend?”

2.6.4 Communicating Meaning

Some individuals with intellectual disability may have difficulty communicating meaning and some of their responses may be pieced together, or stories may run together unconnected making explanations and descriptions difficult to understand (Kernan & Sabsay, 1989). Sometimes, the only way to make sense of a shared story is to listen carefully and attempt to put all pertinent information together into a coherent account by asking questions for clarification (Kernan & Sabsay, 1989). The semi-structured and active interviews were tape-recorded and transcribed verbatim which allowed me to review the data for clarification and detailed analysis. Triangulation was useful in determining the meaning the participants ascribed to their experiences. Triangulation is the use of multiple methods, sources, and investigators to provide credibility to the findings and supporting evidence for a theme or perspective.

The duration of the semi-structured and active interviews were dictated by the motivation, fatigue, and comfort levels of each participant. Interview times were flexible

in that scheduled appointments could be adjusted, particularly if I recognized that the participant was having a ‘bad’ day.

2.6.5 Providing Informed Consent

As is the case for all researchers, concentrated effort must be made to ensure that participation is voluntarily and the participants are fully informed of their rights (Knox, Mok, & Parmenter, 2000). When collaborating with people with intellectual disabilities, the ability of the participants to give informed consent presents a serious ethical issue (Morris et al., 1993). I felt that the participants of this study possessed sufficient cognitive ability to understand the conditions of their participation in this minimal risk study. The participants were highly functioning adults in that they were employed, lived with minimal support, communicated verbally, and travelled within the city with minimal supervision. Simple language was used to explain the purpose, commitment, risks and benefits of the project to provide the participants with the most comprehensible information possible. Please refer to Chapter 2, Description of the Cases, in the thesis. Staff signed, dated, and witnessed the consent form (see Appendix A). A summary of the strategies incorporated in this study to address the recollection of past experiences for participants with intellectual disabilities is located in Table 2.2.

2.7 Leaving the Setting

“Qualitative researchers recognize that they are a part of the research process and what they observe, hear, and experience is filtered through various lenses including the emotional” (Wincup, 2001, p.18). The qualitative research process affects emotions of both the researcher and the participants. Rapport, and most importantly trust, is essential to qualitative inquiry (Michrina & Richards, 1996). Long periods of time were spent

Table 2.2

Strategies for Addressing Recollection for Participants with Intellectual Disabilities

Consideration	Strategy
Acquiescence	<ul style="list-style-type: none"> a) Semi-structured interviews b) Simple vocabulary using terms appropriate to participant context and experiences c) Presented ideas one at a time d) Reminders that there are no right or wrong answers e) Probes were used for clarification of responses
Communicating Meaning	<ul style="list-style-type: none"> a) Tape-recorded interviews b) Interviews transcribed verbatim c) Triangulation of data d) Flexible interview times e) Recognizing if participant was having a 'bad' day
Informed Consent	<ul style="list-style-type: none"> a) Participants lived and worked in community with minimal support b) Use of simple, context appropriate language c) Minimal risk study d) Support of group home supervisor
Understanding Abstract Concepts	<ul style="list-style-type: none"> a) Provided examples from environment to clarify meaning
Recalling Past Experiences	<ul style="list-style-type: none"> a) Asked open-ended questions b) Interviews occurred within leisure activity setting c) Use of specific cues from immediate context to enhance recall ability

participating in and observing the everyday lives of the participants. An emotional engagement was anticipated between myself and the participants due to the amount of time that was spent in the field, approximately 10 hours per week for 10 weeks. Thus, a plan for withdrawing from the lives of the participants, or emotional disengagement, was essential.

2.7.1 Field Exit

The women and staff were kept up to date on the progress of the study (interviews, transcription, analysis, write-up, etc.) to keep them informed of how many weeks of the study had transpired and when I had to leave to “go back to school.” I, or the staff person within the group home, explained what was to occur next in the research process. This tracking of progress was readily available to both participants and staff members through discussion with me. I maintained contact with the participants after the close of data collection. These connections were maintained through visitations at their places of employment and in some cases, the group home itself. Once interviews were transcribed, the transcripts of the staff personnel were sent to them for their review. They were encouraged to review the document and add, delete, or alter information within the transcript to ensure it reflected what they said or intended to say. All staff participants signed and returned the Transcript Release form thereby releasing their transcripts for analysis and inclusion in the study. As mentioned, once data analysis was completed and themes were developed, member checking was carried out to bring closure to the participant involvement in the study and thank them again for their participation.

Chapter 3

3.1 Results

Three themes emerged from the analysis of the data that described the women's experiences of leisure. They were: (a) leisure at home, (b) leisure in the community, and (c) leisure with family and friends. The themes were similar in that the women of both homes participated in leisure at home, in the community, and with family and friends, however each group home environment provided distinctly different leisure experiences. Although the group homes were similar in their staffing policies, administrative structures, and physical amenities, the subthemes clearly illustrate the differences in the leisure experiences of the women in the two homes (see Table 3.1).

The uniqueness of the experiences in each home appeared to be determined in large part by opportunities for the women to provide input into their leisure experiences. The leisure experiences for the women of Elm Home were defined, in large part, by planned and scheduled events in the home. The leisure experiences were planned around the activities needed in the daily management of the group home, and appeared to take precedence over both opportunities for leisure experiences and the women's input into the nature of their leisure experiences. The women of Cairn Home experienced opportunities for input into spontaneous leisure at home as well as in the community. Even when staff support was required to engage in an activity, the type and amount of support was usually determined by the

Table 3.1

Summary of Descriptive Themes and Subthemes

Themes	Sub-themes Elm Home	Sub-themes Cairn Home
<i>Leisure at Home</i>	Supervised Self-Directed Leisure	Independent Self-Directed Leisure
	Supervised Directed Leisure	Staff Supported Self-Directed Leisure
<i>Leisure in the Community</i>	Supervised Outings	Independent Outings
		Accompanied Outings
<i>Leisure with Family and Friends</i>	Awaiting a Connection with Others	Connecting with Others

women. To begin, the results of Elm Home are presented. The results of Cairn Home follow.

Please note that the name and numbers following direct quotes indicate the specific transcript and page number where the quote can be found (e.g., 'Shannon, 1' indicates that the quote was taken from page one of the transcript of Shannon's interview). The letters EH and CH refer to Elm Home and Cairn Home respectively. A designation of 'AT' indicates the information was acquired during an active interview. In summary, a quote that is labeled Shannon, EH, AT1, 1 indicates the quote was from Shannon from Cairn Home, active tape one, page one of the transcript. Field notes I took are labeled as participant observation notes and notes labeled daily log book were recorded by a staff person during the course of their working day.

3.2 Elm Home

The experiences of the women in Elm Home are those of Brie and Daria. The supporting statements are provided by group home staff members Mike (full-time staff) and Natasha (programmer). For the women of Elm Home, leisure at home was both self-directed and staff initiated, but always supervised. Leisure in the community such as shopping and going to the library was also supervised as staff members were always present during outings. The women spent time with family and friends during their leisure, however, these get-togethers were not self-initiated but organized through staff members.

3.2.1 Leisure at Home

To begin, I will describe a typical weekday at Elm Home. Weekday mornings, the programmer would come into the home at 6:00 a.m. and assist the house manager get everybody out of bed in time for work, serve breakfast, and get all the residents ready to catch the bus to work. Brie and Daria would get on the bus just before 8:00 a.m. and be shuttled to work. Brie's vocational program provided opportunities for her to work in the community with the assistance of a job coach. Daria spent her weekdays at an activity centre engaged in educational (e.g., socialization skills, daily living skills), and recreational programs. The women would return home just before 4:00 p.m. where the house manager as well as the afternoon programmer would greet them. The women would put away their lunch pails and the staff ensured a snack was always ready. They would visit with the staff and discuss the day's events. Everyone appeared to enjoy this time together and the women were excited to tell the staff and housemates about their

day. Before supper, the programmer would inform the housemates of plans for the evening and provide suggestions on how to prepare for the activity (e.g., if it was a community outing the women were required to brush their hair or change their clothes). The house manager would prepare supper and the programmer would spend time with the women while they watched television or engaged in household chores or personal tasks (e.g., laundry, cleaning).

I observed that staff most often guided the leisure activities the women engaged in. I observed that leisure experiences at home included watching television, playing games, and exploring personal interests such as baking and crafts. However, staff chose which programs to watch on television, staff directed the women to play games during leisure, and staff determined the women's involvement in baking and crafts. At this point, it is useful to revisit the definition of leisure so as to understand the leisure experiences of the women. Again, for the purpose of this study, leisure was defined according to Parker's (1981) parameters and was defined as time away from work that one is able to choose how to spend time and no activity has been pre-planned.

Supervised, self-directed leisure. The women spent time engaged in supervised self-directed leisure. Activities included watching television and at times, experiencing leisure in their rooms. I did not observe the women engage in any craft activities or other leisure pursuits such as doing puzzles or listening to music. During my time in the home, I observed the women to have a limited self-directed leisure repertoire.

The activity the women often engaged in during leisure was watching television. Notes throughout the daily log book indicated that this was a common activity in the Home. "Watched TV in the p.m." (September 23, 2003), "Relaxed in p.m. to movie (new

DVD I [staff person] got) (October 5, 2003), “Relaxed in p.m. to boob tube” (October 18, 2003), were examples throughout the book. When I was in the home, I did observe the women to watch television, but I observed the programs were always chosen by staff (participant observation notes, November 22, 2003). Mike indicated that, at times, he did attempt to involve the women in the selection of programs, however, his efforts were half hearted and only gave a perception of input: “Basically, [you] just open the TV Guide and [they] point to something and you just basically watch whatever the hell you want to anyways cause [they] think that’s what it is!” (Mike, 10). Although staff put forth effort for the women to perceive they were exercising choice-making, further efforts could have resulted in leisure skill development for the women (e.g., learn how to use the remote control to make a personal TV viewing choice). Teaching leisure skills to the women would have recognized their abilities to experience self-directed leisure. Furthermore, teaching leisure skills to the women would allow them to experience independence and eliminate the need for staff supervision during leisure.

Daria spent very little of her leisure time alone. Much of her time was spent in the company of others, particularly staff. This appeared to be due to leisure activities she would engage in that staff members felt were inappropriate. I observed that one of Daria’s favorite pastimes was shredding paper. Yes, shredding paper! Any paper that Daria could get her hands on, she enjoyed ripping into tiny pieces; store fliers, the TV Guide, or catalogues. She would sit quietly in the living room on the sofa, watch television, and would rip paper into long, narrow strips, and then again into smaller pieces, tossing them into an ice cream bucket. I likened it to watching someone knit in their living room, with their feet up, while watching television. It appeared that Daria had

engaged in this activity before, for it appeared to be such a natural activity for her. I was left with the impression that she thought it was a completely acceptable way to spend one's leisure time. Sometimes, she would spend time alone in her room shredding paper.

Although to some, Daria's favorite pastime would not be considered 'productive', it did seem to be a preferred activity she chose to pursue when given the opportunity. But, due to varying staff perceptions of appropriate leisure, there was inconsistency in how Daria's 'shredding' activity was addressed in the home.

Some staff in the home did not approve of Daria's chosen paper shredding activity. It was obvious that Daria had been reprimanded several times for it. This was echoed in statements I heard her make about herself. It should be noted that Daria often referred to herself in the third person. One evening after she had torn some paper she was writing on she said, "I should know better not to have paper all around! All I do is rip...it! You have to get out of that habit, dear! You cannot have paper!" (Daria, 17). Daria described an incident that occurred when she was shredding paper and a staff person indicated disapproval of the activity, "My mom bought, give me a whole bunch of paper...[A staff person] threw it all out and said 'I should know better not to have paper all around'. All I do is rip it!" (Daria, 16-17). Although it would appear that her mother felt she was supporting Daria's leisure, some staff members suppressed this preferred activity and hence an opportunity for autonomous leisure.

Mike expressed his acceptance of Daria's leisure preference of paper shredding as it gives her control over something that is important to her, hence a form of autonomy and psychological empowerment:

"[Some staff] say that I let [the women] do whatever they want...I pamper them way too much...that's [an] issue. [Staff say] I let [the women] do whatever they

want and the point is, it's their bloody home! I think that if Daria wants to rip and shred paper ...I don't see any problem with that. [Another staff person] is totally against the shredding thing. So I think that's kind of deprived [Daria] of something [she] actually enjoys (Mike, 9).

Mike's sensitivity to Daria's choice of leisure activities allowed her to make her own choices about what to do during leisure. But, because of inconsistencies among staff about what appropriate leisure was, Daria was inconsistently afforded the opportunity to experience autonomous leisure. Because not all staff recognized the subjective nature of leisure, staff made the leisure decisions on Daria's behalf thereby reducing opportunities for her to make leisure decisions without external coercion or experience personal control over her leisure time. The removal of these tenets of self-determination resulted in Daria experiencing primarily supervised leisure.

It is interesting to recognize, at this time, the complexity of Mike's behaviours regarding choice in leisure. If you recall his behaviour when providing opportunity for Brie to choose a television program, he was apathetic when she 'pointed out' what program she wanted to watch. Although he recognized the importance of offering choice, the approach he used was not reflective of Brie's functional ability (i.e., Brie could not read so choosing a program from the guide listings would be impossible) and did not implement strategies for her to truly make a choice. However, Mike appeared to be more enthusiastic to recognize Daria's choice to shred paper during leisure. He even suggested that because "it's their bloody home" (Mike, 9) the women should be able to do what they choose. I question why his behaviours varied between the women and their leisure activities. On one hand, his reaction to choice appeared patronizing, while another incident led him to behave selflessly to recognize a woman's choice. He was not

consistent in his responses to the women's choices in leisure, which may have caused confusion for them.

It was not only Daria's leisure that was supervised. Brie also experienced leisure under the watchful and directive eye of staff members. I noticed that if Brie was ever out of sight from staff, they questioned her whereabouts. I observed the staff to call her name, seek her out, and 'check on her' when she was not in their presence (participant observation notes, December 13, 2003). Again, staff appeared to feel it was their role to supervise any activities the women engaged in. When staff felt the need to do this, they eliminated opportunities for the women to truly enjoy an autonomous leisure experiences.

The women's bedrooms were downstairs in the basement. Although each woman's room housed personal belongings, I did not gain a sense of *who* the women really were. Brie's room, although much more personalized than Daria's, was noticeably plain. Few items adorned her shelves, and few pictures were on her walls (see Figure 3.1). However, Daria's room was even plainer (see Figure 3.2). Her corner room, was dark. Her bed sat under a small window in the corner. She had a few small items surrounding her bed including an empty terracotta plant pot and a plastic lawn owl sitting on a chair. She had a nightstand and two dressers in her room. The only leisure 'tool' she had in her room was a television. However, I never observed Daria watch television in her room. Staff indicated that she always chose to watch television in the shared space with staff and other housemates (participant observation notes, November 21, 2003). What I found most striking in Daria's bedroom was a blank bulletin board which hung over her bed. There were no photos of family, no souvenirs from events attended, or other personal items. It was very noticeable when placed against the plain white wall. Daria



Figure 3.1 Brie's bedroom (researcher photo).

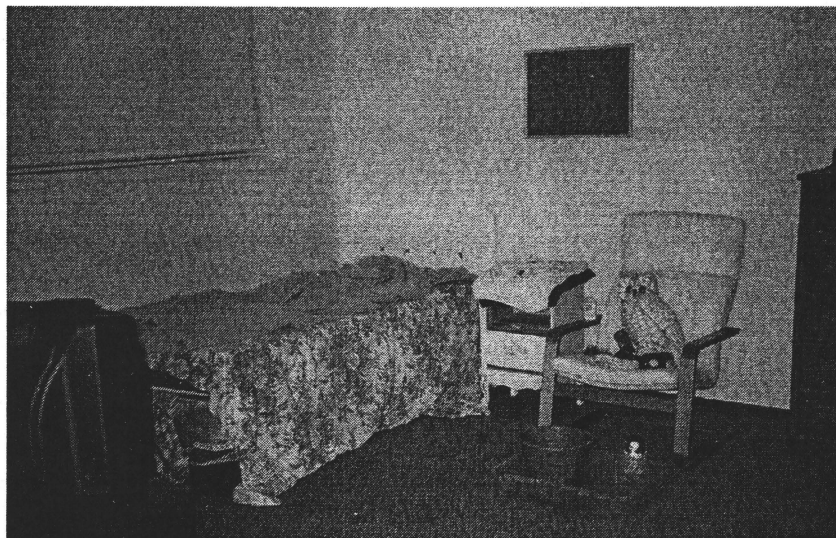


Figure 3.2 Daria's bedroom (researcher photo).

indicated that she was unable to have items on her bulletin board because staff said she might rip them (participant observation notes, November 21, 2003). Daria's room seemed to lack 'personality'. It was neither warm nor inviting and it projected a 'clinical' feel.

When one considers the amount of time the housemates spent together at work and at home, much of their day was supervised and in the company of others. In Elm Home, self-directed leisure experienced at home was predominantly a shared experience, there was little opportunity to explore personal interests, and staff members oversaw the choice of activities. The range of activities was also observed to be very narrow in scope and primarily included watching television, spending time in their bedrooms, and engaging in leisure activities that were questioned, by some staff, to be inappropriate.

Supervised, directed leisure. There were times when the women required support to successfully participate in leisure activities, either for safety reasons (e.g., using the stove), or because the women did not possess the complete range of skills required to complete the activity (e.g., reading and following a recipe), or the staff perceived that they needed to be doing ‘something’. The staff often selected what these activities would be and provided structured support for their completion. The degree to which the women were actively engaged in the activities was directly related to the degree to which the staff intervened in the activities. My separate discussions with Daria and Mike provided insight into how staff support was, as times, in conflict with the women’s desire to experience autonomous leisure, develop their leisure skills, and become self-realized in the expression of their leisure pursuits.

Daria particularly enjoyed baking at home for she had an incredible sweet tooth! Daria often perused cookbooks and used the photos to choose recipes that matched her culinary tastes. Upon learning of Daria’s interest in cookbooks, I asked, “How often do you bake?” She responded, “Not often enough!” (EH, T1, 19). When asked if she baked the treats she selected from the cookbook, she responded, “No, the staff does.” (EH, T1,

19). Curious as to why Daria did not assist in creating the culinary delights she desired so much, Mike provided some insight. He suggested that some staff “can’t handle it” when Daria assists with cooking and baking because it is time consuming (Mike, 9; participant observation notes, November 25, 2003). Even though the women enjoyed the product of the baking they would not learn or receive the leisure benefits involved in the process of baking because staff did not involve them in the process. The activity of baking is very sequential and guided by discrete steps, therefore very well suited to the expression of the tenets of self-determined behaviour. Baking involves decision making, planning, responding appropriately to the requirements of the task, and achieving desired outcome. Daria identified an appropriate leisure activity, but staff did not appear to recognize that the process of baking is as important as the product. In Daria’s instance, the experience of self-determination through the leisure activity of baking was lost.

I observed that when there were no activities planned for the women, staff would provide suggestions as to what they should do during their leisure. When I was in the home one afternoon, Daria and Brie were waiting to go on an outing with Natasha (programmer). Both Brie and Daria were in the kitchen when a staff person began to suggest activities for them to engage in (participant observation notes, October 18, 2003). First, he asked Brie what she wanted to do, “Do you want to listen to the radio or watch TV.?” Brie did not respond as she stared blankly into his face. “Brie,” he said, “Do you want to listen to the radio or watch TV?” Upon hearing the question for the second time, she responded, hesitantly, “Radio”. “Well away you go then”, the staff person said, and Brie went downstairs to her bedroom. Although she was given the opportunity to indicate her preference between two leisure activities, the options were staff generated, or stated

differently, her leisure activity was staff directed. She was presented with two options and was required to make a forced choice in order to experience leisure. If the question had been phrased, “What would you like to do now?” Brie would have had the opportunity to exercise self-determined behaviours (e.g., decision-making and problem solving). Without experience, self-determined behaviours cannot fully develop and Brie’s leisure may continue to be directed and she may become dependent upon or become resigned to this form of external support.

Daria experienced a similar interaction with the staff person. “Go downstairs and see if you can find a board game. Bring it up and we’ll play a game” he said to her. Daria went downstairs to choose a board game. She returned a few minutes later with Yahtzee. The staff person took the game out of the box, set out the dice, the shaker, and the score pad. Once we were ready to play, the staff person explained to Daria how to play. “Just shake the dice in the cup”, he said, “and roll them onto the table.” Daria did just that, and we each took our turn. After we played three rounds, the staff person noticed that when Daria rolled the dice out of the cup, the dice would bounce around on the kitchen table making a rather loud clatter. The staff person instructed her not to ‘dump’ the dice out so loudly. Not clearly understanding what he wanted her to do, again Daria rolled the dice out of the cup rather loudly as they bounced on the kitchen table. At that point, the staff person intervened and rolled the dice for her. He did this for the remainder of the game.

This experience is significant for two reasons. Firstly, Daria was directed to a leisure activity rather than provided the opportunity to make the decision on her own. Thus, without opportunities to exercise self-determined behaviours (e.g., decision-making and problem solving) a reliance on staff to determine her leisure may result. Secondly,

when Daria was involved in leisure (e.g., playing the game) her experience was passive. She did not play the game in a manner that was perceived by staff to be appropriate and staff removed Daria from an active leisure experience. Strategies to teach Daria to 'quiet' her involvement would have allowed her to remain as an active participant. Taking the time and effort to teach skills for leisure would have allowed her to be an active participant during the experience.

3.2.2 Leisure in the Community

Each participant was involved in weekly community outings and it was the responsibility of the programmer to ensure they took place. In a meeting with the executive director (November 24, 2003), I learned that within each individual's Personal Program Plan, which was reviewed every six months to one year, depending on their goals and needs, community outings were a requirement. Programmers were held accountable to the house managers and administrative staff if these requirements were not met. Each housemate had a monthly activity calendar and when outings occurred, notes would be made documenting the outing. At the end of the month, the calendars were submitted to the administrative staff at the agency office. This guiding principle for community involvement was in place because, as the executive director stated, "it's a lot easier [for the women] to sit at home" than to go out and be involved in the community (participant observation notes, November 24, 2003). The community outings I observed included going to the library and shopping.

Supervised outings. The daily log book outlined the community outings the women experienced during the week, for example, "Brian [staff person] and Brie did banking today" (September 25, 2003), "Brie and I out for a walk" (September 29, 2003),

“Brie and Daria went shopping with Natasha [programmer] and stopped for a treat” (October 18, 2003). Daria often commented that she and other housemates could not ‘go out’ unless there was a staff person available to go with them. When asked, “What would you do if Natasha [programmer] didn’t come [to the home]?” Daria responded, “I don’t know. Sit around, I guess” (EH, T1, 8). It appeared that staff support was required for the women to leave the house to experience leisure in the community, even if it was to walk in their own neighborhood.

One of the first outings in the community I experienced with the women was shopping at a craft sale (September 30, 2003). Before we left the group home, the house manager suggested to Natasha how much money she should take along for Brie to spend at the sale. Natasha took \$45 from Brie’s ‘petty cash’ account at the house and put it in her own purse. I observed that Brie did not take her purse along. On the way to the craft sale, Brie discussed what she was hoping to purchase. She indicated that she was very interested in purchasing a new watch. When we arrived at the craft sale, there were, literally, hundreds of craft tables to explore. As we shopped, I observed that Natasha encouraged Brie not to touch things. “Be careful...” she would say as Brie explored the trinkets at each table. When looking at the variety of crafts, Natasha would ask Brie if there was anything that she liked, and Brie always responded “Yes” and pointed to something. I observed that if it was within Brie’s budget of \$45, Natasha would ask Brie if she desired that particular item, and Brie always responded, “Yes”. Before making a purchase, Natasha would ask Brie at least three times, “Are you sure you want this?” If Brie agreed, which staff recognized as Brie responding “Yes” all three times, it was purchased. At that point, Natasha opened her purse and handed Brie some cash to pay for

the item. Natasha watched as Brie interacted with the merchant (see Figure 3.3). Once the transaction was complete, Brie passed the change back to Natasha to place in her purse. When Brie purchased a delicate ceramic item, Natasha said, “Let me carry that” and watched over her purchase just as she watched over her finances.



Figure 3.3 Brie at craft sale (researcher photo).

This community outing is significant in that it demonstrates the women were free to make purchases with their own money. It was interesting to note, however, that the women did not handle their own money, or take responsibility for the safe keeping of their purchases.

What was absent from the women’s craft fair outing was the opportunity to learn about budgeting, how to handle money, how to be careful with purchases, and how to interact with community members. Staff did not work with Brie to develop these skills, perhaps because there was an expectation she could not learn them, or perhaps they were not important skills as she would always be accompanied into the community.

One afternoon when Natasha, Daria, and I were out and about running errands for the home, we found ourselves with some extra time on our hands (participant observation

notes, November 1, 2003). Natasha asked Daria, “What do you want to do now?” Daria quickly responded, “Go to the library”. The staff person provided Daria with an opportunity to express her leisure preference and Daria made the decision to go to the library. The staff person responded positively to Daria thereby reinforcing her ability to respond to the request and make a decision, or in other words, demonstrate self-regulated behaviour. The library was one of Daria’s favorite outings. This is where she could further explore her interest in baking and pick up new cookbooks to look at during her leisure at home.

Once we arrived at the library that afternoon, Daria and I followed Natasha to the cookbook section. I observed that Natasha stood close by ready to assist Daria, if required when she began choosing books off the shelf and flipping through the pages (see Figure 3.4). Knowing that Daria could not read, I was curious as to how Daria chose a cookbook. It was apparent that she was looking for something in particular as she flipped through the pages in each book scanning each sheet with her eyes. My curiosity prompted the following dialogue:

- Brenda: “Daria, how do you pick a cookbook? How do you know that that’s a good cookbook?”
 Daria: “I don’t know.”
 Brenda: “But what does it have that makes you think ‘I want this cookbook’.”
 Daria: “I don’t think that’s a good one, Brenda.”
 Brenda: “How come?”
 Natasha: “The pictures, that’s what you look at.” (EH,AT1, 20)

Daria used the pictures in the cookbooks to determine if it was a book worth choosing and, ultimately, taking home. Being involved in the process of choosing a book provided an opportunity for Daria to express her personal leisure interests. In addition, it

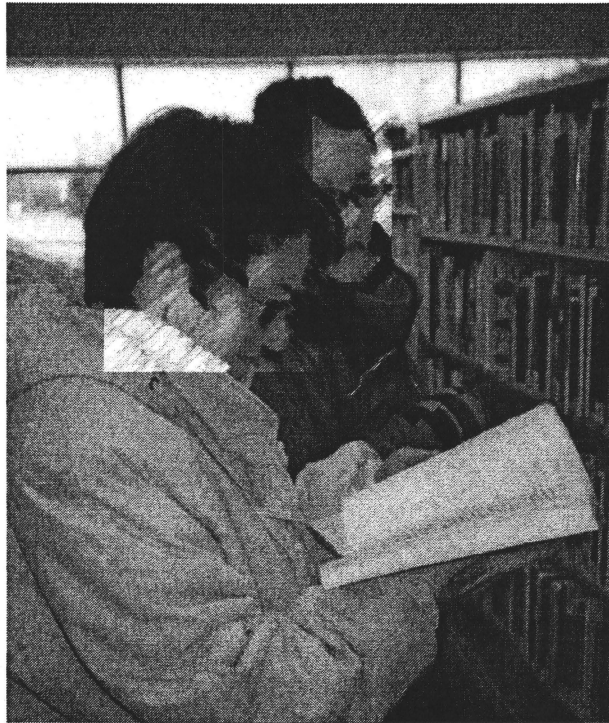


Figure 3.4 Daria examines a book at the library (researcher photo).

was her opportunity to provide input into her leisure experiences. The outings to the library were rich and interesting for Daria.

As with many library users who take books off the shelves, books are often reshelfed incorrectly. I observed that Daria mistakenly placed the books in the wrong spots back on the shelf. In an attempt to avert further misplacements, Natasha offered support. “What kinds of books do you want?” she said. “Don’t just take them off the shelf. Just tell me what kinds of books you like. Cookies? Desserts? What?”

“Desserts”, Daria responded.

“Okay” said Natasha, as she stepped in front of Daria and began to look at titles on the shelf. I took the photo (below) when I saw Daria step back and patiently wait for Natasha to choose a book (see Figure 3.5).

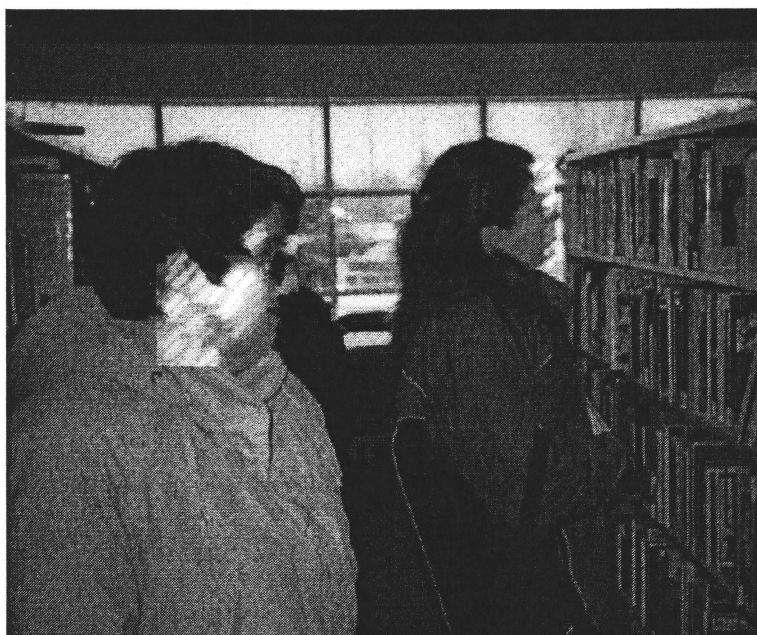


Figure 3.5 Natasha selecting cookbooks (researcher photo).

When Natasha found a dessert cookbook she would ask Daria, “Is this one okay”, or “Do you want that one?” providing Daria with the opportunity to indicate her preference of the options presented to her. When Daria approved, it would be placed in the pile of books to be checked out. When it was time to check the books out, Natasha passed the books to Daria and she carried the books to the checkout desk. Once the books were checked out, we were on our way home.

The trip to the library provided Daria with an opportunity to provide input into her leisure experiences, however, the books Daria chose to take home were a result of the options the staff person presented to her. Had opportunities to teach library based leisure skills been seized (e.g., teaching Daria how to access the correct section of the library for cookbooks, not to resshelf books, how to choose the best cookbooks) the potential for Daria to experience a more independent trip to the library in the future would be possible. Also, teaching Daria the skills needed to experience leisure in the community, without the supervision of a staff person, may instill feelings of accomplishment, pride, and self-

realization (i.e., realizing her abilities to successfully experience community leisure by herself).

Although the recommendation for the women to experience community outings twice per week was developed with good intentions, at times, it prevented the women from contributing to their leisure experiences and left staff with little or no time to accommodate personal leisure choices of the women. At times, it was difficult for Natasha to meet the community outing requirements for each housemate. She indicated that, at times, she was frustrated even though she understood why the rule was in place:

I understand...because some houses don't take their guys out. And I understand that it's supposed to be all about normalcy and bringing them into the community...but sometimes it's hard to [take them out] cause sometimes they just don't want to go. Sometimes it's too cold to go, sometimes a staff isn't in to go [with them], and then you're left on Saturday with four people who still need to go out (Natasha, 5).

Support and administrative staff felt Daria benefited most from this guideline. Natasha stated that, "If Daria spent her free time how she wanted she'd never leave the house...She doesn't care if she goes out or not...She just likes staying at home" (Natasha, 2). However, regardless of personal preference, the women were required or even 'forced' to experience leisure in the community. "Support has to be given" said Natasha of Daria's reluctance to experience leisure in the community (Natasha, 4). Natasha stated that she had to say to Daria on several occasions, "No matter what you have to go somewhere today!" in order for her experience leisure in the community (Natasha, 4).

It is important to recognize that when community outings are planned, the participants are no longer experiencing leisure given the working definition used in this study. Planned activities occur in what is often referred to as recreational time. Although

content at home, Daria was required to experience a recreational outing *during* her leisure. Thus, opportunities for Daria to experience choice-driven leisure were directly affected by the community outing policy (i.e., she was required to ‘go out’ during her leisure). Incidentally, opportunities to exercise choice-making were eliminated and external influences determined her leisure experience.

As indicated earlier, Natasha from Elm Home provided feedback regarding the themes that resulted from the analysis of the data. Upon reviewing the themes presented to her, Natasha wrote to me indicating her continued frustration with the outing guideline as well as the frustration that the women experienced as well. She reiterated the influence the administration of the agency had over the leisure experiences of the women. Her comments also suggested that the personal choices of the women were often not considered appropriate:

It was difficult for the girls to pick their own activities because the office didn’t want them to be doing the same thing all of the time (i.e., Brie wanted to go out for coffee for her outings [but] she would only be allowed to once or twice a month because [supervisor] would say we weren’t integrating them into the community. Therefore, even if they were asked what they wanted to do, they really had no control over it because staff would get into trouble for letting the [women] do the same activity all of the time, even though it was their choice to do so. It’s the office that makes it hard because they try so hard to have them participate in “normal” activities that it seems that they do not have the [women’s] interest at heart (member check feedback, Natasha).

Natasha’s feedback is significant because it demonstrates her awareness of the importance for personal decision-making in the leisure experiences of the women. However, Natasha also recognized the influence the ‘office’ had on the leisure experiences of the women. Her statement also indicates that the women were capable of choosing a leisure activity, but the ‘office’ neglected to acknowledge the subjective nature of leisure and the personal meaning we give to what we do in our leisure time.

The outing policy created problems and caused tension between Daria and the programmer due to her occasional behaviour that was under the watchful eye of the public. At times, Daria would respond negatively to recreational outings that were forced upon her during her leisure time. She would become upset or display frustration at home and in the community. One evening, while at a play in the community, Daria displayed, what staff described as an outburst (described as yelling, swearing, and flailing her arms about), because she did not want to be there. Natasha stated that Daria had the “fit” because “she said she didn’t want to go and she had to go cause she’d only had one outing [that week]...” (Natasha, 5). Natasha felt that Daria’s behaviour was a direct result of her frustration with the outing policy that staff were required to adhere to. Daria’s behaviour made Natasha quite uncomfortable, and Natasha shared with me, what she described as a “humiliating” experience:

I was embarrassed. We were sitting in the middle of the bleachers and it was packed. Some people were even sitting on the stairs. She got up and started whipping her coat around hitting people on the head. Hit a lady in the face with her sleeve. And then she started swearing. Like swearing at the top of her lungs in the middle of a school play. I don’t like taking her out. (Natasha, 4)

Both Daria and Natasha experienced difficulties when adhering to the outing guideline. Both women experienced a struggle. Daria’s struggle was to be *heard*. Through de-normalizing behaviour, Daria communicated her frustration when the opportunity to make choice was removed from her environment. Interestingly, staff were aware that the lack of choice would cause distress for Daria. Natasha’s struggle was experienced when she was required to adhere to the outing requirements and eliminate choice from Daria’s leisure experience. In her member check feedback, Natasha

identified the frustration the women experienced and indicated what she truly felt was the ultimate purpose for the outing guideline:

It's all about appearances, even if the [women] are miserable. The office always says, "They're adults, let them decide" but really they have no say. They are forced to participate in activities they don't enjoy as well as being forced to go out twice a week even if they don't want to. The [women] are supposed to have their own choices, but it only goes so far before the office steps in (member check feedback, Natasha).

Natasha recognized the feelings the women may experience due to the lack of opportunity to make choices regarding leisure. She wrote, "It's very sad, they would be much happier if the rules were set out for them based on how much happiness it can bring them, not what [activities are] socially acceptable" (member check feedback, Natasha). This quote indicates that Natasha was aware of the subjective nature of leisure and recognized the importance for the women to experience choice-driven activities. However, policy took precedence over the women's self-determined leisure experiences.

3.2.3 Leisure with Family and Friends

The women enjoyed leisure with their families on a regular and scheduled basis. This time was spent primarily with their mothers during a weekend visit. During the week, I never observed the women initiate opportunities to experience leisure with family and friends.

Awaiting a connection with others. Both Daria and Brie had family who lived in the city, and both women identified their mothers as their closest family member. Both women spent at least one weekend per month with their mothers, and when holidays arrived (e.g., Thanksgiving and Christmas) more time was spent in their mothers' homes. However, scheduled meetings were the only times I observed the women to connect with their family. I never observed either woman initiate a phone call to connect with a family

member. Any opportunities to talk on the phone with family appeared to be initiated by family members or staff. Throughout the 10 weeks of log book notes examined, it appeared that Daria only called her mother once, "Daria called her mom tonight" (November 8, 2003). It was difficult to determine why the women did not use the phone. Perhaps the women did not desire to use the phone because they knew family would call them and they would see family soon. Or, perhaps they did not feel comfortable using the phone-or they were not taught the skills to use the phone. In retrospect, I would like to have known if the phone was considered somewhat "off limits" as a form of leisure, or if the women simply preferred not to call others.

As indicated before, when the women would spend time with family face-to-face it was a scheduled outing. Paratransit would pick the women up on a Friday evening and they would return home the following Sunday evening. Brie spent time with her mom on a regular basis. "Brie goes home a lot. Like, every other weekend she's at home" (Natasha, 2). In my conversations with Brie, she described going to McDonalds with her mother, getting haircuts, cleaning house and spending time with her mother's friends. Brie valued time with her family, stating that "family" makes her happy (Brie, 21).

During an interview, Daria said that she saw her mother "every two weeks" (Daria, 6). Although both Brie and Daria saw their family regularly and I was aware of how important their families were to both of them, Daria painted a clearer picture of the significance her family had in her life. Through conversations with Daria, I learned that her time with her mother was incredibly meaningful to her. Daria spoke to me about the numerous activities she and her mother would engage in. These included shopping (particularly for food items like cookies, cakes, crackers, and M&M's, which Daria

enjoyed immensely), visiting her mother's friends, and going out for meals. One afternoon, we were discussing the time that she spent with her mother and what they did during their time together. While she spoke of their shopping trips and going to visit her mother's friends, she quickly changed the course of the conversation in a direction I was surprised and not at all prepared for. In the following excerpt taken from that conversation, I began to understand how important her mother was to her, how important her time with her mother was, and how meaningful she viewed mothers are to everyone's life:

- Daria: "What would happen if I didn't have a mom? I would have to stay here right?"
- Brenda: "Yah, maybe. You wouldn't be able to go to your mom's if you didn't have a mom."
- Daria: "But you have a mom. Some ladies at work they...what does fortunate mean? Can you explain that to me, Brenda?"
- Brenda: "Fortunate? Fortunate means that...you're lucky."
- Daria: How?
- Brenda: "Like if I say, 'You're fortunate to have your mom'..."
- Daria: "What does that mean exactly?"
- Brenda: "That means, Daria, you're really lucky to have a mom. It's really...it's really nice for you to have a mom. Does that make sense?"
- Daria: "Uh-huh. So how come the ladies at work...how come my favorite ladies, how come they don't have a mom? Well, maybe their mom passed away, maybe they got sick..."
- Brenda: "So what do you think those ladies do at Christmas when they don't have a mom?"
- Daria: "I don't know. (Daria, 8-9)

Daria's leisure time with her mom was meaningful. From the above dialogue, it was revealed that Daria felt that everyone's time with their mom was important. It was apparent that Daria's mother was very important to her and she would feel a sense of loss if she could no longer spend time with her. She also felt others would be at a loss, for she expressed concern for others who may not have opportunity to spend time with 'a mom'. A lost opportunity to experience leisure with her mother would have a significant effect

on Daria's leisure because, as learned, much of Daria's leisure time was spent with housemates and staff in the home. When Daria spent time with her mother, it was an opportunity to experience leisure in an environment that was not shared by housemates and staff. Also, Daria's social network increased when she was able to spend time with her mother's friends. Thus, opportunities to develop social skills in a variety of contexts were available to Daria when she spent time away from the group home and with her mother.

The staff were aware of how meaningful Daria's time with her mother was. So much so, that it was used as a form of behavior management to encourage appropriate behaviors. As recounted by Daria, she was concerned about an incident that occurred in the community when she yelled at a staff person when she was upset. "[A staff person] said I can't go to my mom's...if she had trouble with me I couldn't go and if it happens again where I go somewhere and I act up they have to cancel my visits" (Daria, 13). This would impact Daria's opportunities to spend highly valued leisure time with her mother. The significance of this is tremendous when one considers the lost opportunities to develop social skills, experience leisure in a context away from the group home without housemates and staff, and to experience leisure with someone who was meaningful to her. Because Daria's time with her mother was important, removing the opportunity for Daria to spend time with her mother also removed the opportunity for choice-driven leisure.

The women of Elm Home experienced leisure at home, in the community and with family and friends. Although there were opportunities available for the women to provide input into the nature of their experiences, management of the home and

requirements to be met by staff, at times, took precedence over the autonomous, choice making behaviours of the women. The women's leisure experiences were affected by the behaviours of the staff to adhere to policy and manage the home.

3.3 Cairn Home

The experiences of the women in Cairn Home are those of Ina, Beth, and Jackie. The supporting statements are provided by group home staff Mitzy, Bella (both full-time house managers), and Shannon (part-time recreation worker). For the women of Cairn Home, leisure at home describes self-directed activities engaged in with and without the support of staff members. Activities such as watching television, making crafts, listening to music, or pet care were engaged in without the support of staff. At times, however, some of their chosen leisure activities required the support of staff for guidance, resources, or supervision. These included activities such as cooking or baking. The degree of support provided by the staff was gauged by the individual abilities and desires of each woman.

The women also experienced supported and non-supported self-directed leisure in the community. The women would make decisions and initiate activities in the community by determining with whom, how, and when to experience leisure (e.g., going out for coffee with a friend). At times, in order to experience leisure in the community, the women required supervision if the environment was unfamiliar to the women or if assistance was required for travel to locations which were not immediately accessible.

The women initiated contact with family and friends during their leisure. They made decisions to contact family by telephone or by walking to family and friends' homes if they were within walking distance. These connections were self-directed and

supported by staff only if the women required assistance using the telephone or the family or friend's home was not in walking distance of the group home. When support was required, the women determined for themselves how much support they wished to receive from staff by verbally indicating what they specifically needed help with (e.g., dialing the phone).

3.3.1 Leisure at Home

To begin, I would again like to describe a 'typical' weekday at home. The women experienced routine more so during the week than on the weekend due to their vocational responsibilities and weekly pre-scheduled recreational activities. The women, who each owned an alarm clock, would get up in the morning when their alarm rang (around 6:30 a.m.) without the assistance of staff. While the women were getting ready for work, the staff prepared the morning coffee and set out breakfast items (e.g., cereal, pastry, yogurt, or toast). Once breakfast was completed, the women would gather the items they needed for work (e.g., lunch pails containing the lunches the women made for themselves the evening before), footwear, notes for workplace staff) and be waiting for the bus by 7:45 a.m. The bus was contracted by the vocational centre to transport its workers. The women would spend from 8:00 a.m. until 3:00 p.m. at work.

Ina's vocational program provided opportunities for her to work in the community with the assistance of a job coach. The job coach supported her in community businesses such as restaurants and office buildings where she would help with dishes and meal preparation or filing and office cleaning. Ina would often visit two businesses a day, one in the morning and one in the afternoon. Beth and Jackie spent their weekdays together at an activity centre and spent their days making crafts, filing, and participating in

educational programs (e.g., socialization skills, daily living skills). When 3:00 p.m. arrived, the women would get back onto the bus which would then shuttle them home.

When the women arrived home from work at approximately 3:30 p.m., the staff ensured that coffee was always brewing. The women greeted the house manager, put their lunch pails away, and poured themselves a cup of coffee. The women would sit around the dining room table and discuss their day. Often, the staff person would either sit down with them during their coffee discussion or would be preparing supper in the kitchen, all the while present as the women shared their stories. The women would talk about what happened at work, what happened on the bus on the way home, and what their plans were for that evening or weekend. All of the women from the group home took part in this coffee talk session. It appeared that they enjoyed spending the time together as they laughed at each others' stories and asked each other questions about the details of their day. Once the coffee pot was empty and the cups were put away, the women would go their separate ways and take advantage of leisure time available before and after supper.

Independent self-directed leisure. Leisure at home consisted of spontaneous and independent self-directed leisure activities. The women experienced leisure at home independently and of their own choosing. I observed the women in Cairn Home engage in activities such as watching television, creating a pleasing home environment, exploring hobbies and personal interests, and spending time with the house pet. These activities were considered spontaneous and self-directed because the women initiated these activities without external influence. Again, for the purpose of this study, leisure was

defined as time away from work that one is able to choose how to spend time and no activity has been pre-planned (Parker, 1981).

Watching television was a popular leisure activity for the women. Watching television was an activity that all women in the home participated in during their leisure time. Television viewing was not monitored by staff, programs were not selected according to the house schedule or staff interest, and the women chose programs they preferred to watch. When asked what she did during her free time, Beth responded, “watch TV” (Beth, 1). I observed that Beth often spent her leisure time watching television, particularly after work when the coffee talk session was over, and while staff prepared supper. Beth indicated that her favorite shows to watch were the Price is Right, Bewitched, and I Dream of Genie. To find her favorite shows, Beth said she just “turn[s] the channel” herself (Beth, 4), and, “...find[s] whatever is on” (CH, AT1, 1). I noticed that the remote control had colored stickers on it. The stickers were strategically placed, by staff, on the power button and the channel-up and channel-down buttons. The staff developed this system so the women could have choice in the programs they watched by being able to independently choose channels on the television. I observed Beth freely change the channel on the television using the remote control to find a desired program. There was no staff involvement or support needed. Beth indicated that she enjoyed having time to “relax...on the couch” with others and watch television (Beth, 1) (see Figure 3.6).

Television watching was an opportunity to experience independent, choice driven experience at Cairn Home. The strategic energies and creativity on the part of the staff created an environment that encouraged and permitted spontaneous and choice driven



Figure 3.6 Beth watching television (researcher photo).

independent leisure.-In essence, staff recognized the women's abilities to learn a leisure skill and with the use of environmental prompts taught how to use the remote control.

The women enjoyed creating a pleasing environment during leisure. During my time at Cairn Home, I observed the women enjoying leisure time in their bedrooms. In reviewing my field notes, I came to understand the importance of this private space to the women. On two occasions, I observed how Ina used her leisure time to personalize her room. In my participant observation field notes, I recorded:

She is very meticulous about how her room is arranged. It is always neat and organized, sometimes even rearranged differently each time I go there! No dust on anything! Her room is colorful. (December 11, 2003)

On another occasion, I described her room as:

Very colorful, lots of pictures, artwork she has done herself, stuffed animals, pictures of her family and Dan [her boyfriend]. Everything is neatly organized. Ina loves color! (November 1, 2003) (See Figure 3.7).

Similar to Ina's room, each woman's bedroom was an expression of personal interests, personality, and color. Each woman created a comfortable, personalized leisure

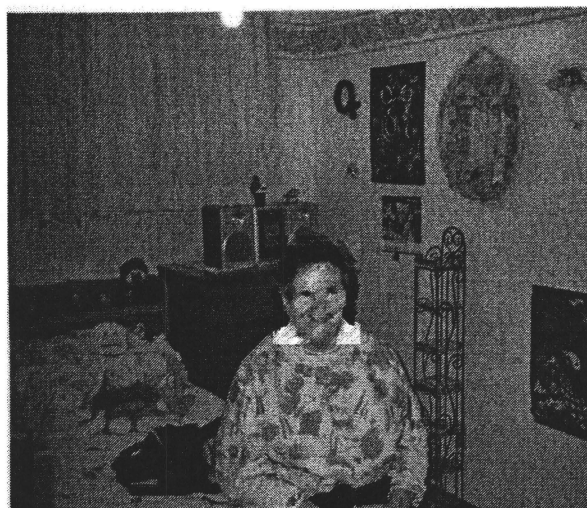


Figure 3.7 Ina in her ‘personalized’ bedroom (researcher photo).

environment. Beth’s bedroom was decorated with pictures of her boyfriend and family. Her bed was lined with stuffed animals, and her movies and CD collection were organized just the way she liked. Beth enjoyed listening to music and had her own CD player in her room. She was so pleased with having her own CD player that she could use whenever she chose, she showed me one evening how to use it (participant observation notes, November 1, 2003).

Jackie’s room had pictures of kittens on her walls, photos of family on her bed stand, and a small metal calendar strategically placed on her bookshelf that she made sure to change the date everyday. The women spent their leisure time in their rooms and created spaces that reflected their own interests. The personalization of the women’s rooms reflects the atmosphere of a home and not a 24 hour staffed facility. The daily log book stated that on September 22, 2003 “Ina changed her room around. She told me [staff person] where to put things.” This indicates that staff supported the women in expressing their desired ‘look’ for their personal space and did not interfere. The staff in Cairn Home provided opportunities for choice, control, and encouragement of expression in one’s

personal space. Thus, the women were able to experience leisure by creating their own personal spaces and then enjoy leisure in a unique, comfortable environment that they could call their own.

The importance of having a comfortable, inviting space to call one's own is significant when consideration is given to the amount of time the women and staff spent together in the home. Several areas of the home were 'common' areas in which all housemates shared space (e.g., the living room, the basement, the kitchen, the bathroom, the yard). Staff knew that each woman's bedroom was her own and was a non-negotiable space. Staff ensured that each woman had total control of her personal leisure space and experienced comforts in her bedroom that did not have to be shared with others (e.g., a television, radio, CD player).

Independent self-directed leisure time was also spent exploring hobbies and personal interests. Ina, for example, spent her free time creating beaded jewelry and accessories. Her beading tools were always accessible to her. If she ever felt like beading, she would take her beads, needle and thread downstairs and sit at the large table in the rumpus room and bead. Some evenings, when I was at the home, Ina would bead the entire two hours I was there! She chose when to bead and decided what to make (e.g., bracelets, necklaces, key chains). During the time of data collection, Ina worked diligently preparing for an upcoming craft sale of which staff made her aware. They knew that an opportunity for Ina to share her leisure interests and activities outside of the home was a unique opportunity. I have observed in other group homes previous to this study that leisure interests are only shared with the housemates in a group home. The

craft sale was an occasion for Ina to showcase the products of her leisure with people in her community.

If we were to look to the conceptual framework to understand the significance of Ina's participation in the craft sale, we would see that Ina's choice to make crafts during leisure allowed her to exercise skills of (a) decision making (deciding what crafts to make), (b) problem solving (determining when and where to create beadwork), (c) goal setting (identifying how much time was available and how many items were needed for the sale), and (d) self-evaluation and outcome expectancy (recognizing that by applying her skills of beading she would achieve her desired outcome). The staff recognized Ina's abilities and encouraged her to further develop her skills. In fact, the staff encouraged all of the women to further explore their own interests. When observing the women in their bedrooms, I would often ask, "Where did you get...?" of the many items in their bedrooms. The women indicated that staff would purchase Christmas and birthday gifts for the women that contributed to their interests, hobbies, or collections. For example, gifts for Beth were often compact discs or DVDs of Elvis or Anne Murray, Jackie's gifts were most often cat-related, and of course, Ina's gifts were beads or beading tools. The staff created an environment that was conducive to the expression of self-directed, independent leisure.

Another way the women experienced leisure at home was with their cat, Frost. From my experience working with group homes, having a pet was not common because of possible allergies and the cost required to care for the pet. Cairn Home, as I observed, was an exception to a 'no pets' rule. At the time of data collection, the cat had lived at the home for nearly 2 years. I observed the women spend a lot of time with Frost and it was

apparent that the cat was very important to them. All of the women took turns caring for the cat, feeding him, ensuring the water dish was full, and playing with him. When the cat was not underfoot or roving around the room, the women would actively seek him out. They would look in his favorite chair where he liked to sun himself in front of the kitchen window. They would look for him under furniture and in bedrooms. They would even search downstairs near his litter box to see if he was there! The women spent much time talking to, or about, the cat. The cat was integral to their leisure experience at home.

Beth stated that in her leisure time, she enjoyed to, “play with Frost” (Beth, 1) and enjoyed giving the cat ‘high-fives’ (see Figure 3.8). Beth clearly indicated how important that cat was to her during an interview session when she was asked, “Is there anything that makes you happy?” Beth responded, without hesitation, “The cat!” (Beth, 19).



Figure 3.8 Beth giving the cat a ‘high-five’ (researcher photo).

Ina also appeared to enjoy the company of the cat. I observed her to pray with him and manipulate his furry paw to gesture the Sign of the Cross while she would say, “In

the name of The Father, The Son, and The Holy Spirit” (participant observation notes, November 24, 2003). Ina referred to herself as Frost’s ‘Mommy’ and even behaved as though she was his guardian, choosing not to go on group outings so she could stay home by herself and “look after Frost” (participant observation notes, November 24, 2003).

When the cat was behaving badly (digging in the plants or walking on the coffee table), Ina would use a water bottle to spray the cat as a form of discipline. “Listen to Mom!” she would yell at him. Ina indicated one of her favorite photos was one that she had taken of Frost under the Christmas tree (see Figure 3.9).



Figure 3.9 Cat under the Christmas tree (photo taken by Ina).

The staff recognized the importance of the cat to the home and respected the women’s involvement in ‘raising’ him. “He’s incredibly important to the household...I think other people have brought their own [pet] but this is the first animal that’s the ladies” (Mitzy, 5). Staff created an opportunity for a unique leisure experience. Staff

allowed the women to exercise autonomous decision making by choosing to stay home and care for the cat instead of attending a group or community outing. Staff recognized that the women felt a sense of responsibility to the cat's well being and allowed them to use their leisure time to fulfill that responsibility.

Staff supported, self-directed leisure. Not all self-directed leisure activities were engaged in without the support of the staff members. At times, the women needed support following directions or using home appliances. The activities I observed with staff support were baking and cooking for pleasure. When cooking during leisure, the women were observed to assist with menu planning, preparing the meals, and baking. These activities were staff supported when the women required guidance (e.g., identifying steps required to complete a task), resources (e.g., ingredients, equipment), or supervision (e.g., to ensure safety).

Statements in the daily log book revealed the women were often involved with cooking and baking. "Ina and I [staff person] made supper together" (daily log book, November 12, 2003), "Ina and I [staff person] made cookies" (daily log book, November 23, 2003), and "Beth and I [staff person] made a nice chicken supper together" (daily log book, November 21, 2003) are a few examples supporting their involvement. Beth indicated to me in an interview that on a day off from work, her and Ina made supper for their housemates. "Me and Ina made stew. And dumplings...And Bella helped" (Beth, 3). Although the women did require support during these activities, staff always recognized the women's contribution during the activity. When the women assisted with meal preparation, staff insisted on telling me that the women prepared the entire meal by themselves! Throughout the daily log book, notes such as, "Beth made dumplings for

supper” (November 15, 2003), “Ina made chocolate chip cookies” (November 15, 2003), and “Jackie made 5-cup salad” (November 30, 2003) provide evidence that the women were active participants while baking and cooking and that staff recognized their contributions. When the women assisted with meal preparation, they would always tell me about it the next time I saw them. They would begin their sentence with, “Guess what we did last night...!” I could tell it was important for the women to contribute to the home and to share in the decision making regarding meals.

I learned that Beth loved puffed wheat cake. One afternoon while I was at the home, Beth made a decision to make puffed wheat cake for an upcoming Christmas party (participant observation notes, November 28, 2003). Beth made the cake with the assistance of a staff person in the home. As seen in the photo I took (Figure 3.10), staff played a minor role while Beth was baking.

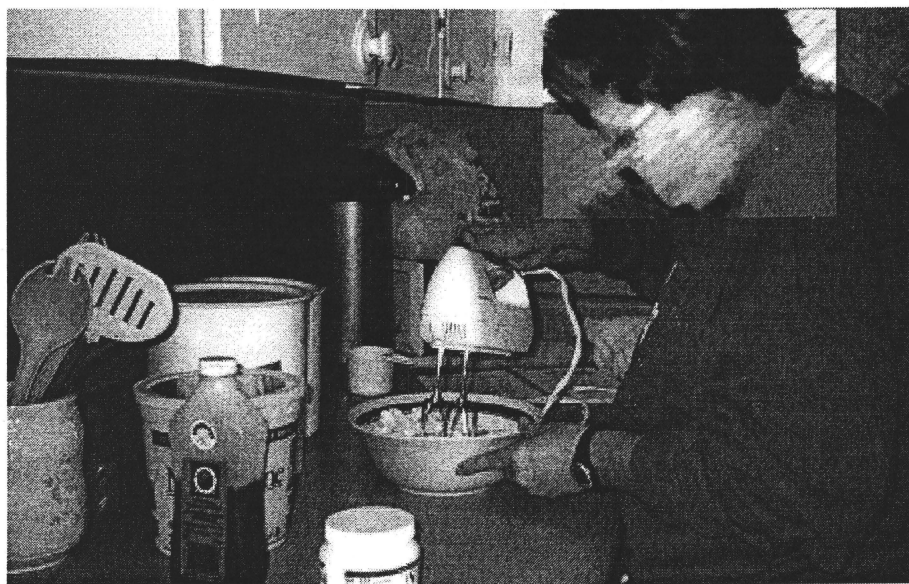


Figure 3.10 Beth baking at home (researcher photo).

I observed the support Beth received during this particular leisure activity and recorded this in my participant observation notes (November 28, 2003). I observed that when Bella requested for Beth to fill a measuring cup with an ingredient, Beth would never fill it quite to the top, (perhaps due to fear of spilling the contents Beth would pass the cup in front of Bella and ask, "How's that Bella?" If the cup was not quite full, Bella would present Beth with a question that would encourage her to problem solve. She would say, "Is that full, Beth?" allowing Beth to determine for herself if the cup was full enough. Beth would add a little more of the ingredient and then ask Bella again, "How's that?" If the cup was still not full, again Bella would simply respond, "Is that full, Beth?", again providing Beth with an opportunity to learn and practice how to accurately measure the ingredients. Again, Beth would nervously add more until she had filled the cup to the top. When it was full, she poured the contents into the bowl and moved on to the next ingredient on the list.

Although this was a time consuming process for Bella, it provided an opportunity for Beth to experience supported leisure in a respectful and self-realizing context. Overall, I observed the staff created an environment in which the women could experience pride and accomplishment through kitchen focused leisure activities. The process of preparing meals and baking appeared to be as important as the product of their efforts.

From my experience, it is not common for housemates of a group home to spontaneously engage in cooking or baking. What is common is a scheduled 'baking night' when extra support staff are called in to the home to assist with the activity. Thus,

baking or cooking becomes a recreational activity that is planned and executed on a particular day at a particular time.

For anyone, preparing meals and baking are activities that require attention to detail and time. Decisions need to be made about what to make, ingredients need to be gathered and prepared, and several elements must be combined to create a meal. The staff in Cairn Home recognized the process and time required to cook and bake and put forth effort, patience, and consideration to allow the women to engage in the process. The significance of this is apparent when one considers that the time and patience required to teach someone these skills can slow the process of cooking and baking. When taking the time to teach someone, the process is interrupted, inefficient, and delayed as opposed to timely and fluid. The staff appeared to give less priority to strict schedules for meals and other household routines than the process of teaching and creating an environment that would ultimately lead to the women being independent in their chosen leisure activities. Staff recognized the importance for the women to be engaged in the process and learn daily leisure skills. The women were active participants, not passive onlookers.

3.3.2 Leisure in the Community

Leisure in the community was experienced in a similar way to that in the home. The women experienced leisure independently with no staff support, or they experienced leisure with minimal staff support. The nature of their leisure experience depended on the proximity of the community leisure environment to the group home. If a desired location was within walking distance, the women experienced leisure independently and spontaneously. Leisure was staff supported when the activity posed safety risks, the environment was unfamiliar to the women, or the location was far from home.

Independent outings. Mitzy said during an interview that, "...[the women] talk about being out in the community [because] being part of the community is important to them" (Mitzy, 5). The opportunities to experience independent self-directed leisure were observed to include going for a walk and going out for coffee.

A typical independent leisure experience in the community was a trip to the local donut shop which was five blocks away from the group home. In the evening or during a weekend afternoon, the women would simply say that they were going "for coffee" and leave to go to the shop. Ina and Beth were the two women who most often took advantage of this particular independent, community leisure experience. Due to a medical condition, Jackie only attended the excursion to the coffee shop when a staff person went along.

In order for the women of Cairn Home to experience independent leisure in the community, staff spent a considerable amount of time (weeks and sometimes months) teaching the women the skills required to experience a safe, independent outing. The staff worked with the women to develop the familiarity and knowledge required to experience independent leisure outside of the home. Mitzy described how the opportunity to teach the skills to go to the donut shop came about:

...[Ina] started going out for walks by herself and she went over to Dan's [boyfriend] all the time by herself. She seemed to have no difficulty with the concept of being safe. So I was talking to...the lady who works with Dan and she said that Dan goes all the time for coffee to [a donut shop]...couldn't he and Ina go together? So I asked Ina if she'd like to do that and she was like, absolutely! (Mitzy, 3)

Staff recognized that Ina could experience leisure independently, presented her with the opportunity, and worked with her for several weeks to teach her how to safely traverse to and from the local donut shop. Mitzy described the strategies used to teach Ina

the safety skills she needed to exercise decision-making, problem solving, and autonomy during leisure:

When it's to do activities on their own we go through a slow process where we'll go with them for a bit and then pull back [support]. At first...we all went together and she was the leader and pushing the button to cross the street so...that we knew she knew what to do. After that it would be I wouldn't cross the street with her. She would cross the street by herself and I would just kind of be on the other side watching to make sure she would be okay. And then just let her go. (Mitzy, 3).

Incidentally, once Ina was experiencing independent leisure in the community, Beth decided that she also wanted the same opportunity. Mitzy told me during an interview that her and Bella thought it was appropriate for Ina to be the teacher and share her knowledge and skills with Beth (Mitzy, 4). Bella described how excited Ina was about being the teacher and that Beth was equally excited at the prospect of Ina teaching her "...instead of...[staff] teaching her always" (Bella, 7). The psychological empowerment created by the staff for Ina reflected their understanding of and commitment to the women's quality of life.

Although staff could appreciate that the women had a desire to experience self-directed leisure in the community, they were not without reservations. They were somewhat apprehensive at the thought of the women walking to the shop by themselves. "It's like when you have to finally let your kids walk to school by themselves... sometimes you have to go hide behind parked cars!" (Bella, 7). Mitzy described feeling "really anxious" (Mitzy, 3) about the whole process:

...when they [Beth and Ina] went together...I was nervous because usually Ina goes with her boyfriend who...knew how to cross the street no problem. I was comfortable with Ina going but I wasn't as sure that Beth would follow Ina's lead...Beth isn't as good at crossing the road. (Mitzy, 3)

Ultimately, Ina and Beth both learned to safely walk to and from the donut shop and did so independently. "I dropped Beth and Ina at Robin's Donuts and they walked home" was written in the daily log book by a staff person, thus indicating the women experienced leisure independently (September 26, 2003).

Although anxious, staff supported the women and provided them with an opportunity to learn the skills required to experience autonomous leisure outings. It was apparent that staff interpreted their role to include teaching skills that would allow the women to experience independent and spontaneous leisure in the community. This is significant when one considers the apprehension they experienced while relinquishing their traditional supervisory roles to provide opportunities for the women to exercise decision-making, autonomy, and self-awareness during leisure. Furthermore, staff held expectations about the women's abilities to learn the skills required to experience autonomous leisure. It was very exciting for me to see the women take an active role in their leisure experiences. The opportunity to actively engage in this leisure experience was attainable because (a) staff trusted the women to utilize good judgment, (b) staff recognized the value in experiencing community leisure, and (c) staff realized the importance for the women to experience autonomous leisure.

Accompanied outings. At times, the women required support in the community, particularly if the chosen destination was not within walking distance. Most often the support was in the form of transportation to a desired community location or guidance through an unfamiliar activity. The activity most often observed was shopping.

On numerous occasions, I observed the women decide to go shopping when asked by a staff person what they would like to do during an afternoon away from work. The

women and the staff would pile into the car and head to the mall or Wal-Mart, depending on what the women requested. Bella described a typical shopping experience at the store:

If we have to go pick up stuff, we'll take a cart and we'll all go to the section that we have to pick up...you know pick up your toothpaste and your shampoo and your bubble bath. And then usually if I have some shopping I have to do for myself I'll say 'I'm gonna go do some shopping, you guys can go and look around'. Or maybe Ruby [housemate] and I are going to look for something to buy and I'll say 'Ruby and I are going to the clothing department, you guys can go look at whatever you want' (Bella, 8).

If you recall the vignette I used to open my thesis, I described the women's previous shopping experiences in which they would follow me through a store and only stop to shop when I did. Bella's quote is an indication how opportunities to develop and exercise skills for self-determination (i.e., problem-solving when identifying what items needed to be purchased and decision making when choosing which items to purchase) can lead to autonomous leisure experiences. Shopping is more than simply going to the mall. Similar to baking, shopping is a process that requires the person to be actively engaged to truly experience the activity. The staff recognized this and provided opportunities for the women to develop skills so they could experience leisure as independently as possible.

One evening when I was at the home, Shannon was scheduled to take Jackie on an outing. Nothing had been pre-planned for the evening, so Shannon provided Jackie with the opportunity to direct her own leisure experience. "What would you like to do tonight?" Right away, Jackie responded that she wanted to go shopping for her mother's Christmas present, "a soap thing" (CH, AT2, 14). The 'soap thing' was a small wicker basket containing small, sample-sized bottles of bubble bath and body wash. Jackie noticed it in a flyer that came in the mail with the Sunday paper. The women often

perused flyers and catalogues to shop for clothes, groceries, videos, and presents, using the pictures to choose desired items. Sometimes, the women would cut the picture out of the flyer or save the page out of the catalogue for when they went to the store (see Figure 3.11)

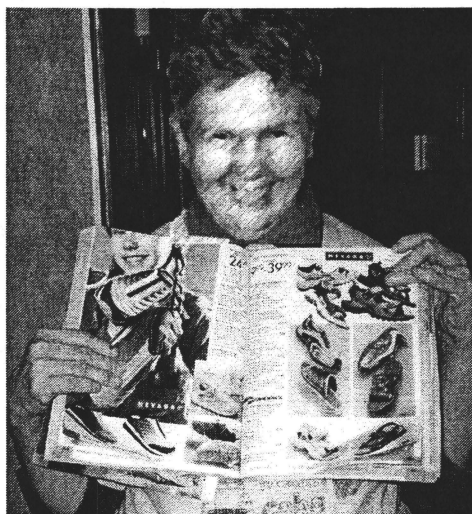


Figure 3.11 Ina shopping for a new pair of shoes (researcher photo).

Support staff responded to Jackie's self-determined behaviour of requesting a shopping trip, and with the permission of both Jackie and Shannon, I accompanied them.

When we arrived at the store, I asked Jackie to remind me what we were shopping for:

- Brenda: "What are you buying tonight?"
 Jackie: "[A gift] for my mom."
 Brenda: "Is it for Christmas?"
 Jackie: "yah."
 Shannon: "Do you remember what it is Jackie?"
 Jackie: "A soap thing."
 Brenda: "For her bath?"
 Jackie: "For her bathroom." (CH, AT2, 14)

As we walked through the store in search of the desired item, Shannon noticed the bin of bath baskets Jackie was looking for and guided her in the right direction:

- Shannon: "I think these are the ones we saw."
 Jackie: "That's like the flyer."
 Brenda: "So you saw it in a flyer?"

Shannon: "Yah, she saw these in the flyer and said she wanted to buy it for her mom's bathroom. So then someone threw it [the flyer] out so we had to go searching through...which one would you like Jackie? What color is your mom's bathroom? Do you remember?"

Jackie: "This one."

Shannon: "Is your bathroom blue or what color is your bathroom?"

Jackie: "Blue."

Shannon: "Blue, or purple, or pink?"

Jackie: "How much?"

Shannon: "They're all 5 dollars."

Jackie: "I'll take that one."

Shannon: "You'll take that one? So you like that one?"

Jackie: "Yah."

Shannon: "That one has lavender and it looks like is has shower gel, lotion, and body mist. These other ones have bath beads and shower gel and soap."

Jackie: "Oh I like that!"

Shannon: "Would you like it in purple? Let's see if I can find one..."

Brenda: "There's another one down there or does that not have the same stuff?"

Shannon: "Do you like the purple?"

Brenda: "That one's nice."

Shannon: "That one's green."

Jackie: "That's green."

Shannon: "Do you like green? Oh, here's purple. Here's kind of bluey-purple."

Jackie: "I'll take that one." (AT2, 15)

It was apparent that Shannon wanted Jackie to be aware of all of her options.

Shannon recognized the importance for Jackie to make her own choice. She did what she could to inform Jackie and searched to the bottom of the bin to find every possible colour of gift basket. This allowed Jackie to truly make a personal choice while shopping. Figure 3.12 is a photo I took of Shannon providing support to Jackie.

When it was time to pay at the checkout, Jackie stepped up to the register and placed her item on the counter. Shannon supported Jackie during the purchase only when she needed it, "Get a looney, a quarter..." Shannon patiently encouraged Jackie to search through her wallet to find the correct change, even when there were customers waiting



Figure 3.12 Jackie shopping for Christmas present (researcher photo).

behind us (participant observation notes, November 3, 2003). Shannon did not rush Jackie through the checkout by digging in her wallet to find the correct change for her, but ‘coached’ her through the problem solving required to truly experience shopping with minimal staff interference. It would have been a lot quicker to get through the checkout if Shannon had looked through Jackie’s wallet herself and counted out the correct change. But what Shannon did *not* do during Jackie’s time at the till is significant because it provided Jackie with the opportunity to problem solve.

Once Jackie paid, collected her change, and gathered her shopping bag, it was time to move on to the next leg of the leisure outing:

Shannon: “So Jackie you’re done shopping?”
 Jackie: “Yah.”
 Shannon: “Would you like to go for coffee?”
 Jackie: “Yah.”

Shannon: "Where would you like to go for coffee?"
 Jackie: "Anywhere."
 Shannon: "That's a pretty..."(long pause)
 Brenda: "Do you want to go to Winnipeg for coffee?"
 Jackie: "Yah!"
 Shannon: (Laughter.) "Do you know how far Winnipeg is? It's about 5 hours. Should we drive 5 hours? And we'll get back tomorrow morning in time to go to work and you'll have no sleep?"
 Jackie: "Yep!"
 Shannon: "You're silly!"
 Jackie: "I'm just joking darling!"
 Shannon: "Where would you like to go?"
 Jackie: "Over there."
 Brenda: "What's over there?"
 Shannon: "Do you know the name of a place?"
 Jackie: "McDonalds."
 Shannon: "Would you like to go to McDonalds for coffee?"
 Jackie: "Yah!" (CH, AT2, 16-17)

Jackie's outing that evening was indeed leisure, for Shannon created opportunities for Jackie to be spontaneous in her leisure activity, to express choice, and bring personal meaning to her leisure experience. The staff at Cairn Home used individualized support strategies to respond to each woman's needs to experience decision-making and autonomy during leisure.

3.3.3 Leisure with Family and Friends

Leisure for the women living in Cairn Home was experienced through connections with family and friends. The proximity and availability of family members played a key role in determining the frequency and nature of these experiences (e.g., face-to-face contact or telephone calls).

Connecting with others. The telephone was used on a regular basis by the women to connect with family and friends. The daily log book revealed that in just over a one month period each woman had telephone contact with an important person in her life. For example, "Beth phoned Jill [sister]" (September 22, 2003), "Jackie called her mom"

(October 11, 2003), “Ina talked to Olga [sister]” (October 26, 2003). The women were free to use the telephone whenever they chose and simply had to ask a staff person to assist them in dialing. I observed that Ina often made telephone calls to her sisters. When she had a desire to connect with her sisters, she would simply ask, “Phone Marie?” and the staff immediately knew that she wanted to call her sister.

From my experience, phone calls in many group homes tend to be ‘managed’. Often, residents are required to ask permission before using the phone. In some environments, residents are not even aware that they have the option to make a phone call. The staff in Cairn Home permitted unrestricted use of the phone which permitted the women to experience spontaneous leisure by connecting with someone important to them. This is significant because, when one considers the amount of time the women spent together at work and in the home, it provided opportunity for the women to expand their social networks and connect with others outside of their daily social group.

If a friend or family member lived in close proximity to the group home, the women were able to experience leisure face-to-face with the individual. Beth was thrilled to have her niece, Joni, live across the back alley from the group home. Beth visited at least once a week, riding her bike or walking to Joni’s. “Beth goes to see her once or twice a week...sometimes for just 10 minutes or she’ll stay and have a visit, kind of depending on what Joni is doing” Mitzy said of Beth’s visits (Mitzy, 8). I observed that staff did not interfere when Beth indicated that she was going to visit her niece, although Mitzy did offer suggestions on how to get the most out of her time with Joni. “[Beth] doesn’t [call before she goes]. I’ve tried to work on that with her and she’s just not interested so I’ve stopped. It’s...not my relationship so [she] can do whatever [she]

wants” (Mitzy, 8). This statement is significant because although Mitzy saw an opportunity to ‘manage’ Beth’s leisure, she relinquished her traditional, supervisory role and allowed Beth to have total control of the experience. She respected Beth’s relationships and did not interfere with her personal affairs allowing her to experience autonomous leisure.

Ina was fortunate to have her boyfriend, Dan, live down the street from the group home. Dan and Ina’s relationship began over 25 years ago when they met at the vocational centre they both attended. In the beginning, their time together was exclusive to their vocational context. As time progressed and they developed a fondness for each other, they attended dances together in the community. Throughout the years, Dan and Ina developed a strong, personal relationship and found themselves in search of more opportunities to spend time with each other. They both joined Special Olympic Bowling and bowled together every Saturday. Staff indicated that when Ina would decide to spend time with Dan, she would say, “I’m going over there or he’s coming over here’ ...or ‘We’re going out for coffee’”(Mitzy, 2).

Ina’s time with Dan was so meaningful to her that she made decisions to sacrifice outings with housemates and support staff to spend time with him. “They [Dan and Ina] spend all their time together. When Ina has stopped going out for things, like she wouldn’t go see the lights [in the park] in case Dan came over” (Bella, 5). This was also indicated within the daily log book which recorded that, “Ina didn’t come out with us...she was waiting for Dan” (October 17, 2003). It was obvious that time with Dan was extremely important to Ina.

Mitzy recognized the importance for the women to develop and nurture relationships with others:

Any strong relationships that they have with another person are more important and the leisure activities they do with that person are more important than, say, going out to a movie with the group. They do have a strong identity as a group as well. Those leisure activities just don't have the same importance. The individual time seems to be more important. (Mitzy, 6)

Ina's time spent with Dan is significant because staff respected her choice to spend time with someone who was important to her. Furthermore, staff did not see the need to manage Ina's leisure by insisting that she take part in group activities and although staff recognized the group identity the women shared, they also recognized the importance for the women to connect with others outside of the home. Having the opportunity to develop relationships with others outside of the home permitted the women to develop their own sense of identity, expand their social networks, and ultimately their leisure repertoire.

3.4 Elm Home and Cairn Home: A Summary of Leisure Experiences

Although the themes that emerged from the analysis of the data were similar (leisure at home, leisure in the community, leisure with family and friends) the uniqueness of the environments within each group home influenced the leisure behaviours of the women. There were distinct differences in how leisure was experienced in the two homes.

In Elm Home, the implementation of a policy pertaining to weekly recreational outings was instrumental in determining the leisure experiences of the women. Staff viewed their role as a caregiver or 'manager' to the women and the home. The opportunities for the women to develop and experience self-determined behaviours were

quite different from those of the women who lived at Cairn home. In Cairn Home, staff continuously relinquished their caregiver/manager role and created an environment that supported the development and utilization of self-determined behaviours. Staff recognized the importance for the women to own and express their individuality in their leisure pursuits and accepted this as priority in the home.

Chapter 4

4.1 Discussion

The definition of intellectual disability has changed over time. Intellectual disability was acknowledged to be more than the outcome of psychological testing. Adaptive behaviour is dynamic and linked to the contextual factors present in the environment. In short, intellectual disability is not a condition that someone possesses, but rather a state of functioning people experience in particular contexts (WHO, 2001). Or, stated differently, the social context can facilitate or debilitate individual functioning. The findings from this study illustrate two very different social contexts, one that facilitated self-determined leisure, and one that was less successful in doing so.

Leisure has four components (Parker, 1981): flexibility, spontaneity, self-determination, and choice. Flexibility (having the choice to do what you want when you want), spontaneity (the ability to do something at one's own choice on the spur of the moment), self-determination (the ability to determine when, where, and how leisure is experienced), and choice (the ability to choose how to spend one's leisure) are required for a true leisure experience. The findings illustrated that when opportunities are available to exercise choice making, decision making, spontaneity, and problem solving, people with disabilities can become self-determined within the context of leisure.

4.1.1 The Environment and the Experience of Self-Determined Leisure

In Cairn Home, the women were the focal point in the home and the activities in the home and the behaviours of the staff functioned around this. Staff in Cairn Home adopted a philosophy that was based on teaching the skills required for independent, spontaneous, and choice based leisure. The staff completed the duties required to manage the home in conjunction with the leisure interests of the women. Cairn Home was 'person-centered' in that the women were, to some extent, the administrators of the home. The staff appeared to regard their roles as that of mentors and facilitators and less as managers of a shift of duties based on the management of the home (see Figure 4.1).

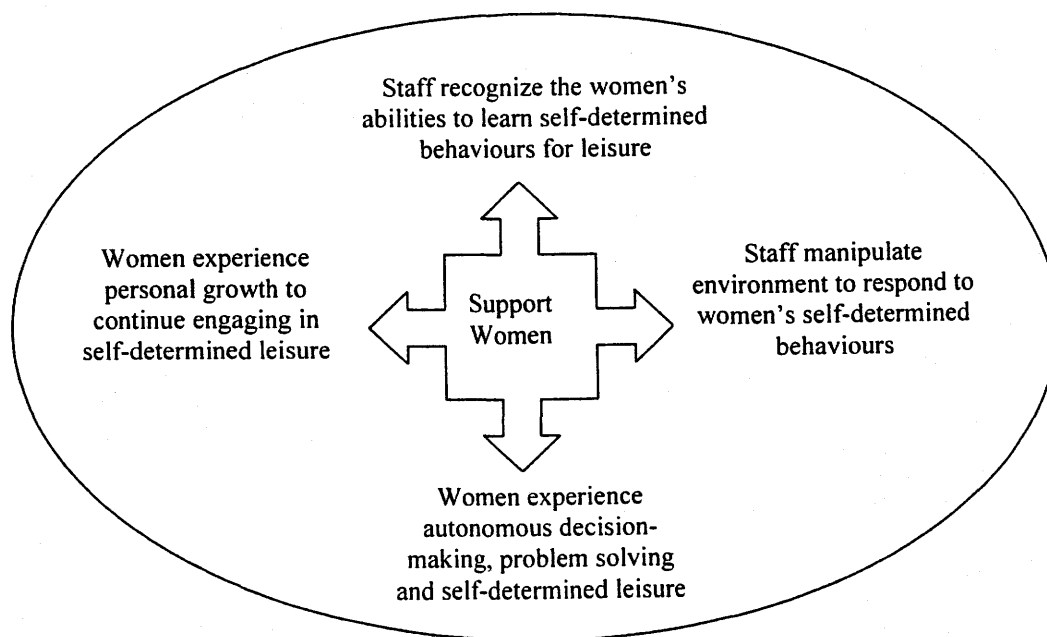


Figure 4.1 Staff of Cairn Home view the growth of the women to be their primary responsibility.

The staff implemented small steps to build the women's confidence and comfort with making choices and experiencing independent leisure not only at home, but in the

community, and with family and friends. Slowly, the staff presented opportunities to the women, they began to develop leisure skills and ultimately self-determined leisure behaviours. Staff were eager to respond to the self-determined behaviours of the women. However, staff were not only reactive, but proactive in that they actively sought opportunities for the women to experience independence. Staff were cognizant of the women's interests, skills, and potential and offered opportunities for the women to experience independence. Staff had expectations that the women could experience independent leisure and manipulated the house schedules and the environment so it was responsive to these behaviours. This reality of expectation was echoed in the way the staff identified the women during interviews. The staff viewed the women as adults and used the term 'ladies' when referring to them. Staff recognized that the roles they played in the women's lives were not simply to 'manage' them, but to provide opportunities for growth. Staff seemed to view their role as that of a teacher and companion. They felt a responsibility for the continued development of the women's learning and independence. When one considers the strategies the staff initiated to allow the women to experience independence and the vast opportunities for them to experience self-determined leisure, it is not preposterous to suggest that the staff were potentially working themselves out of a job! Because staff worked with the women and developed strategies to allow them to demonstrate self-determined leisure, the women's leisure repertoire continued to grow. It is safe to say that the environment in Cairn Home supported and encouraged self-determined leisure behaviours.

In contrast, Elm Home adopted a service-provision philosophy in which the women were seen as 'clients' that had to be cared for and their affairs had to be managed.

Staff even used the term “girls” when referring to the women in the home, perhaps a reflection of their true perceptions of the women and their abilities. Use of the term girls suggests they are children and such an assumption may influence expectations. The policy of planned weekly recreational outings and support practices of the staff had a significant influence on how the women experienced leisure. It appeared that adherence to policy and home management took precedence over providing opportunities for the women to experience self-determined leisure (see Figure 4.2). The staff in Elm Home viewed their role as a caregiver and a manager. The attitude held by staff had a direct impact on the environment of the home in that self-determined behaviours were not encouraged. The opportunities for the women of Elm Home to experience ‘true’ leisure (Parker, 1981) were not as accessible as they were for the women of Cairn Home.

Although, at times, the environment was responsive to flexibility, the women’s leisure experiences were affected by the policy of the agency and the perceived roles of the staff. Ultimately, the administrative structure of Elm Home resulted in it being very difficult to take advantage of the opportunities leisure provided to promote self-determination.

Although the women of Elm Home experienced leisure at home, in the community, and with friends and family, they were frequently supervised and the activities and the leisure activity selected were often staff selected.

Unlike the environment in Cairn Home, opportunities for self-determined leisure experiences were not investigated nor sought after. Without the presentation of opportunities for self-determined behaviours, the women were unable to develop the skills of decision-making and problem-solving in leisure. Leisure for the women of Elm Home was observed to be staff directed and repetitive. At times, the women’s

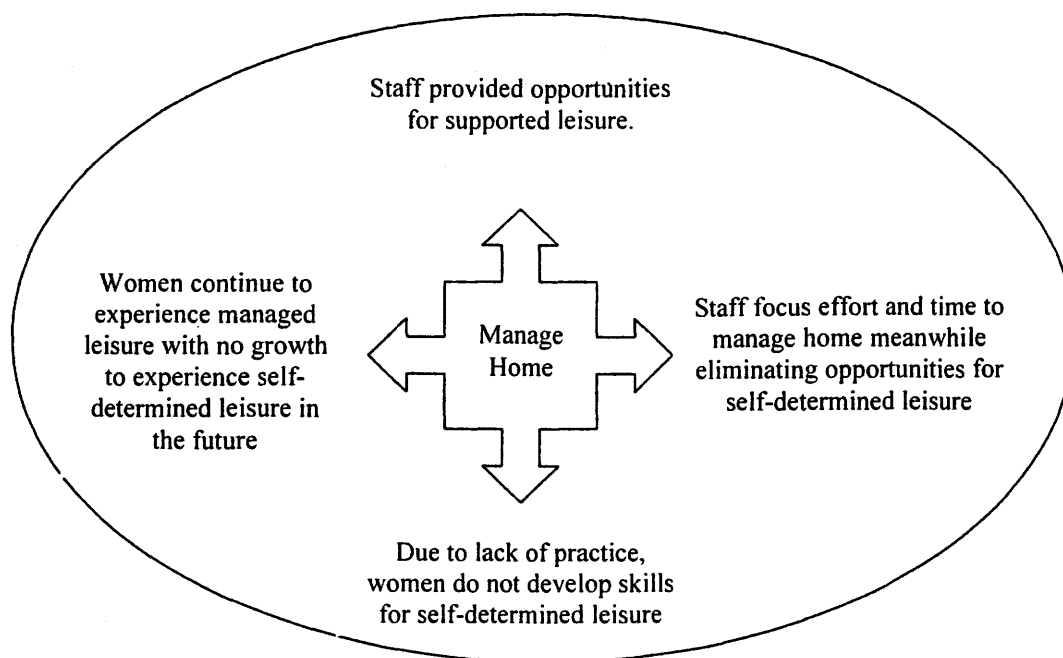


Figure 4.2 Staff of Elm Home view the management of the home as their primary responsibility.

expressions of dissatisfaction with their leisure experiences appeared to be manifested through behavioural outbursts when personal choices were not honored. Leisure was at times associated with feelings of frustration, disappointment, and anger.

In summary, the environments observed in the two group homes were very different, resulting in qualitatively distinct leisure experiences for the women residing there. Although all of the women experienced leisure at home, in the community, and with friends and family, the Cairn Home staff members encouraged self-determined leisure by supporting personal choice, decision making, autonomy, and spontaneity in their leisure. When support was required, it was individualized and faded back as the women became more skilled and confident in newly acquired skills. In contrast, although the women of Elm Home experienced leisure at home, in the community and with friends and family, it was often policy driven which decreased the opportunity for individual

choice, spontaneous and autonomous leisure. The support provided by staff was instrumental to the success of the activities, but the staff did not encourage increasing independence by structuring the environment or teaching skills that would enhance the opportunity for self-determined leisure.

4.1.2 Barriers to the Leisure Experience

Polloway et al. (1996) suggested that people with disabilities have few opportunities to learn the skills that enable them to become self-determined, particularly if supports are being delivered based on the service delivery paradigm in which the daily activities and routine for individuals with intellectual disabilities are programmed by a staff member. Kishi et al. (1988) and Hoge and Dattilo (1995) also identified the lack of opportunity to practice skill development. When programming is in place, there is no need for adults with intellectual disabilities to exercise self-determination because there is no 'room' to do so. A program model to leisure reflects the environment of Elm Home. When the programmer selects activities for the women, there is no opportunity for the women to exercise self-determined leisure behaviours, nor is there reason for them to make decisions regarding leisure. When one 'programs leisure' it becomes more of a recreational experience, a planned activity in which one must adhere to structure, rules, and expectations established by others. Leisure, which is subjective by nature, is lost. When leisure is lost, so are opportunities for choice-making and personal expression. Leisure has then become an experience of 'outcome', rather than of process.

Another barrier to developing self-determined behaviour is the lack of awareness and understanding by service providers (Kishi et al., 1998). Lack of patience when attending to choice making behaviours has also been cited as a constraint (Smith et al.,

2001). Within Cairn Home, skills were being developed to exercise self-determined leisure behaviours because staff provided opportunities for the women to have input into their leisure experiences. Cairn Home clearly engaged the women in processes of choice, decision making, and empowerment that increased control over their lives and involved capacity change within the individual (Arai, 1997).

The staff at Cairn Home developed strategies that enabled the women to make choices during leisure (i.e., Shannon patiently waiting for Jackie to choose the basket to purchase for her mother) and exercise self-determination (i.e., teaching Ina and Beth how to walk to the donut shop). In Elm Home it was difficult for the women to develop the skills for self-determination and feel confident in exercising those skills.

The service provision models of Cairn Home and Elm Home can be identified within the services based paradigm. In this paradigm services are brought to the people who are perceived to require support (e.g., staff supported group housing) with the goal of preparing them for integration into the community through skill upgrading and education. The assumption of this paradigm is that within these contained environments, individuals would learn the skills and behaviours required to be successful outside of their self-contained setting and reintegrate into mainstream society (Polloway et al., 1996). Although the agency governing Elm Home had established an 'informal' policy to ensure the women were experiencing leisure in the community, the leisure in the community was not true leisure because the women seldom chose how to spend leisure in the community. It was not spontaneous or self-determined. The management of the home and the environment created within the home did not provide opportunity for Daria and Brie to experience increasingly independent, and hence empowered and self-determined,

leisure. There did not appear to be an active interest in teaching the self-determined behaviours required to experience increasingly independent, choice driven, decision based leisure. In contrast, Cairn Home actively sought ways to increase independent leisure by providing opportunities for the women to learn the skills of self-determination. The environment encouraged the women to learn and utilize the skills required for a true leisure experience.

4.1.3 Strategies for Self-Determination

In an attempt to engage individuals with intellectual disabilities in self-determined behaviors, Wall and Dattilo (1995) summarized seven strategies to aid in the process, including: (a) include self-determination goals in individual programs, (b) take a 'team-approach' when encouraging self-determination, (c) assess individual preferences, (d) create a responsive environment, (e) provide opportunity for the expression of self-determined behaviour, (f) respond to self-determined behaviour, and (g) teach skills for self-determination). The findings of this study support the efficacy of the strategies. The group home that was most diligent about incorporating the strategies created an environment that resulted in more varied, and more independent leisure with a wider social network.

The strategies supported by the staff of Cairn Home included: (a) involving the women in planning their leisure experiences by allowing them to choose where, when and with whom to experience leisure, (b) identifying individual preferences (one staff person recognized the importance of personal leisure identity beyond that of the group, (c) creating a comfortable environment in which the women could exercise self-determined behaviour and make choices about how to experience leisure, (d) the staff and

women of the home worked together to provide opportunities for self-determination and recognized self-determined efforts, (e) the staff taught the women skills to enable them to be self-determined in their leisure (walking to the coffee shop) and perhaps most importantly, (f) consistently responded to self-determined behaviour that the women presented in the environment. By applying these strategies in the group home environment, the women of Cairn Home were self-determined in their leisure experiences. Also, because there were many times that only one staff person was on duty in the home, there was not enough staff support to continuously guide the women during their leisure. However, the women were able to make choices for themselves and use their leisure time productively.

The difference in the amount of staff support in each home needs to be addressed. As indicated earlier, it was assumed that the 'functioning level' of the women in each home was considered to be equal due to the similarity of vocational programs attended, context in which they lived, communication style, and activity involvement. However, Elm Home employed more staff to support the women, although they may not have required the extra support. Due to the constant support and 'management' of leisure, the women of Elm Home were not required to be independent. Thus, although the women of Cairn Home may have appeared to be higher functioning than the women of Elm Home, they were not. Perhaps the level of functioning of the women in Elm Home actually decreased as the intensity of staff support increased. When one considers the higher level of independence experienced by the women of Cairn Home, it poses the question, "Would the women of Elm Home become more independent if staff support was decreased?"

In Elm Home, due to the need to meet the responsibilities of the home and the policies of the agency, staff had difficulty incorporating strategies to support self-determined behaviour (Wall & Dattilo, 1995). Although the importance of leisure and community leisure experiences were identified within each woman's Individualized Program Plan, opportunities to provide input into those experiences were limited. The women were seldom personally involved in planning their leisure experiences and they were observed to be passive participants in the activities. This appeared to be the norm for four reasons. First, staff questioned the appropriateness of the women's chosen leisure activities. The women demonstrated that they were capable of making decisions regarding leisure, but staff did not acknowledge these decisions. More specifically, some staff questioned the meaningfulness of paper shredding as a leisure activity. Second, staff saw a need to 'manage' the women's leisure activities. More specifically, when they perceived the women to be 'bored' they would offer suggestions for leisure, thus eliminating opportunities for the women to exercise decision-making and problem-solving. This demonstrates that staff did not feel the women could make decisions regarding leisure. Third, staff prioritized the management of the home over the self-determined leisure activities of the women. Staff did not recognize the importance for the women to exercise self-determination and thus did not take the time nor exercise efforts to respond to the women's behaviours, focusing on the management of the home. Fourth, the need to adhere to the outing guideline infringed upon the leisure of the women. At times, the women were forced to experience an outing during leisure when they would prefer to spend time at home. For example, Daria clearly indicated that she did not want to go on a community outing and was required to attend anyway in order to adhere to

agency guidelines resulting in her communicating her displeasure in a public behavioural outburst. The findings support previous research indicating that persons with intellectual disabilities can make choices for themselves (Realon, et al., 1990; Parsons, Reid, Reynolds & Bumgarner, 1990; Parsons & Reid, 1990). Daria's challenging behaviours were, perhaps, in response to a lack of opportunity to choose her own leisure activity, and yet no steps were observed to be taken to modify the policy which had such a negative impact on her leisure.

4.1.4 The Management of Leisure

The nature of the leisure experiences of the women of Elm Home may have been attributable to support staff underestimating the ability of persons with intellectual abilities to achieve their goals. Kishi et al., (1998) and Neumayer and Bleasdale (1996) identified the impact of organization and agency administration on the leisure experiences of individuals with intellectual disabilities. They reported that support staff can underestimate the ability of persons with intellectual disabilities to achieve their leisure goals independently, and thus, are often present during leisure activities. This was observed in Elm Home as a programmer was on shift anytime the women were at home. The mere presence of staff interfered with the women's opportunities to exercise self-determination. This study lends support to Stancliffe's work (1997) suggesting that the less interference individuals with intellectual disabilities experience from staff, the more opportunities for self-determined behaviours will exist. In addition, the women of the home may come to learn, if they have not already, that staff are required to experience leisure and will rely solely on staff to determine what activities to partake in. Thus, any future leisure endeavors of an independent nature are unforeseeable.

Pedlar et al. (1999) identified the difficulty individuals who reside in group homes may face when attempting to express leisure preferences. At times, there are not enough staff to accommodate the interests of each individual, so leisure may often be experienced as a group. Staff of Cairn Home recognized that it was of great importance for each woman to develop an identity of herself, and the activities that are engaged in alone held more meaning for the women when they were independent from the group. They engaged in activities of personal interest to them, they created a personally pleasing environment, and experienced leisure with those who were most important to them. This stresses the importance of allowing persons with intellectual disabilities to express and exercise their own leisure interests and develop an identity for themselves. Experiencing the benefits of making one's own choice further develops one's own identity in that personal interests are freely expressed.

In Elm Home, programmed activities and the need to adhere to policy of the Individualized Program Plans interrupted the flow of the leisure experiences of the women. The women did have opportunity to provide input into their experiences (i.e., choosing where to go during leisure such as to the library and shopping), but this input was 'managed' according to the needs of the home. When the activity took place (the date and time of day), who would attend (which individuals in the home needed to meet their weekly outing requirements), and who would be in charge of the 'specifics' of the experience were outside of the control of the women (who would carry the money and parcels while shopping). Although Daria and Brie required support to experience leisure in the community, Natasha (programmer), identified the frustration and exhaustion she experienced when she felt she had to always "support" the women during their leisure,

particularly in the community. Perhaps with more opportunities to freely choose one's leisure, both the women and the staff would experience less stress during 'down time' at the home because the women would have opportunity develop the skills required to respond to their leisure environment.

Nirje (1972) argued that for persons with intellectual disabilities to experience and freely choose leisure activities, they must develop self-confidence through authentic experiences within the home and the community. Furthermore, these authentic experiences must not occur solely in the presence of other individuals with intellectual disabilities (Glausier et al., 1995; Hayden et al., 1992; Mahon & Martens, 1995). Thus, due to the availability of authentic experiences for the women of Cairn Home the women developed confidence in their self-determined leisure skills. In contrast, the women of Elm Home had fewer opportunities to develop confidence through authentic experiences.

In closing, this study demonstrates the importance of leisure as a teaching tool for self-determined behaviours. Leisure is an important facet of one's life (Dupuis & Smale, 1995). One can experience the consequences of decision-making, problem-solving, and self-realization in a meaningful aspect of one's life. In addition, exercising self-determined leisure behaviours in a group home is of importance when one considers the amount of time that an individual spends with others in that particular environment. Because of this, it is important to understand the meaning that is ascribed to the leisure experiences of those who live in group homes. Perhaps once the importance of leisure is recognized for these individuals, support workers will be more willing to provide opportunities for people with disabilities to experience self-determined leisure.

4.1.5 Implications for Delivery of Supports and Future Direction

This study brings many issues to light regarding the current support practices of professionals working the field. First, although policy is developed to protect agencies, employees, and the individuals whom receive support, administrators must consider the importance of developing person-centered policies and practices that realize the rights of choice for people with disabilities. It would be beneficial to consult the people who receive the support to ensure their best interests are being taken into consideration. It is also important for administrators, particularly those who are not on the ‘front-line’ everyday, to witness the repercussions of agency policies. Administrators who adhere to the adage, ‘no news is good news’ and rely on staff to inform them of problems in the homes may be making assumptions regarding the well-being of those the agency supports.

Second, staff should receive training on the rights of people with disabilities and recognize the importance of respecting these rights. In addition, staff training on Supported Decision Making (Bodnar & Coflin, 2001), a program that educates service providers about strategies to involve individuals with intellectual disabilities in the process of decision-making, would be of benefit. This training would ensure that (a) everyone is aware of the importance of decision-making and (b) how to deliver this support in a non-biased, objective manner (i.e., not tainting the individual’s choice with their own preference or ‘stamp of approval’).

Third, by making people with disabilities aware of their rights to experience self-determined leisure, they may be more able to identify and seize opportunities available to them. Furthermore, they may be more sensitive to opportunities that are *not* provided or

are removed from their environment. Through their own actions, people with disabilities may make service provider accountable for their actions rather than waiting for the agency director to recognize pitfalls in service provision.

Fourth, the development of leisure skills will have a direct impact on the quality of life for persons with intellectual disabilities as they retire from their places of work. This is the first generation of people who will reach the age of retirement in supported employment placement. It is imperative that leisure skill development begin early in life and be maintained as people age and interests change. Waiting until retirement may be too late and only perpetuate limited and infrequent leisure experiences (Glausier et al., 1995). In my community, I have witnessed the difficulty older adults with intellectual disabilities face as retirement approaches. It is important to create an environment that acknowledges and respects the self-determined behaviours of those who wish to determine their own leisure, for retirement consists of leisure. I cannot help but think of Daria, who described “sitting around” as an activity to do when there is no one present to guide her through her leisure. What will her retirement experience be?

Of particular importance, is the development of relationships with people beyond those they experience at the workplace. Sutton et al., (1993) found that individuals working in supported employment environments, such as the women of this study, found their workplace a major source of friendships. But, once retirement arrives, this source of friendship quickly dissolves and opportunities to connect with others are lost. Research on the lived leisure experiences of retirement could provide insight into the leisure experiences of older adults with intellectual disabilities. Do they feel leisure development is important? Is it important to have choice of leisure activities? What, if anything, has

prepared them for their retirement years? What anticipation do they experience as they approach retirement? If friendships at work are valued, how or will social connections be maintained with those who are still employed? Finally, how does the development of friendship support the notion of self-determination? Do relationships provide opportunity to develop the skills and attitudes required for self-determination? With this information, service providers may gain valuable insight into how to best support these individuals before and after retirement.

Perhaps the best support we could provide is to offer these individuals a lifetime of encouragement and education for self-determination while understanding that empowerment cannot be forced upon someone. Whereas it is imperative to provide opportunities to engage in self-determined behaviours, it is also essential to recognize that, ultimately, it is one's choice to engage in self-determination and respond to empowerment. We cannot assume that every person with a disability wants to, or needs to, be empowered. However, encouragement of the tenets of self-determination, as shown in this study, does enhance leisure experiences. Providing environmental tools (e.g., leisure equipment for participants and outlining strategies for enhancing self-determination to be used by staff) so one can enhance leisure experiences may eliminate the need to establish a 'program' in response to the changing landscape as individuals with intellectual disabilities approach retirement. However, what is most important is to educate both staff and people with disabilities about the right to choice, the importance to develop leisure skills, and the value of self-determined leisure experiences.

4.1.6 Considerations for Future Investigation

Further insight into the leisure experiences of the women with intellectual disabilities would have been gained had data collection occurred over the

changing seasons of the year. At the time of data collection, it was fall and winter was approaching. Leisure activities may, and often do, change from season to season. Perhaps there would have been more opportunity to be outside and fewer barriers to access the community had the weather (which was cool), daylight hours (which were limited), and inaccessible walkways (which at times were snow and ice covered) been more conducive. As the range and depth of the women's leisure experiences may have varied by season, the extent to which they experience independent and staff supported leisure may also have varied. As readers, we may recognize that everyone in society experiences these constraints. However, more detailed planning and increased staff support may be required to overcome seasonal constraints to leisure for persons with intellectual disabilities. A particularly interesting time to spend with the women would be during their summer holidays when they are away from work for three weeks. This would have provided insight into how the women responded to substantial quantities of leisure time and, perhaps, how thoroughly developed their self-determined skills for leisure truly were.

It would also be of value to speak to the families of the women to clearly identify the role they play in the leisure experiences of the women. The importance they place on leisure for their daughters and sisters and the meaningfulness of the visits and phone calls could be gathered from the perspectives of family. It is also important to note that although the women in both homes experienced time with family, other factors may have affected the interactions they had with loved ones. Perhaps the age of the family members, career and domestic responsibilities, and how important one perceives family to be may influence these interactions. This study brought awareness to the

meaningfulness and frequency of leisure with family and friends, however the dynamics of these interactions and their impact on leisure were not thoroughly investigated.

A study is also needed that examines the culture of a home and how it is affected as employees come and go. Leadership qualities of the house managers may very well define the culture within the homes. Group home staff who have not yet made the transition to the paradigm of empowerment (Polloway et al, 1996) and continue to believe that people with disabilities should receive 'services' from staff may influence the work ethic and philosophy of young, impressionable pre-professionals in the field or create tension between staff members as was observed in Elm Home.

Staff transition is inevitable in the field and employees with new ideas may initiate change and, perhaps, even facilitate a paradigm shift within a home such that a service based model gives way to an empowerment model of group home procedures (Polloway et al, 1996). Furthermore, with a change in ideology, people with intellectual disabilities will experience opportunity for growth and development of skills for self-determination, thus creating more independence in their lives. However, in order to determine the influences on such a paradigm shift, an ethnographic approach in which the researcher spends time immersed in the culture of a group home, would be required. This approach would also provide insight into the behaviours, interactions, and the life experiences of and between group members and would provide a more in depth, rich understanding of the influence of group home norms, staff belief systems, and policy on leisure.

4.1.7 Final Thoughts

In summary, the leisure experiences described can only be understood within the contexts of the two homes examined within this study. This study does, however, raise the importance of leisure for those living in group homes and how it provides a vehicle for the expression of self-determination and how it can impact the quality of life of persons living in group homes. It calls to the need for researchers, educators, pre-professionals, staff, and administrative agencies to reflect upon and evaluate their service practices, identify the assumptions they hold about the people they support, and implement strategies that will advance the empowerment of people with intellectual disabilities. More attention needs to be given to the importance of providing opportunities for individuals with intellectual disabilities to make choices regarding their leisure experiences, thus better preparing them for a lifetime of meaningful and enriching leisure. People with intellectual disabilities are rightfully deserving of a satisfactory leisure lifestyle (Hawkins, 1993; Mahon, 1995).

If I had to do it all over again, there are a few changes I would make. The photographs the women took, which were used to elicit conversation regarding their leisure experiences, were disappointing in that they did not turn out as well as hoped. Although convenient and inexpensive, the cameras required a flash to be activated (by pressing a small button on the front of the camera for approximately 10 seconds) for indoor photos. Many of the photos the women took were very dark and underexposed. The cameras also needed to be manually advanced (by turning a small dial to the next frame) before the next photo could be taken. Finally, the viewfinder was quite small and I found that even I had difficulty focusing my 'subject' within the frame provided. Several

of the photos the women took did not contain the items they were intending for the photo (e.g., only a portion of the chosen item was in the photo). To remedy this, it might have been beneficial to take the photos for the women, as they asked, with a higher quality camera. Or, perhaps a higher quality camera could have been left with each home and the women could have taken turns using it as needed.

Another change I would make would be the member checking process that was used for the women. Although strategies were used to confirm their comprehension of the results, I cannot ascertain that they truly understood the ideas as they were presented. Perhaps asking the women to repeat, or state in their own words, what they understood the findings to mean would have provided stronger evidence for their understanding. Or, perhaps the member checking process could have been carried out a second time to further explore their understanding of the themes.

At this time, I would like to share some personal thoughts. This thesis has been a journey. Not solely an academic journey toward the requirements for a Master's degree, but a journey in which I came to better understand who I am as a person, and identify more clearly my working philosophy. Previously in my career development working with persons with intellectual disabilities, I was an observer. I saw what behaviours were demonstrated and developed my own ideas as to what provoked particular actions or responses, perhaps even making unfair assumptions regarding the experiences of people with intellectual disabilities (i.e., assuming that "nothing" was experienced during leisure because they had limited leisure resources such as finances, transportation, partners, etc.). This study has enabled me to have a greater understanding of the leisure experiences of those with intellectual disabilities. I became aware of what steps had to be taken, by the

women and the support staff in their lives, to ensure leisure was experienced. I developed a greater awareness of the role staff played in the women's leisure experiences. I found it interesting that even though staff support is essential for the women to experience leisure, the degree of that support is key in determining the meaning of the experience. 'More' is not always better.

I continue to be involved in the field and make an effort to become involved whenever and wherever I can. I volunteer for sport days for youth with disabilities. I provide guidance to group home agencies who feel they are in need of a 'fresh' approach to service provision. I sit on advisory committees guiding new and exciting leisure and recreational programs for people with disabilities. Specifically, one committee that I volunteer with is the 'Supporting Retirement Program'. This program was designed to provide support to older adults with disabilities in the community. Our approach is unique in that we did not develop a 'program' in order meet the needs of retiring older adults with disabilities, but to assist older adults with disabilities to access already existing community-based programs. The participants of our program access the same leisure and recreational resources and facilities that any of their peers (without disabilities) would. We simply provide support in the older adult community if they require it. This support for older adults with disabilities is essential, for some require assistance to understand, accept, and fulfill the new found leisure in their lives when retirement approaches.

New participants to the program are somewhat timid. They have entered the unfamiliar (and somewhat feared) territory called 'retirement'. For some, only a few days ago, routine dictated the course of their days. Suddenly, schedules are insignificant. The

only concern they have regarding 'time' is how to fill it. The women of this study are only a few years from retirement. In fact, Beth's caregivers and family have recently expressed concerns regarding Beth's future. They have noticed that, albeit slowly, Beth's health is failing. Currently, she continues to attend work everyday, but she moves a lot slower and, at times, requires a wheelchair for mobility when she is in the community. Age does not discriminate and the women of this study are no exception. It is only a matter of time before all of the women of this study will experience the aging process. Their work will be affected, and they may be asked or required to work shorter days, or shorten their work week altogether. When this occurs, it is inevitable that retirement, and a wealth of leisure, will find them. When I reflect on the leisure experiences of the women in this study, I ask myself, 'Where will these women be in a few years? What will they be doing? What will they do for *leisure*?' Because everyone is entitled to a satisfactory, fulfilling leisure experience, I can only hope that in the company of staff, family and friends, these women will have the most pleasant, pleasing experiences they ever imagined.

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5.1 Appendix A

Agreement to Participate (Women)

You are invited to participate in Brenda's school project.

It is your **choice** if you take part in Brenda's project.

It is okay if you decide not to take part.

Why is Brenda working on this project?

Brenda is doing this study to learn more about what I do in my leisure time. For example, how do I experience leisure? What opportunities do I have to contribute to my leisure choices and experiences? What meaning do I give to those opportunities?

What will happen if I decide to take part in this project?

If I decide to take part, Brenda will interview me 6 times for 10-15 minutes each time. Brenda will ask me questions about what I do in my free time or during 'rec'. If I feel uncomfortable at any time, I can say "I do not want to answer that question" or "I do not want to take part in this project anymore". No one will be angry or upset with me.

During fall, from **September to November**, Brenda will be spending time with me at my house and on outings during 'rec'. If at anytime I do not want Brenda to spend time with me at my house or on outings, it is okay to tell someone. No one will be angry or upset with me.

Only if I say it is okay, Brenda will take pictures of me at my house and on outings. She may also ask to see photos that I have of myself doing activities that I like. If I do not feel comfortable having my picture taken, showing my pictures to Brenda, or allowing Brenda to use them for her presentation, it is okay to say "No". No one will be angry or upset with me.

Confidentiality

Everything I do and say will be kept private. Only Brenda and her teacher will know what I have said or done during my time involved in the research project. **My real name will not be used in Brenda's schoolwork or presentations.**

Will anything bad happen to me?

Brenda's teacher and her school have given her permission to work on this project. They guarantee that nothing bad will happen to me if I decide to take part in this project.

My right to stop participating.

It is my choice to take part in this study. **If I decide that I do not want to continue to take part in this study, I can tell Brenda. Nothing bad will happen to me and no one will be upset with me.** Brenda will destroy all of the information she has about me. Also, if Brenda feels that helping with her project is interfering with my other jobs, chores, or

activities (e.g. work, Special Olympics) then she can decide that I can no longer participate.

Questions

If I have any questions about this project I can ask Brenda. I can also contact Brenda's teacher, Donna, at 306-966-6513. The Office of Research Services at the University of Saskatchewan in Saskatoon can answer any questions I have about my rights. Their phone number is 306-966-2084. The University of Saskatchewan Behavioural Science Research Ethics Board approved this research on July 8, 2003. Brenda has given me and the house supervisor a piece of paper with these important phone numbers so I can call her anytime I want to talk to her about helping with her project.

Consent to Participate

I understand the information provided above. Brenda has answered any questions that I have. I agree to participate in this study and understand that I am able to stop participating whenever I want.

I also give permission for the pictures I provide to be used under the following circumstances:

- _____ Only Brenda and her teachers are allowed to see my photos.
- _____ My pictures can be used for Brenda's schoolwork as long as they do not reveal who I am (e.g. show my face).
- _____ My pictures can be used for Brenda's schoolwork. It is okay if my face is in the picture.

Participant Name _____

Verbal Consent to Participate Given ____ Yes ____ No

Date _____ Time _____

Place _____

House Supervisor Present ____ Yes ____ No

Signature of House Supervisor _____

Date _____ Time _____

Signature of Executive Director _____

Date _____

Signature of Researcher _____

Date _____

5.2 Appendix B

Historical Sketch Form

Name_____

Address_____

Phone Number_____

Birthday_____

Number of Years at Current Residence_____

Previous residence was:

(a) With family members

(b) group home

(c) private approved home

(d) institutional setting

What is the residential history of the participant?_____

Where do family members currently reside?_____

Is family contact valued by this participant?_____

How often does participant have contact with family members?_____

5.3 Appendix C

Interview Guide (Women)

1. What do you do when you get home from work?
 - b. Before supper, I...
 - c. After supper, I...
2. What did you do this past weekend?
 - a. Did you...watch TV?...listen to records?...go shopping?...visit with a friend or family member?
 - b.
 - c. Was anyone with you or were you by yourself?
 - d. What would you have liked to do that you didn't?
3. When you get dressed for work in the morning, how do you decide what you are going to wear?
 - a. How do you decide what you are going to wear to the bowling banquet or dances?
4. How do you decide what you are going to eat for breakfast in the morning?
5. How do you decide what you are going to pack for lunch at work?
 - a. How do you decide when you are going to buy lunch at work?
6. How do you decide what to spend your money on?
 - a. Where do you like to go shopping? Why?
 - b. What do you buy when you go shopping?
7. What does it mean to you when I say 'free time'?
 - a. What is 'free time'?
 - b. When would you have free time?
 1. When you get home from work?
 2. When you have holidays from work?
 3. On weekends?
8. When do you have 'free time'?
 - a. Do you always have 'free time'?
9. What do you do when you have a day off from work?
 - a. How do you decide what you are going to do?
10. What do you do during your summer holidays?
11. If you could pick any activity to do in your day off from work what would it be?

- a. Have you ever seen somebody do something that you would like to do?
 - b. Would do this activity with someone? Who would it be? Why?
12. What personal items do you have that would tell me what your interests are?
- a. A movie collection?...Crafts?...Books?...Photos?
13. How do you feel when you have free time/a day off from work?
- a. Happy?...Scared?...Excited?...Worried?...Proud?
14. What do you do that really makes you smile, laugh, and feel happy inside?
15. If you could make a commercial for T.V. what would it be about? Who would be in it? What would you do?
16. Where do you spend most of your free time?
- a. In your house?...Where?
 - b. In the community?...Where?
17. How would you feel if you did not have free time?
18. Tell me something that might stop you from enjoying your free time.
19. If your favorite person was coming to visit with you for a day, and you could do anything that you wanted with that person, what would you do?
20. If you could plan any holiday, what would you do? Where would you go? Who would be with you?

5.4 Appendix D

Interview Guide (Group Home Staff)

1. How do you define free time?
 - a. Describe how the women you work with spend their free time.
2. How do you define leisure?
 - a. Do the women require support in choosing leisure activities?
 - i. If no, describe why not.
 - ii. If yes, describe what kind of support they required and how they get this support.
3. What do you like to do in your free time?
 - a. Do your leisure experiences influence the leisure activities of the women you work with?
4. What factors influence the free time activities of the women?
 - a. Money? Staff availability? Time constraints? Weather?
5. Are the women afforded opportunities to make choices with respect to how their free time is spent?
 - a. When do these opportunities occur?
 - b. How do you know, as a support person, when to pull back support and when to reach out?
6. Do you feel that the women think that having the opportunity to make free time choices is important?
 - a. If yes, describe a time when they indicated it was important.
 - b. If no, how did they reveal this? What was their behaviour? What did they say?
7. What do the people you support get out of their current leisure experiences?
8. What meaning do the women you support ascribe to their current leisure experiences?
9. What risks and benefits do you see for the women when they experience leisure?
10. How do you think the women would answer these questions?
 - a. If your favorite person was coming to visit with you for a day, and you could do anything that you wanted with that person, what would you do?
 - b. If you could pick any activity to do in your day off from work what would it be?

5.5 Appendix E

Transcript Release Form

College of Kinesiology
University of Saskatchewan

Transcript Release Form

Title of the Study: Self-Determination and the Leisure Experiences of Women with Intellectual Disabilities Living in Two Group Homes

Researcher:

Brenda Rossow-Kimball

I, _____, have reviewed the complete transcript of my personal interview in this study, and have been provided with the opportunity to add, alter, and delete information from the transcript as appropriate. I acknowledge that the transcript accurately reflects what I said in my personal interview with Brenda Rossow-Kimball. I hereby authorize the release of this transcript to Brenda Rossow-Kimball to be used in the manner described in the consent form. I have received a copy of this Data/Transcript Release Form for my own records.

Participant

Date

Researcher

Date

5.6 Appendix F

Ethics Approval



UNIVERSITY OF SASKATCHEWAN BEHAVIOURAL RESEARCH ETHICS BOARD

<http://www.usask.ca/research/ethics.shtml>

NAME: Donna Goodwin (Brenda Rossow-Kimball)
College of Kinesiology

BSC#: 03-1032

DATE: July 2, 2003

The Behavioural Research Ethics Board has reviewed the revisions to the Application for Ethics Approval for your study "Opportunities for Personal Input Towards Leisure Experiences in the Lives of Women with Intellectual Disabilities" (03-1032).

1. Your study has been APPROVED.
2. Any significant changes to your proposed method, or your consent and recruitment procedures should be reported to the Chair for Committee consideration in advance of its implementation.
3. The term of this approval is for 5 years.
4. This approval is valid for five years on the condition that a status report form is submitted annually to the Chair of the Committee. This certificate will automatically be invalidated if a status report form is not received within one month of the anniversary date. Please refer to the website for further instructions: <http://www.usask.ca/research/behavrsc.shtml>

I wish you a successful and informative study.

Dr. David Hay, Acting Chair
University of Saskatchewan
Behavioural Research Ethics Board

VT/ck