This dissertation is dedicated to the athletes of Special Olympics Nebraska and Special Olympics Florida, who inspired this project.
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The aim of several human service professions is to enhance the quality of life of individuals with developmental disabilities, through the use of interventions such as recreation and leisure services. These services are often based on the Normalization Principle. The concepts of quality of life and leisure are subjective in nature, and therefore are interpreted indifferent ways by different people. The purpose of this study was to determine how young adults with developmental disabilities perceive their own leisure experiences.

Semi-structured, face to face, in-depth interviews were conducted with ten individuals (ages 21 to 32 years) who have developmental disabilities. Each participant was interviewed twice. In addition, the parent or parent(s) of these individuals were interviewed. All ten of the participants in this study live, work, and play in a variety of settings with different levels of support. All of them are white; live in an upper-middle-
class, suburban area of a moderate-size city in the heartland of America; and have supportive families.

Using constant comparison, several themes emerged from the data. The two most prevalent themes suggest that the leisure experiences of these individuals are existential and social in nature. These young adults with developmental disabilities seem to establish a hierarchy of preferences regarding activities and social interaction. Most of the participants in this study prefer spending time with friends and family.

Grounded theory and symbolic interactionism were used to guide this study. The leisure experiences of this population appeared to be based on the interactions that these individuals have with others, which is consistent with the ideas of symbolic interactionism. Grounded theory was used to generate a model that describes how the leisure experiences of this population involve internal and external dimensions. Overall, the leisure experiences of young adults with developmental disabilities reflect the leisure experiences of young adults without developmental disabilities.
CHAPTER 1
INTRODUCTION

In America, there are approximately seven million individuals with a developmental disability such as: mental retardation, autism, Down syndrome, or cerebral palsy (ARC, 2004). These individuals with developmental disabilities have values, preferences, and a desire for happiness. Over the years, many people have developed stereotypes and clinical labels, in order to describe this population. These descriptors, however, tend to mask individual differences and abilities, thereby allowing society to hinder the individual’s ability to reach his or her potential. To counter society’s perceptions, services have been designed to minimize differences, to expose abilities, and to enhance quality of life. Many of these service providers use recreation and leisure interventions to meet these goals. My study explores the subjective nature of leisure from the perspective of individuals with developmental disabilities.

This study uses a case study approach to examine this phenomenon, in a unique community embedded within a state known to provide innovative services for individuals with developmental disabilities. A variety of programs have been used by members of this community to enhance quality of life. These programs include: residential services, vocational services, special education services, recreation programs, parental support and advocacy services, and community outreach, education and awareness programs. National corporations that offer residential and vocational services to this population (i.e., Bethage, Martin Luther Homes) developed within this state. Special education programs within the public school systems were initiated decades before the implementation of
Public Law 94-142. Disability awareness programs such as The Kids on the Block puppet shows are prevalent throughout the community. The state had one of the first chapters of Special Olympics. Likewise, there are other recreation opportunities such as camps and sports leagues available for this population. I grew up in this community. I was the product of these disability awareness programs. I worked in the schools and the recreation programs.

This case study uses a variety of qualitative research methods to describe the leisure experiences of young adults with developmental disabilities who live in this community. A qualitative study recognizes the role of the researcher, and acknowledges his or her subjectivities. Every study begins when the researcher identifies a problem or an issue which the researcher feels is important. The researcher begins to explore this problem or issue from a perspective based on personal experiences and values. The researcher adopts a method that best helps explain and describe the issue at hand. Throughout this project, I will use both first-person and third-person terminology to describe the role of the researcher. First-person terminology is used to emphasize those situations where my subjectivities might influence this study. Therefore, this chapter begins where my interest in this topic began, and it explains the process through which this study came to fruition.

The Problem

I was guest lecturing a few weeks ago on therapeutic recreation for people with developmental disabilities. At the end of the class, one of the students approached me. “Do you consider me to have a developmental disability?” she asked. The student, who was driving an electric scooter, told me that she had cerebral palsy. I thought about her question for a few moments and gave an ambivalent response. After all, there are clinical
definitions, like the one I used when I proposed this study nearly a year ago; and, there are stereotypes, our own perceptions of a label based on experiences.

**Stereotypes**

My response to her question is as follows. “I know clinically, that cerebral palsy can be a developmental disability if it impairs functional skills in a few areas of life.” I did not mention the idea of developmental onset because she was a young adult and it not seem important at the time. I knew that was not what she wanted to hear, so I continued. “But in my mind, I tend to think about developmental disabilities in terms of cognitive delays. I worked at a camp for children with developmental disabilities during high school and college, and several of my co-workers had cerebral palsy or spina bifida — I never considered my co-workers to have developmental disabilities. For the most, part they had physical disabilities,” I explained.

This response reflects on stigma associated with developmental disabilities. I often hear wheelchair athletes say “I am not a Special Olympian, I’m not retarded.” They continue to differentiate themselves from individuals with developmental disabilities stating, “I’m an athlete . . . I’m not in it for hugs.” This particular student with a physical disability didn’t make statements such as these. She was just looking for me to tell her what label I associated with her. I do not know if she viewed one label as being more positive than the other. We didn’t discuss the connotations associated with these labels.

Therefore, I didn’t point out the similarities between myself and individuals with developmental disabilities. I didn’t talk about how we all have needs, wants, and desires. I didn’t talk about how we all feel happy and sad; how we all experience love, fear, joy, pain, hope and despair. I didn’t talk about our commonalities. I assumed that this student knew this; after all, I was labeling her a “therapeutic recreation” student. I assumed that
therapeutic recreation students were empathetic and accepting. If I was talking to a
different audience, I would emphasize these commonalities in hopes of breaking down
some of the negative stereotypes associated with the labels of “developmental disability,”
“mental retardation” and “Down syndrome.” The perceptions that some people have
regarding these labels can mask the abilities of individuals who have one of these
disorders.

A few years ago, I was working with a boy who had Down syndrome. For the
purposes of this example, I will call him Billy. I was hired to help facilitate an inclusion
program within a general recreation program for individuals without disabilities. Billy
was an excellent swimmer; he swam laps with proficiency using a picturesque freestyle
form. On our first day at this general recreation program, the lifeguards conducted a skills
test on all of the children, including Billy. Billy passed the test and the lifeguards told
Billy that he could swim anywhere in the pool. Later in the afternoon the director of the
recreation program visited the pool. He was shocked to see Billy in the deep end of the
pool. He vetoed the lifeguard’s initial decision, and instructed us that Billy was only
allowed to play in the shallow end of the pool. We protested his decision, and educated
him on Billy’s abilities. Eventually, through our advocacy efforts, Billy was able to swim
anywhere in the pool. The director’s preconceptions were consistent with stereotypes
perpetuated throughout society.

Several stereotypes associated with the labels of developmental disabilities have
been perpetuated over the years. Many people view individuals with developmental
disabilities as being helpless; and therefore people pity them, and want to take care of
them (Devine, 1997; Funk 1987; Hey & Willoughby, 1984). People with mental
handicaps are stereotyped as being incapable of thinking, speaking, and acting for themselves (Dudley, 1987). Danforth and Navarro (1998) found that people use the term “mental retardation” when people describe a group of people, things that are “abnormal”, special places, and people of whom they are afraid.

As society embraces stereotypes such as these, people associated with a given label (e.g. mental retardation) are stigmatized (Goffman, 1963; Bedini, 2000). Bedini suggests that stigma breeds animosity, pity or fear; which can be one of the greatest barriers to pursuits of individuals with disabilities. She implied that as people resist perceived stigma, they strive to make interactions in the community more acceptable.

Other have suggested that stigmatization can be reduced, if labels such as mental retardation are deconstructed and eliminated. Kauffman (1999, 2003), however, suggested that in some instance, removing labels can mean removing services. He suggested that labels exist for a reason – people have special needs, and they receive special services to address these needs. Labels (e.g., mental retardation, developmental disability) have been used by professionals who provide education, health care, and other human services to individuals with special needs.

**Clinical Definition**

The National Association of Developmental Disability Councils (NADDC, 2003) defines a developmental disability

- As a severe, chronic disability of a person five years of age or older,
- Attributable to a mental or physical impairment or combination of mental or physical impairments;
- Manifested before the person attains age twenty-two;
- Likely to continue indefinitely;
- Resulting in substantial functional limitations in three or more of the following areas of major life activity: self-care, receptive and expressive language, learning,
mobility, self-direction, capacity for independent living, and economic self-sufficiency

- Reflecting the person's need for a combination and sequence of special, interdisciplinary, or generic care, treatment, or other services which are of lifelong or extended duration and are individually planned and coordinated, (except that such term, when applied to infants and young children means individuals from birth to age 5, inclusive, who have substantial developmental delay or specific congenital or acquired conditions with a high probability of resulting in developmental disabilities if services are not provided).

The term developmental disability is a collective term used to describe a variety of disabilities, including mental retardation, Down syndrome, autism, and cerebral palsy.

The NADDC, and other organizations (e.g., The Association for Retarded Citizens, ARC; and The American Association for Mental Retardation, AAMR) advocate for people with developmental disabilities.

As previously mentioned there are approximately 7.2 million people with mental retardation or a related developmental disability (ARC, 2004). During the 2001-2002, academic year, approximately 26% of the students (ages 18-21 years) who received special education services, had either mental retardation or autism (IDEA data, 2003).

**Quality of Life**

On behalf of individuals with developmental disabilities, organizations (like those mentioned earlier) advocate that people with developmental disabilities have access to (and opportunities to excel in) employment, education, and community living. In turn, agencies strive to provide services that enhance these individual’s quality of life.

Quality of life is a complex and abstract phenomenon. Despite being a complex concept, the goal of many health care, human service, and education professions is to enhance the quality of life of their clients (Iso-Ahola, 1980). The concept of quality of life is used by these professions when planning and evaluating services for people with disabilities (Dennis, Williams, Giangreco & Cloniger, 1993; Halpern, 1993). Several
studies have examined how the phenomenon of quality of life pertains to the lives of individuals with developmental disabilities (Fisher, 1991; Goode, 1990; Malik, 1988; Schalock, Harper, & Carver, 1981; Schalock, 1990a; Schalock et al, 2002). Traditionally, leisure services have been used as a means to enhance the quality of life (Coyle, Kinney, Riley & Shank, 1991; Iso-Ahola, 1980; Leitner & Leitner, 1996; Romsa, Bondy, & Blenman, 1985).

Much of the quality of life literature (e.g. Dennis et al, 1993; Halpern, 1993; Heal & Sigelman, 1990; Schalock et al., 2002) suggests that the phenomenon is conceptualized in a variety of ways. People all have different ideas of what quality is. People define their quality of life based on “expectations and hopes which are chiefly the result of the social environment in which they live,” and they revise these expectations based on “what they have seen and heard others to have or to be” (Iso-Ahola, 1980, p. 392). Flanagan (1978) examined 15 factors that defined quality of life. These 15 factors were grouped into 5 dimensions. Of these 15 factors, 6 areas (material comforts, health, work, active recreation, learning, and creative expression) were highly correlated with overall quality of life. Flanagan’s work serves as the foundation for much of the work addressing the issue of quality of life (Dennis et al., 1993; Fisher, 1991; Heal, Khoju & Rusch, 1997; Iso-Ahola; Keith, 1990; Schalock, 1990b)

Others (Iso-Ahola, 1980; Dennis et al., 1993) have suggested that quality of life is characterized by feelings of happiness, life satisfaction, and psychological well-being. Halpern (1993) suggested that physical and material well-being, performance of adult roles and personal fulfillment are three basic domains of quality of life of people with
disabilities. Recently, a panel of experts examined the conceptualization of quality of life (Schalock, et al., 2002). Schalock et al., (2002) stated that quality of life:

- Is composed of those same factors and relationships for people with intellectual disabilities that are important to those without disabilities;
- Is experienced when a person’s needs and wants are met and when one has the opportunity to pursue life enrichment in major life settings;
- Has both subjective and objective components but is primarily the perception of the individual that reflects the quality of life he/she experiences;
- Is based on individual needs, choices, and control; and
- Is a multidimensional construct influenced by personal and environmental factors, such as intimate relationships, family life, friendships, work, neighborhood, city or town of residence, housing, education, health, standard of living and the state of one’s nation. (p. 460)

Several models of quality of life consider leisure to be a domain of quality of life (Flanagan 1978; Halpern, 1993; Heal et al, 1997; Stark & Goldsbury, 1990). If quality of life is directly related to the amount of control a person has over his or her own life (Iso-Ahola, 1980; Fisher, 1991; Wehmeyer & Schwartz, 1998), and if self-determination and intrinsic motivation are concepts associated with leisure (Iso-Ahola, 1980, 1999; Mannell & Kleiber, 1997; Wearing & Wearing, 1988;), then it seems that leisure and quality of life would be a natural fit.

**Leisure**

Like the concept of quality of life, leisure is a complex phenomenon. Many definitions of leisure have been proposed over the years. Leisure has been viewed via a temporal perspective. Most lay people perceive leisure as being *free time*. Brightbill (1960) uses two measures of free time: time that is free from work, and time that is freely chosen. A second definition of leisure is based on the notion that leisure is an experience that can occur anywhere, at anytime. DeGrazia (1962) and Pieper (1963) embrace this notion, by calling leisure a “state of mind.” This state of mind involves feelings of
positive affect (enjoyment), and relative or perceived freedom. They postulate that anytime we have these feelings, we can experience leisure. The *classic definition* of leisure is also hard to measure. The *classic definition* of leisure, as postulated by Aristotle, discusses the concept of schole (de Grazia). Arististole’s definition is based on a notion that leisure is a means by which we contemplate, we seek self-fulfillment, we learn for the sake of learning (de Grazia, 1962). Other scholars (Godbey, 1990; Kelly, 1999) claim that leisure is one of life’s domains; a social institution in and of itself, much like school, work, family, and church. Rather than define leisure as an institution, scholars such as Veblen (1899) postulates that leisure choices are related to social class, race, and occupation. Veblen describes the bourgeois class as the leisure class. He suggests that they embody the idea of freedom of choice, and are able to attend school only if they want to, work if they want to, and play if they want to. Veblen uses the term “conspicuous consumption” to describe the elaborate use of products to display the leisure lifestyle of this class of people.

Leisure is a difficult concept to define, because it is a subjective experience (Mannell, 1999). Leisure means different things to different people. Furthermore, the leisure experience is a complex process, and as such is difficult to measure. Therefore, Coalter (1999) suggests that it is time to attempt to understand the meaning of leisure.

Over the years, the subjective nature of the leisure experiences has been examined among men and women and the young and the old. However, there little research has been conducted regarding the subjective nature of the leisure experience of young adults with developmental disabilities. Much of the leisure-related research pertaining to this population focuses on recreation participation patterns (Hoge & Dattilo, 1995;

Malik and her colleagues (Malik, 1990; Malik, Ashton-Shaeffer & Kleiber, 1991), however, used interviews with individuals with developmental disabilities to gather information about their leisure interests. We know from the literature on self-determination (e.g., Dattilo & Barnett; Mahon & Bullock) and leisure interests (Malik; Malik et al.) that individuals with developmental disabilities are capable of making decisions that reflect their needs, interests, wants, and desires. The question remains, however, do these individuals have the opportunities to make and act upon leisure-related decisions that affect their quality of life?

This study will build on the existing body of knowledge in developmental disabilities and leisure. By understanding how individuals with developmental disabilities perceive leisure experiences, service professionals will be able to enhance recreation and leisure service-delivery practices.

**The Dynamic Research Process**

During the course of conducting this study, I often questioned what the overall purpose of this project was. After weeks, months, and years of agonizing over this question, it finally became clear that my purpose was to describe the leisure phenomenon
that I bear witness to, from the perspectives of the individuals with developmental disabilities whom I have come to know over the years, and from the perspectives of their families. Initially I set forth to examine the subjective nature of the leisure experience by asking individuals with developmental disabilities about their leisure experiences. In doing so, it was appropriate to adopt a naturalistic research perspective and a theoretical framework that included grounded theory and symbolic interactionism. This research perspective allows the data to guide the research process – ultimately influencing the purpose, research questions, and design. The dynamic nature of this whole research process is told throughout the chapters that follow. This information is addressed as the methods, findings, and implications are presented.

**Theoretical Framework**

Initially, as I proposed this study, I adopted a theoretical framework based on two principles: grounded theory and symbolic interactionism. Grounded theory was chosen to allow for the data to guide the study. My humility prevented me from being an “all knowing” scholar. My anti-authoritarian view of scholars allowed me to be open to the world of the participants. It was my belief that the participants in my study would open the door to their worlds, their perceptions, and their realities. They would be the authorities on their own leisure experiences. I adopted a symbolic interactionist perspective that valued the meaning that these “authorities” placed on their own experiences and could help us understand how such meaning was formed.

**Grounded Theory**

One way to examine the subjective nature of the leisure experience for people with disabilities is to ask them about their leisure experiences. A naturalistic research perspective embraces the idea that “an emerging propositional or theoretical
understanding . . . is grounded in the real lives and the real worlds of the persons and the phenomenon being studied” (Bullock, 1993, p.29). To truly view the world from the perspectives of those individuals who are being studied, the researcher cannot enter the research process with pre-conceived ideas. The data need to speak. The process whereby theory is “derived from the data” is known as grounded theory (Strauss & Corbin, 1998). Strauss and Corbin proposed that grounded theory be used to generate new theories or expand on existing theories. Strauss and Corbin (1998) said, “theorizing is the act of constructing . . . from data an explanatory scheme that systematically integrates various concepts through statements of relationship . . . it enables users to explain and predict events thereby providing guides to action (p. 25).

Although the grounded theory approach stresses that the researcher enter a research project without pre-conceived notions, the truth is that every research project begins with a research question. These research questions are formulated based on the researcher’s experience and background. Strauss and Corbin suggest that these research questions emerge from (a) suggested or assigned research problems, (b) technical or non-technical literature, (c) personal and professional experience, and (d) the research itself. The same information that guides our research questions also guides our initial data collection. Although this information serves as the foundation for study, researchers are open to and encourage additional data to emerge, thus broadening their perspective on a given phenomenon.

**Symbolic Interactionism**

One perspective frequently adopted (as a theoretical rationale in the field of leisure studies) to understand leisure experience and meaning is symbolic interactionism (Kelly, 1983, 1987; Rossman & Schlatter, 2000; Samdahl, 1986, 1988). According to Hewitt
symbolic interactionism “provides a distinctive way of understanding human social conduct and group life” (p.5). Symbolic interactionism is a perspective that blends the individualistic elements of psychology with the social influences of sociology (Blumer, 1969; Hewitt, 1991; Mead, 1962). This perspective embraces the notion that individuals are capable of internally developing meanings associated with external influences. Central to symbolic interactionism is the concept of meaning proposed by Mead (Blumer). Mead explains that meaning is the “relation between the gesture of a given human organism and the subsequent behavior of this organism as indicated to another human organism by that gesture” (p. 179). He further explains that meaning is associated with social processes. Therefore, suggesting that as people meet others, they form opinions based on this interaction.

Symbolic interactionism is based on the premises that (a) “human beings act toward things on the basis of the meanings that the things have for them”; (b) “the meaning of such things is derived from, or arises out of the social interaction that one has with one’s fellows,” and (c) “these meanings are handled in, and modified through, an interpretive process used by the person in dealing with the things he encounters” (Blumer, p.2). Therefore, symbolic interactionism attempts to describe how people interpret and describe their life experiences.

Numerous authors have suggested that leisure behavior may be examined via a symbolic interactionist perspective (Kelly, 1983, 1987; Rossman & Schlatter, 2000; Samdahl, 1986, 1988). A symbolic interactionist perspective embraces the idea that leisure should be viewed as a “characteristic relationship between the individual and the social milieu” (Samdahl, 1986, p. 22). Samdahl elaborates on this premise stating that
“leisure is a particular definition of the situation” (p. 22). Rossman and Schlatter similarly state that “leisure is a special meaning attributed to specific social occasions that are created by the individuals involved through interaction with objects in the occasions” (p.23). According to Rossman and Schlatter, when using a symbolic interactionist perspective, the leisure experience involves three phases: anticipation, participation, and reflection. The leisure participant assigns meaning to the leisure objects involved in each phase of the leisure experience. They further explain that these leisure objects can be physical (e.g., equipment, supplies), social, or abstract (e.g., ideas, philosophies).

Therefore, when examining leisure from a symbolic interactionist perspective, emphasis is placed on understanding the meanings that individuals perceive during the leisure experience. These meanings may be associated with definitions, motivations and/or satisfactions. In essence, from a symbolic interactionist perspective, emphasis is placed on analyzing the relationships between the research participant and the leisure objects that he or she perceives to be involved with the leisure experience.

**Purpose**

In the beginning, I set forth to understand the subjective nature of the leisure experiences of young adults with developmental disabilities. In doing so, I aimed to a) examine what leisure means to young adults with developmental disabilities, b) investigate the motivations and constraints of these individuals regarding their leisure, and c) determine the primary socialization agents that influence this experience (e.g., school, family, work).
**Research Questions**

Based on the purpose of the study stated above, the following questions were used to guide the initial phases of this study.

1. What does leisure mean to young adults with developmental disabilities?
2. What role do primary socialization agents (i.e., parents, school) play in the leisure of young adults with developmental disabilities?
3. What are the constraints on leisure experienced by young adults with developmental disabilities?
4. What are the facilitators of leisure for young adults with developmental disabilities?

**Limitations and Delimitations**

Limitations are those things which potentially limit the internal validity of the results of a study (Pyrczak & Bruce, 1998). In this study, limitations may be associated with the cognitive impairments associated with the individual’s developmental disability. These impairments may have affected the research participants’ ability to answer all questions and actively engage in the interview process. An acquiescence scale was used to screen the participants. I attended to the research participants’ needs, prompting and clarifying when appropriate. To prevent fatigue, the length of each interview was limited to no more than 45 minutes with most lasting under 30 minutes. Multiple interviews with the participants and their parents were also used to ensure the consistency and accuracy of the responses. My personal subjectivities might also have influenced the internal validity of this study. I attempted to expose most of my personal subjectivities as I explained this project. I had external reviewers review the transcripts to verify themes that emerged.

According to Pyrczak and Bruce, “a delimitation is a boundary to which the study was deliberately confined.” Delimitations also have implications pertaining to the generalizability of the findings. This study was delimited to individuals with
developmental disabilities who lived in Prairie View and who met the criteria for this study. Due to the nature of the community being studied, all participants were white caucasian, were of an upper middle class socio-economic background, and all of these participants had strong parental support. Most of these participants were participating in organized recreation programs or had done so in the past. Therefore, this study is limited in its generalizability. It is however, generalizable to similar populations (i.e. those with similar characteristics.

**Summary**

I wanted to know what leisure meant to people with developmental disabilities. I predicated this study on a variety of concepts associated with the leisure experience (i.e. motivations, constraints, satisfaction). I attempted to examine the role of special education, in preparing individuals for post-school leisure.

Yet, as I set forth to determine how these concepts were perceived by individuals with developmental disabilities, things changed. The leisure experience was broader in scope than initially thought. Other socialization agents (i.e., friends, family) appeared to be more influential than the schools. The overarching idea of quality of life, appeared to be ever more important. The one thing that remained constant was that the study remains focused on how young adults with developmental disabilities perceive their own leisure experience.
CHAPTER 2
LITERATURE REVIEW

The intent of this chapter is to provide an overview of literature that helps us understand the overall phenomenon being studied. In Chapter 1, I described the concept of quality of life, as it serves as the basis for the realm of services that individuals with developmental disabilities receive. Quality of life has been a catalyst for the development of philosophical positions such as community integration and normalization. As these philosophies emerged, recreation and leisure services adopted them as guiding principles. At the same time that the philosophies regarding the human services surfaced, the manner in which leisure was being studied also evolved. Leisure studies shifted from examining leisure as a philosophical construct to examining it as a construct that can be explained from theories in the social sciences (Kelly & Freysinger, 2000). As this chapter progresses, the evolution of human service principles and the conceptualization of leisure is explored. The concept of leisure is described by examining the characteristics and the nature of the leisure experience. Specific implications for individuals with developmental disabilities are also addressed.

Quality of Life

While the concept of quality of life was introduced in Chapter 1, the implications of this construct were not. In Chapter 1 the idea was presented that quality of life is multifaceted concept with several dimensions (e.g. leisure, health, financial security). As we explore the concept further, it can be noted that quality of life can be measured in numerous ways (e.g., life satisfaction, economic impact, health indices). Another way to
examine the concept of quality of life is by looking at social movements and philosophical principles founded on the idea that the quality of life of individuals with developmental disabilities can be enhanced.

The concept of quality of life served as the impetus for movements associated with deinstitutionalization, community integration, community adjustment and normalization (Fisher, 1991; Heal, 1994; Hemming et al., 1981; Malik, 1988; Schalock, 1990c). During deinstitutionalization, a movement in the 1960s and 1970s, individuals with disabilities were moved from large state-run institutions to the community (Bullock & Mahon, 1997; Nirje, 1994; Wolfensberger, 1994). The act of being in the same communities as people without disabilities is considered to be community integration (Kleiber, Ashton-Shaeffer, Malik, Lee, & Hood, 1990; Schleien, Ray & Green, 1997). According to Fisher, as people are integrated into the mainstream of society, a process known as community adjustment occurs, whereby individuals with disabilities adapt to the physical environment, and learn to cope with societal attitudes. Bullock and Mahon suggest that society’s attitudes may change via the process of normalization, which encourages people to treat individuals who have disabilities with the same respect that would be shown to individuals who do not have disabilities. The evolution of these principles is based on the idea that the quality of life of individuals in institutions was horrendous.

Deinstitutionalization

As mentioned previously, deinstitutionalization refers to an era when individuals with disabilities were moved from large state-run institutions to the community (Bullock & Mahon; Nirje; Wolfensberger). This idea emerged as people became aware of conditions in these institutions via photographs (Blatt & Kaplan, 1966), investigative
journalism (Terry, 1968), and the written word (Bogdan & Taylor, 1982, preface). The following is how Bogdan and Taylor described their encounter with these institutions.

We were taken first to the “model living units” housing young children with rare conditions and deformed bodies. Amid expensive equipment and busy aides, thirty, perhaps forty, unattended children lay helplessly in seemingly endless rows of cribs. “Society doesn’t want to care for these children,” commented one aide to an observer. “We do the best with what we’ve got.”

We were also profoundly struck by the wards full of older men and women. There were several coloring books strewn about. A television encased in wire mesh sat high on one wall. Several of the people were rocking. Most sat quietly, just passing the time. There were no obvious signs of abuse or neglect. Yet the atmosphere was one of boredom and depression, of wasted lives and lost opportunities.

With mixed emotions we toured the locked units, the institutions’ “back wards.” Our anxiety heightened as we approached the wards for “severely and profoundly retarded, aggressive, ambulatory, young adult males.” The combined smells of antiseptic and excrement were overpowering. Haunting screams filled the air. An overwhelming desire to flee accompanied the turning of the key to the locked ward door. And there they were, an anonymous mass of unwanted humanity. The images are unforgettable: some nude, but most in baggy institutional garb; several in straightjackets or tied to long wooden benches; all with close-cropped hair; many with scars; some hunched over; some drooling (preface).

As people saw the conditions in these institutions, advocacy groups were formed, legislation was passed, and efforts were made to improve the quality of life of individuals with developmental disabilities (Schalock & Braddock, 2002). People with developmental disabilities moved from the institutions to their home communities. They were given the opportunities to attend school and otherwise partake in other community activities. As people left the institutions to live in the communities, efforts were made to aid in this transition. These efforts fell under the auspices of the concept known as community integration.

**Community Integration**

Community integration involves two components: physical integration and social integration (Kleiber et al., 1990; Smith, Austin & Kennedy, 1996). According to Kleiber
and colleagues physical integration involves placing people in environments that foster opportunities for social interaction. They define social integration as the act of social interaction. Initially, the physical act of integration merely meant providing opportunities within local communities. As such, special schools, special recreation programs and special workshops were created.

Individuals with disabilities were physically living in the community; but they were not learning, working or playing in the same settings as individuals without disabilities. Efforts were made to physically bring individuals with disabilities into the same schools, workplaces, and recreation centers as people without disabilities. The phenomenon known as “mainstreaming” was conceptualized to define these efforts. The mainstreaming efforts led to special self-contained classrooms in the neighborhood schools, and led to adapted aquatics programs in the neighborhood pools.

But still, individuals with and without disabilities lived their lives independent of one another. As such, the idea of inclusion was brought to the forefront. Inclusion promotes interaction among individuals with and without disabilities in the world of individuals without disabilities. Several questions remain, however. Do integration, mainstreaming and/or inclusion actually address the idea of quality of life? How are people affected by these practices? To answer these questions, the concept of community adjustment emerged. Community adjustment goes beyond integration by involving personal, environmental and psychosocial variables (Burchard, 1994).

Community Adjustment

Community adjustment is a complex idea. It involves an awareness of the self, (Burchard, 1994; Fisher, 1991; Kleiber et al., 1990), an awareness of others (Burchard; Fisher; Halpern, 1985; Kleiber et al.) and an awareness of the environment (Burchard;
Halpern). According to Fisher, an awareness of self involves how an individual copes with one’s disability. Kleiber et al suggest that an individual’s ability to cope with his or her disability may manifest itself via feelings of self-worth and/or self-esteem and his or her general mood. In the realm of social adjustment they allude to the degree of satisfaction associated within the context of their interactions. Fisher suggests that an awareness of others involves understanding how others perceive disability. Halpern states that environmental adjustment involves adapting to the conditions associated with residential living and employment (Halpern, 1985).

The outcome of community adjustment involves overcoming the obstacles that a person with a disability encounters while meeting normal challenges associated with human development (Fisher, 1991). As such, human service agencies aim to promote independent functioning and a normalized lifestyle (Burchard, 1994).

Normalization

As Burchard suggests, normalization is a guiding principle used to develop community programs post deinstitutionalization. Much has been written on the normalization principle over the years, yet few of these studies actually refer to the origins of the principle (Nirje, 1994). I could merely describe normalization in my own words as a process whereby individuals with disabilities are treated in the same manner as those without disabilities. I could discuss the idea of age-appropriate programming and least restrictive environment. But, I would be doing a great disservice to the principle as a whole. Normalization may be one of the guiding principles in this study; as such I feel the historical evolution of this principle is important.

In 1959, a Danish law was promoted by Bank-Mikkelsen. The preamble to this law read “to let the mentally retarded obtain an existence as close to normal as possible”
In 1967, Nirje coined the phrase “the normalization principle” (Nirje, 1994). According to Nirje:

the normalization principle means that you act right when you make available to all persons with intellectual or other impairments or disabilities those patterns of life and conditions of everyday living that are as close as possible to, or indeed the same as, the regular circumstances and ways of life of their communities and their cultures (p.17).

He believes that all people with disabilities should have access to:

1. A normal rhythm of the day.
2. A normal rhythm of the week.
3. A normal rhythm of the year.
4. The normal experiences of the life cycle.
5. Normal respect for the individual and the right to self-determination.
6. The normal sexual patterns of their culture.
7. The normal economic patterns and rights of their society.
8. The normal environment patterns and standards in their community.

Nirje founded these principles upon observing the lives of the individuals with disabilities in Sweden. According to Perrin, Bank-Mikkelsen described normalization as the ‘acceptance of the mentally retarded with their handicap, and offering them the same conditions as are offered other citizens’. He further suggests that “it means making normal housing, working and leisure conditions” (p.183). Eventually, the normalization principle transcended the boundaries of Sweden (i.e. United Kingdom’s Ordinary Life Movement) and made its way to the United States where Wolf Wolfensberger “Americanized it.”

According to Yates (1994), Wolfensberger defined the principle of Normalization as:

The use of culturally normative means (techniques, methods, tools) to enable people’s life conditions (income, housing, jobs, recreation) to be at least as good as those of average citizens. Culturally normative is not used here to mean the average, the normal, the mean, but rather, in the sense of what’s broadly accepted, a range of what is expectable and ordinary, where people would not raise their eyebrows to encounter. Moreover, culturally normative means would be called in to
play to, as much as possible, enhance and support people’s behavior, appearance, experiences, status, and reputation in their own eyes and in the eyes of others (p. 118).

Yates suggested that Wolfensberger also defined Normalization as:

The utilization of means that are culturally normative as possible in order to establish, enable or support behaviors, appearances, and interpretations that themselves are as culturally normative as possible (p.118).

Wolfensberger’s conceptualization of the normalization principle eventually evolved into a concept known as Social Role Valorization (SRV). According to Thomas and Wolfensberger (1994):

SRV proposes that people who hold valued roles in society are more apt than people in devalued roles to be accorded ‘the good things in life’ by their society. Consequently, if people who are devalued by their society, or who are at risk of being devalued, are to be given the good things of life, then they should be helped to as much as possible fill roles that are highly valued in society. Otherwise they will probably be very badly treated (p.126).

Several principles are the basis of SRV, the first pertain to the concept of social roles. Thomas and Wolfensberger suggest that our social roles reflect “behaviors, privileges, duties and responsibilities” which are “widely understood and recognized within society.” They further postulate that these social roles characterize a “particular position within a social system.” Thomas and Wolfensberger imply that these social roles fall along a continuum of perceived value and occur within different domains (e.g.: relationships, work, education, sports, community participation, religious, and residence-related). They also state that these roles may be negative or positive, narrow or broad.

SRV is based on assumptions that humans by their nature value and devalue other people. They suggest that social image and personal competency are two factors that may enhance social role value.
These principles of deinstitutionalization, community integration, normalization and social role valorization all have been designed to enhance the quality of life of individuals with disabilities by including them in society. Furthermore, the aim of these efforts was to make society more accepting of individuals with disabilities.

**Implications for Recreation Service Delivery**

As these principles have evolved, the human service fields (i.e.: therapeutic recreation and special education) have adopted them via service delivery. Concepts like least restrictive environment, mainstreaming and inclusion are rooted in these principles. While these concepts may have affected the field of special education in the 1970s because of legislation (e.g.: PL 94-142), the origins of these principles include recreation services.

As mentioned previously, the normalization principle was specifically applied to the recreation and leisure domains of life. Perrin (1994) reported that one purpose of the Scandinavian normalization movement was to make normal “leisure conditions.” Nirje (1994) reports using his experiences in Sweden’s residential and recreational facilities to develop the principle. Subsequently, Nirje credits Elliot Avedon, a founding father of therapeutic recreation, for introducing recreation to Sweden. But, why were recreation and leisure important in the beginning? Perhaps, it is because as Godbey (1990) suggests leisure is part of the “rhythm of daily life” (p.43). He defends this idea by using time as a measure of leisure.

The principles of community integration and normalization continue to guide the field of therapeutic recreation (Bullock & Mahon, 1997; Smith, Austin & Kennedy, 1996; Schleien, Ray & Green, 1997). These principles serve as the foundation for therapeutic recreation practice (i.e. Austin & Crawford, 1991; Bullock & Mahon; Carter, Van Andel
& Robb, 1995; Schleien, Ray & Green; Smith, Austin & Kennedy). As such, knowledge of these basic principles is considered to be a minimum competency expected of therapeutic recreation professionals (Kinney & Wittman, 1997; NCTRC, 1997). Likewise, these principles guide research projects within the field of therapeutic recreation. (Devine & Dattilo, 2000; Devine & Lashua, 2002; Germ & Schleien, 1997; Hayden, Soulen, Schleien, & Tabourne, 1996; Kleiber et al., 1990; Miller et al., 2002; Richardson, Wilson, Wetherald & Peters, 1987; Schleien, Cameron, et al., 1988; Schleien et al, 1987; Schleien, Rynders & Mustonen, 1988; Schleien & Werder, 1985; Wachter & McGowan, 2002; Wilhite & Keller, 1996).

The most evident implication for therapeutic recreation practice is inclusive recreation. Inclusive recreation involves including individuals with disabilities in those recreation programs designed for individuals without disabilities (Bullock & Mahon; Dattilo, 2002a; Schleien, Ray & Green; Smith, Austin & Kennedy). Smith, Austin and Kennedy suggest that recreation service delivery needs to address elements of society (e.g.: architectural barriers and societal attitudes) which may exclude individuals with disabilities from full participation. Bullock and Mahon emphasize the development of an accepting community recognizes individuals with disabilities as “valued members” and “active participants” in “typical environments.” Inclusive recreation can play a role in helping society value individuals with disabilities (Dattilo; Schleien, Ray & Green). Society will value individuals with disabilities when accommodations are made, participation is encouraged, the unique talents of each individual are recognized and everyone’s choices are respected (Dattilo, 2002; Schleien, Germ & McAvoy, 1996).
The field of leisure studies also addresses “inclusion” from the individualistic perspective via the identification of specific benefits obtained through inclusive programs (Anderson, Schleien, McAvoy, Lais & Seligman, 1997) and through program implementation (Schleien, Ray & Green; 1997). Schleien et al point out that immediate inclusion in recreation programs may not be appropriate for all individuals. And so, from an individualistic perspective, inclusive leisure services are based on each individual’s needs and tends to celebrate diversity.

For the most part these studies have examined the desired outcomes of these inclusive recreation programs. As such, these studies have determined best practices for inclusive programming by examining factors that influence successful integration (Hayden et al., 1996; Wilhite & Keller, 1996). Research related to the best practices associated with inclusive programming describes the role of the program staff (Germ & Schleien, 1997; Wachter & McGowan, 2002) as well as the role of the participants (Devine & Lashua, 2002; Germ & Schleien, 1997) in such programs. Some studies examine the role of inclusive programming on social acceptance (Devine & Lashua, 2002; Miller et al., 2002).

Despite, references to the key principle of normalization, few studies actually explore the role of normalization in relation to the leisure of the “normal” society. The next section of this chapter describes what we know about leisure for people without disabilities.

**Leisure and the “Normal” Society**

In this section, we are going to examine the concept of leisure as a whole. While the philosophical and definitional approaches described in Chapter 1 will not be explored here, it is worth repeating that leisure can be defined in a myriad of different ways. While
there is little agreement related to the philosophical and definitional understanding of leisure, there is much agreement as to certain characteristics of leisure (e.g: freedom and positive feelings). Once the characteristics of leisure have been described, the existential and social nature of the leisure experience will be discussed.

**Characteristics of Leisure**

Two generally agreed upon characteristics of leisure include some degree of freedom and some positive feelings (Godbey, 1990; Kelly, 1990; Kleiber, 1999). As mentioned previously, the idea of freedom can be perceived or it can be relative. The concept of freedom involves the idea that an individual is capable of making choices and that an individual chooses to engage in leisure. Some positive feelings are also associated with leisure. Godbey (1990) uses the terms “personally pleasing” and “intuitively worthwhile” to describe the later characteristic. Kelly, on the other hand, uses the term “intrinsic satisfaction.” And Kleiber uses the term “preferred experience.” Regardless of the terms used, the ideas remain the same. Therefore these characteristics will be explored in further detail here.

**Freedom**

As mentioned previously, the concept of freedom seems to be central to the notion of leisure (Godbey, 1990; Iso-Ahola, 1999; Kelly, 1983, 1987, 1990; Kleiber; Neulinger, 1981). Freedom may be perceived, as Neulinger suggests, or it may be relative. Perceived freedom is conceived in the mind of the person through his or her feelings. Perceived freedom can be exemplified via the following questions. Does the person *feel* free to participate in the experience? Does the person *feel* that he or she may make choices about the experience? Kelly (1990) describes the freedom associated with leisure as being relative, stating “it is more than just a feeling” (p.22). The concept of relative freedom
depends on how society constructs the notion of freedom. For example, if a person is in a prison, society might say that the person does not have freedom because there are bars on the windows and a structured schedule dictating how that person can experience life.

The construct of freedom involves the element of choice implying that leisure is a freely chosen activity (Iso-Ahola, 1999; Mannell & Kleiber, 1997; Wearing & Wearing, 1988). A concept synonymous with choice is self-determination. Self-determination describes our ability to make and to act on our own choices (Deci & Ryan, 1980). It has been suggested that as people make choices about an activity he or she is more likely to participate in that activity for that activity’s sake (Iso-Ahola; Kleiber 1999; Mannell & Kleiber). Iso-Ahola insinuates that as people have more control over an activity pleasurable feelings soon follow. Dattilo and Kleiber (1993) suggest that self-determination and intrinsic motivation are essential to enjoyment.

**Positive Feelings**

Happiness! Enjoyment! Fun! There are so many words that can describe positive feelings. These positive feelings are often associated with leisure (Godbey, 1990; Kelly; Kleiber). Csikszentmihalyi stated, “happiness is the prototype of the positive emotions” (1997a, p.18). Happiness is the outcome of an experience which Csikszentmihalyi calls flow (1975, 1990, 1997a, 1997b). Flow occurs when there is a balance between a person’s skill level and the level of challenge within a given task (Csikszentmihalyi 1975, 1990, 1997a, 1997b). When a person is in flow, he or she is completely focused, his or her self-consciousness disappears, and his or her sense of time is distorted (Csikszentmihalyi, 1997b). According to Csikszentmihalyi, “flow is generally reported when a person is doing his or her favorite activity” (1997a, p.33). Several studies have
linked leisure activities to the flow experience (Ellis, Voelkl, & Morris, 1994; Voelkl & Ellis, 1998; Jones et al., 2000).

And thus, freedom and positive feelings are characteristics associated with the leisure experiences. If my participants do not understand the terms, recreation and leisure, as was the case in Malik (1990), they might have experiences marked by these characteristics.

**The Nature of the Leisure Experience**

The nature of the leisure experience is complex. In order to understand the nature of the leisure experience we need to know if the concept actually exists. Kelly (1987, 1999) explains leisure’s existence via existential sociology. He implies that the nature of leisure is made up of two essential components or truths:

- Leisure is an experience.
- This experience is dependent upon social interaction.

This section describes how we know that leisure is an experience. Multiple facets and processes associated with the leisure experience will be discussed. This section will also elaborate on the social influences associated with the leisure experience.

**Leisure as Experience**

According to Kelly (1987), we know that leisure is an experience because leisure is a decision, a creation, a process that evolves and changes with situations. There are several ways that we can determine the existence of leisure. Kelly further explains that leisure produces meaning and that leisure is an act with its own “history, emotion, interpretation, episodic development and telos” (p. 50). He elaborates stating that we know that it is an experience because it exists within a social context. Attempts to operationalize this experience have emerged as the field of leisure studies evolved.
The existential properties of this experience include an understanding of how the construct evolves and changes over the course of one’s life. Another way we can verify the existence of leisure is to compare the construct to a similar dimension of life such as work. A third method of determining the existence of leisure is to explore how it operationalized. Therefore, in this section, the leisure experience will be explored via the life course, work, participation, satisfaction and meaning.

**Life Course.** One way that we can determine the existence of leisure is to determine the presence of this construct at different periods throughout life. A developmental approach is traditionally used to examine leisure in the context of different phases of life. Many leisure scholars have written about leisure and the life course (Kelly 1990, 1987; Kleiber, 1999; Mannell & Kleiber 1997; Rapoport and Rapoport, 1975). Kleiber describes how development influences the manner in which individuals experience leisure as well as how leisure impacts person’s development. He describes the leisure experience as having four properties that relate to human development. According to Kleiber, leisure can be:

- Derivative – the result of life experience.
- Adjustive – a way to cope with our life experiences.
- Generative – a means to promote the growth process
- Maladaptive – a mechanism that hinders development.

The interaction between leisure and human development occurs at all phases in our life. It may occur when we are young and when we are old. As we age and experience different life events the role of leisure in our lives takes on different meanings. Literature suggests that as people age, they cease, replace or continue participating in certain leisure activities (Iso-Ahola, Jackson & Dunn, 1994).
We can examine changes and continuity, which occur throughout one’s life in a myriad of ways. Kelly (1987) identifies five traditional methods of examining developmental change: He suggests that the *family life cycle* approach studies the role of family in various life stages. The *life span* approach was defined by Kelly as being focused on age-related change. Whereas, he defined the *life course* approach as being focused on stages linked by transitions. When describing the *crisis model*, Kelly emphasizes struggles that occur at different stages of life. And, the *developmental model* is described by him as involving task achievement at various stages in life.

In this study, we are examining the period of life in which people are young adults. This period of life is marked as the time in which individuals leave their parent’s home, but before they establish a family of their own (Rapoport and Rapoport, 1975). According to Kelly, this transition period is marked by a life stage when a person is challenged to embrace a life that is self-directed, while becoming less connected to his or her family. Young adults are faced with the crises of finding their own identities while attempting to establish intimate relationships. This struggle may result in role confusion or social isolation (Erikson, 1982). Leisure can assist people in successfully making the transition from adolescence to adulthood (Kleiber, 1999; Mannell & Kleiber, 1997). During this period of life many changes occur regarding our leisure interests. Mannell and Kleiber suggest that this is the time when the leisure activities that we enjoyed as a child mesh with the leisure interests that we enjoy in adulthood.

As we age, the institutions that exist in our lives define us (e.g. school and work). For example, children ages birth to five are often called “pre-schoolers”; next, we group children as those in either elementary or secondary school, then there is life after school.
Similarly, the dimension of work can be used to define us. It is often said that “play is child’s work.” In high school, students may identify with the camp, pool, grocery store, or gas station that they worked at. After high school parents ask “what are you going to do with your life” referring to the occupational choices that young adults pursue. Adults are often defined by their occupation (i.e. teacher, lawyer, doctor, therapist). When a person retires, the lack of work in his or her life allows them to form a new identity (e.g. snowbird — as in the case of older adults who migrate to warmer climates for part of the year).

**Work.** Since leisure is like other domains of life (e.g. school and work) from a developmental perspective, the existence of leisure can be established by comparing leisure to work. The relationship between leisure and work has long been examined (Godbey, 1990; Kelly, 1990,1999; Mannell & Reid, 1999)). The relationship can be measured temporally or it can be studied attitudinally. The temporal perspective measures work and leisure using time (Kelly, 1990; Brightbill, 1960; for examples see Hunnicut, 1989; Schor, 1991). Whereas, the attitudinal perspective examines work and leisure using constructs such as satisfaction and enjoyment (Csikszentmihalyi 1975, 1990, 1997). Regardless of the perspective used to study this relationship, it is evident that this relationship is complex.

If leisure is defined as “time that is free from necessity” and if work is defined as “accomplishing something that needs to be done”, one would expect this relationship to consist of two dimensions which contrast with each other (Kelly, 1990). Yet, if we examine actual activities that we consider to be leisure such as gardening, we see that there may be some necessity. Likewise, there are aspects of work that are enjoyable.
As we look at the construct of work for a moment, we see that work is multifaceted. We can define work by the tasks we do and perform. We can describe work by the amount of money and/or amount of power that comes from the occupations that we choose. The tasks, the money, the structure and the environment can satisfy us or we can look for something better. In some cases, we might not be in it for the money. We might be fulfilled knowing that we are making a difference in people’s lives. Therefore exploring the concepts of participation, satisfaction and meaning can operationalize the experience of work. Such factors are also examined as we operationalize the experience of leisure.

**Operationalizing the leisure experience.** Mannell describes three ways that leisure scholars have traditionally examined the subjective nature of the leisure experience. These three perspectives include the definitional approach, the immediate conscious experience approach, and the post-hoc satisfaction approach (Mannell, 1999; Mannell & Kleiber, 1997; Mannell & Iso-Ahola, 1987).

The definitional approach involves “identifying the attributes and meanings that people must perceive as being associated with an activity or setting for it to be construed or defined as leisure” (Mannell, 1999, p.235). The immediate conscious experience approach involves “measuring the quality or texture of what people experience during leisure and examining the impact of the physical and social setting as well as personality factors on experience” (p.237). The post-hoc satisfaction approach “is an ‘after the fact’ assessment or experiential consequence of an earlier involvement or set of involvements” (p.238). These three approaches to studying the subjective nature of the leisure experience suggest that the leisure experience is composed of three facets: participation,
satisfaction and meaning. Participation describes what exactly we do and how we go about doing it. Meaning refers to how we define each of these experiences by examining the why, where, when and with whom we do or do not do things. We have needs, wants, and desires in all areas of our life, satisfaction describes the degree to which these needs, wants, and desires are met.

**Participation.** As mentioned previously, leisure participation involves the behaviors associated with being engaged in an activity that is freely chosen and enjoyable. When attempting to operationalize leisure participation, scholars examine specific activity involvement, motivations, and constraints.

**Specific Activity Involvement:** is measured by examining those activities that people find enjoyable. This construct can first be examined by looking at the types of activities in which people participate (Burlingame & Blascho, 2002). When examining specific activity involvement, diversity of interests along with frequency and duration of participation are examined. A person may spend 20 hours a week playing rugby, but do they do anything else? Another person may spend the same 20 hours at dance class, riding a bike on trails, eating out with friends and watching a movie. When attempting to examine participation patterns, additional factors help explain why people engage in certain activities.

**Motivation:** Motivation theories describe *why* people engage in certain behaviors (Deci & Ryan, 1985, p.3). In the field of leisure studies the concept of motivation has been addressed in numerous ways (Beard & Ragheb, 1983; Iso-Ahola, 1980, 1989; Mannell & Kleiber, 1997; Neulinger, 1981; Tinsley, Barrett & Kass, 1977). Theories of motivation can be based on needs, preferences, or a combination of the two.
One of the earliest ideas of motivation was Maslow’s (1954) hierarchy of needs. According to Maslow, human beings strive to ensure that certain physical, social, and psychological needs are met. Additionally, leisure scholars have postulated needs based theories of motivation (Iso-Ahola, 1980; Mannell & Kleiber).

As motivation theories evolved, many began to examine needs based on leisure preferences (Tinsley, Barrett & Kass; Beard & Ragheb, 1983). Tinsley, Barrett and Kass identified a list of 45 needs associated with leisure activities. They examined whether these needs were present in five activities: watching TV, reading, attending plays, bicycling, and drinking. According to Beard and Ragheb, there are four reasons why people are motivated to participate in leisure activities. They suggest that the first type of motivation is *intellectual*, which pertains to wanting to participate in an activity because an individual has a need to learn, to explore, to discover, to create, or to imagine. Their second form of motivation is *social*, which refers to the need to develop friendships and esteem for others. The third form of motivation described by Beard and Ragheb is called competency or mastery. Examples of competency and/or mastery motivation include participating in an activity for the purposes of achieving, mastering, challenging, or competing. The last type of leisure motivation that Beard and Ragheb mention is *stimulus/avoidance*. This type of motivation occurs when people avoid social contacts, seek solitude, and seek to rest and unwind themselves.

Neulinger suggests that the three levels of motivations associated with the leisure experience include: extrinsic motivation, intrinsic motivation and a combination of the intrinsic and extrinsic motivations. Extrinsic motivation involves participation in an activity because of “some payoff from the activity” (Neulinger, 1981, p.17). He suggests
that intrinsic motivation involves participation in an activity because of the activity itself.
Although there are several motivational theories, the field of leisure studies has generally
focused on the theories of intrinsic motivation and self-determination (Iso-Ahola, 1980,

While intrinsic motivation assumes “that people are active organisms working to
master their internal and external environments” (Deci & Ryan, 1980, p. 35) self-
determination is “the capacity to choose and to have those choices rather than
reinforcement contingencies, drives or any other forces or pressures, be the determinants
of one’s actions” (p. 38). Intrinsic motivation and self-determination are frequently
mentioned in the literature as integral components of the leisure experience (Iso-Ahola,
1999; Mannell & Kleiber, 1997; Wearing & Wearing, 1988; These concepts relate to the
leisure experience, since “leisure means full autonomy, freedom and control” (Iso-Ahola,
p.39). He illustrates this idea, stating “one participates in an activity because he or she
finds it intrinsically interesting, for its own sake, out of sheer pleasure and enjoyment”
(p.39).

There are many times when we all want to do things, but do not. The reasons why
we do not engage in activities that we would like to has been described by the idea of
constraints. Leisure constraints are those things that prevent people from participating in
the activities that they choose (Crawford, Jackson, & Godbey, 1991; Jackson, Crawford
& Godbey, 1993; Raymore, Godbey, Crawford & von Eye, 1993). Crawford et al.,
suggest that there are three types of constraints: intrapersonal, interpersonal, and
structural.
Intrapersonal constraints are those factors within a person that interfere with an individual’s ability to act on their preferences (Crawford & Godbey, 1987). According to Raymore et al., intrapersonal constraints include issues related to: a person’s psychological health (i.e. stress, anxiety or depression), his or her personal values; and his or her perceived competency. Interpersonal constraints involve situations when a person does not participate in an activity because of his or her interaction with other people. They suggest that an example of an interpersonal constraint would be if individuals do not participate in an activity because they could not find someone to do that activity with them. Structural constraints are those external factors such as financial resources, time and opportunity which that interfere between a person’s leisure preferences and his or her participation (Crawford & Godbey, 1987; Raymore et al, 1993). Intrapersonal constraints directly affect leisure preferences, interpersonal constraints affect the linkage between leisure preferences and interpersonal compatibility and structural constraints affect the linkage between interpersonal compatibility and the level of participation. Samdahl and Jekubovich (1997) found that these types of leisure constraints do indeed occur in the leisure experiences of adults who were 30 to 65 years old. They also found that there are other factors that influence leisure participation. Shaw, Bonen & McCabe (1991) examined how the presence of 11 different barriers related to levels of participation in 35 physical activities among 18,293 Canadians aged 18-69. Their findings challenge the assertion that constraints reduce participation. They suggest that societal factors such as gender and class may be more influential than inter and structural constraints per se.
Specific activity involvement, motivations and constraints are ways that leisure scholars can examine the idea of leisure participation. While leisure participation examines the act of engaging in leisure activities, the concept of leisure satisfaction examines the outcomes of such engagement.

**Leisure Satisfaction.** Leisure satisfaction is measured once a person engages in a leisure activity. According to Mannell, (1989) leisure satisfaction can also be conceptualized as *molecular*, focusing on a few specific activities; or *molar*, that is exploring the overall phenomena of leisure. He suggests that the concept of leisure satisfaction can be used to determine whether preferences, expectations and needs were met during the participation phase of the leisure experience. Beard and Ragheb (1980) define leisure satisfaction “as the positive perceptions or feelings which an individual forms, elicits, or gains as the result of engaging in leisure activities and choices” (p.22).

Leisure satisfaction measures are often related to the concept of motivation discussed previously (Mannell; Beard & Ragheb). Ragheb and Tate (1993) suggest that motivation can either lead to participation, or it can directly influence satisfaction. According to Beard and Ragheb, there are six types of leisure satisfaction: psychological, educational, social, relaxational, physiological, and aesthetic. They describe psychological satisfaction as pertaining to the satisfaction that is the result of the leisure experience: being intrinsically motivated, fulfilling self-actualization needs, instilling a sense of accomplishment, and/or providing an outlet for self-expression. According to Beard and Ragheb, if an activity provides for intellectual stimulation; allows participants to seek new experiences, and/or satisfies the participant’s curiosities, that activity is a source of educational satisfaction. They state that social satisfaction occurs when
participants are able to maintain and develop freely chosen social relationships.

Satisfaction which meets the needs associated with rest, relaxation and stress reduction is called relaxational, according to Beard and Ragheb. They believe that if a person is challenged and restored physically, if he or she develops physical fitness and enhances health; or if his or her physiological needs are met, that he or she is physiologically satisfied. Finally, they imply that aesthetic satisfaction occurs if the physical environment is pleasing.

As mentioned previously, the different types of satisfaction identified by Beard and Ragheb (1980) are similar to the different types of motivation (Beard & Ragheb, 1983). For example, a person may be psychologically satisfied if he or she is motivated intellectually. Likewise, people may be both motivated and satisfied by their social interactions. Someone motivated by stimulus/avoidance may be satisfied via relaxational satisfaction. And a person motivated by competence and mastery might experience physiological satisfaction.

Another component used to understand the leisure experience is leisure attitude (Ragheb & Tate, 1993; Ragheb & Beard, 1982). According to Ragheb and Tate, attitude has two components -- one cognitive, the other affective. Ragheb and Beard suggest that the cognitive component of attitude is “affected by our knowledge and beliefs about leisure activities” (p. 156). They state that the affective component of attitude relates to the person’s likes, dislikes, and other feelings about a given leisure activity. There is a direct relationship between the cognitive component of attitude and motivation (Ragheb & Tate). Whereas the cognitive component of the model is only directly related to
motivation, Ragheb and Tate believe the affective component is directly related to
motivation, participation and satisfaction.

While satisfaction examines an individual’s perception of the outcomes associated
with leisure activities, leisure meaning explores how a person perceives the leisure
experience and is used to determine how a person values such experiences.

**Leisure Meaning.** Therefore, according to Mannell (1999) the third component of
the leisure experience is leisure meaning. Kleiber (1999) defines leisure meaning as
“what people think of when asked about the feelings they associate with it” (p.3). Lawton
(1993) describes two types of leisure meaning that have been explored in leisure studies.
He uses the term *denotative meaning* to describe “observable properties of an object, that
is, physical characteristics, uses, history, and so on” (p.25). As such, Lawton suggests
that leisure studies have examined the denotative meaning of leisure by grouping types of
activities. He uses the term *connotative meaning* when referring “to the more abstract,
affective and linguistic characteristics of the object” (p.25). Lawton suggests that leisure
studies have examined the connotative meaning of leisure when dimensions of the leisure
experience (e.g. leisure attitude and leisure satisfaction) have been explored.
Furthermore, Lawton postulates three categories of leisure meaning: experiential,
developmental and social. He suggests that experiential leisure meanings embrace
concepts such as: intrinsic satisfaction, solitude, diversion, and relaxation. He states that
the developmental meanings use concepts such as intellectual challenge, personal
competence, health, expression and personal development, and creativity. And Lawton
says that social leisure meanings include concepts such as social interaction, social status,
and service. Similarly, Kleiber suggests that ideas such as: perception of freedom or
choice, intrinsic motivation, freedom from evaluation, relaxation, and enjoyment are reflected in the research on leisure meaning.

Shaw (1985) examines the meaning of leisure in everyday life. When reviewing the literature she identifies three ways that leisure meaning had been explored. The first method looks at how people define leisure. The second method examines the values and satisfactions associated with leisure. The third approach examines “factors believed to be associated with leisure” (e.g. freedom and motivation). Shaw chooses to conduct an exploratory study of leisure and tests “perpetual dimensions” (e.g. enjoyment, relaxation, effortless, satisfaction, free choice, personal development, intrinsic motivation, spontaneity, no evaluation, and social interaction) identified in the literature. Using interviews and time diary procedures, she compares the respondent’s perceptions in leisure and non-leisure activities. The focus of her article was to define leisure. Shaw uses a symbolic interactionist paradigm, to examine “the process by which an individual in a given situation comes to define that situation as leisure or as work, or as some other category of experience” (p.5). Using this perspective she was “primarily concerned with attitudes toward and perceptions of a situation rather than with the objective situation conditions in terms of understanding definitions and meanings” (p.5).

And so, the leisure experience is a complex phenomenon comprised of three facets participation, satisfaction, and meaning. Since a human being is capable of engaging in such behavior and since humans are capable of assigning meaning to this experience, the idea of leisure must exist. This idea is present throughout the life course and is similar to other domains of life. But, according to Kelly (1999) the nature of leisure is not merely existential. It requires some interaction with others.
The Social Nature of Leisure

The social nature of leisure has long been recognized (Avedon, 1974; Kelly, 1999; Samdahl, 1992). Leisure is prevalent in the presence of family and friends (Samdahl, 1992; Shaw, 1984). As Kelly explains the social nature of the leisure experience is used to help define the leisure experience using the meanings associated with our social interactions. Eight social interaction patterns occur within our recreational pursuits (Avedon, 1974; Peterson & Gunn, 1984; Peterson & Stumbo, 2000; Stumbo & Peterson, 2004). These social interaction patterns describe those activities that are done with others and those which are performed in the absence of others. A description of the eight social interaction patterns identified by Avedon follows:

- Intra-individual activities occur within the mind of the participant.
- Extra-individual activities occur between an individual and an object.
- Aggregate activities occur between an individual and an object while other individuals perform similar tasks independently.
- Inter-individual activities involve one person competing against one other person
- Unilateral activities involve competition among three or more individuals, one of whom is an antagonist.
- Multilateral activities involve competition among three or more individuals.
- Intra-group activities involve two or more people cooperative working towards a mutual goal
- Inter-group activities involve competition between teams of two or more.

While these social interaction patterns are common in recreation and leisure pursuits, little attention is given to these social interaction patterns when studying leisure behavior. The social structure associated with leisure pursuits have been found to enhance overall health and well-being (Crandall, 1979; Iso-Ahola & Park, 1996; Lin, Simeone, Ensel & Kuo, 1979). The benefits of this social structure come from the social supports provided by our relationships with family and friends. Therefore, much
attention is devoted to understanding the social nature of leisure via our relationships with friends and family (Freysinger, 1995; Green, 1998).

**Friends.** Friendships help people live longer, healthier and happier lives; therefore, increasing levels of life satisfaction (Johnson, 1996; Lin et al.; Lowenthal & Haven, 1968). Like leisure, the word friend is hard to define, yet several characteristics of friendships are prevalent in the literature. The literature illustrates that while friendships are important for all subgroups of society, the perceptions of friendship differ among men and women (Green 1998; Green, 2002; Wright, 1969) and the young and old (Adams, 1993; Field, 1999; Green, 2002; Jerome, 1981). There are certain elements of friendships that are commonly recognized in the literature. Friendships are voluntarily chosen (Field; Jerome) for reasons unique to each individual (Adams, 1989; Field). Furthermore, Jerome highlights the ability of friendships to adapt to changes.

Weiss and Lowenthal (1975) examined the characteristics associated with friendships. In this study, 216 respondents (of varying ages) were asked to describe their friends. They suggested that friends are people with whom one has shared interests, experiences and activities, and with whom one feels comfortable talking. In this study, friends were also seen as people who are supportive, dependable, understanding, and accepting.

More recently, Green (2002) interviewed 10 women (ages 50-87 years) who lived in two rural communities in Florida. She found that friendships were characterized by reciprocity, similar interests, trust, and transcended time and place. Green defines reciprocity, as a “system of exchange” (a give and take relationship) which involves such actions as helping, providing emotional support, and confiding. Furthermore, the women
in Green’s study placed their friendships in the context of what it would be like to be without friends. Green also examined the role of leisure in friendship. She found that certain specific leisure activities facilitated friendships. Leisure time among these women was spent with friends. Furthermore, many of these women identified communicating and staying in touch with friends as being a leisure interest.

The examination of leisure in the context of friendships and friendships in the context of leisure reveals an interactive relationship between these two dimensions of life (Adams, 1993; Green, 1998; Green 2002). The nature of this relationship has been examined in the lives of men and women, older adults, and individuals with disabilities. We have learned from these studies that: 1) people meet friends while participating in leisure activities, 2) people enjoy spending time with friends during leisure; 3) leisure activities provide opportunities for friends to interact with each other (Adams, 1993; Freysinger, 1995; Green, 1998; Green 2002).

Family The role of family has also been examined in the context of the leisure experience (Kelly, 1999; Rapoport & Rapoport, 1975; Willming & Gibson, 2000; Zabriskie & McCormick, 2001, 2003). In order to understand what the relationship between leisure and family is, we need to understand what a family is. When we grow up our family is made up of our parents or guardians or those people who raise us. We may have brothers or sisters, aunts or uncles, cousins, nieces, nephews, and/or grandparents. Shaw (1997) suggests that the nature of families is changing and non-traditional families are emerging (e.g, single parent families, gay and lesbian families, blended and non-custodial families, and families without children). For some of us they are a source of support, people we trust, people who are there forever. might be able to choose our
friends, but we have no choice in our families. As mentioned previously, some researchers such as Rapoport and Rapoport (1975) track the changes in our life, based on the family life cycle. There are those moments when we are children and we are dependent on our parents to take us to ballgames, on vacation or to the zoo. As we grow we tend to rebel against the parental forces and attempt to find our way in the world – sometimes our parents watch us fail, other times they are there to support us. Then we reach a point in life when we have children, take them to ballgames, on vacation or to the zoo. Then there are times when we take care of our parents – take them to ballgames or the zoo. The family life cycle is cyclical. The family remains constant in a world of change. The family is just that – family.

Rapoport and Rapoport suggest that the relationship between leisure and family changes throughout the course of a life. They suggest that when people have children they tend to do pursue different leisure experiences than families without children. Willming and Gibson (2000) discuss how having a family can get in the way of the parent’s pursuit of leisure. Others have discussed how leisure has brought families closer together.

And so, leisure is a complex phenomenon with the characteristics of freedom and positive affect. The nature of this phenomenon is existential and involves social interaction and societal influence. We know that leisure exists throughout one’s life and is often compared to other domains of life such as family and work. Leisure is an experience in which people participate and from which people derive satisfaction. This experience is unique to each individual and involves motivations and constraints. Furthermore, the leisure experience often involves some form of social interaction. This
is what the leisure experience is about in the “normal” society. Is the experience similar or different for individuals with developmental disabilities?

**Leisure and Individuals with Developmental Disabilities**

If the primary purpose of most human service agencies is to enhance the quality of life of their clients with developmental disabilities, and if the normalization principle is a reflection of quality of life, then it is essential to determine whether or not the leisure of young adults with developmental disabilities reflects the leisure of the normal society. So in this section, we will examine what we know about leisure and young adults with developmental disabilities. Using the format of the previous section we will examine how the characteristics of leisure are present in the lives of young adults with developmental disabilities. We will also examine the existential and social nature of the leisure experiences of this population.

**Characteristics of Leisure**

Recall from the previous section that leisure has two generally agreed upon characteristics. The first is that leisure is something in which a person freely chooses to engage. The second characteristic is that leisure generates positive emotions such as happiness. The literature supports the notion that individuals with developmental disabilities are capable of experiencing these two characteristics.

**Freedom and Self-Determination**

In order for individuals to experience freedom it is essential that individuals with developmental disabilities be given the opportunity to make choices. And while this may not always have been the case, recent developments in the human service fields promote practices such as person-centered planning and self-determination. We know that when
individuals with developmental disabilities are given the opportunity, they can make choices about their lives.

Individuals with developmental disabilities historically have had few opportunities to make choices in their lives (Mahon, 1994). Perhaps one reason why these individuals have had so few opportunities is because of their dependence on social institutions (e.g.: the educational system, the health care system, and families) to meet their needs (Wehmeyer, 1995). A lack of opportunities to make choices should not be confused with an inability to make choices, however. Dattilo and his colleagues have consistently demonstrated that individuals with mental retardation are indeed capable of making choices (Dattilo, 1988; & Dattilo & Barnett, 1985).

Dattilo (1988) assessed the music preferences of three individuals with severe mental retardation. Using a single subject research design, he asked each participate to identify which type music (Classic, Pop, Christmas and Rock) each participant preferred. He found that each individual could use an electrical switch system to rank his or her preferences and to decide which types of music he or she prefers.

Dattilo and Barnett (1985) studied the relationship between choice making and pleasure among four individuals with severe mental retardation using a single subject research design. Facial expressions and vocalizations were the units used to measure affect in this study. They found that there is a difference in affect depending on situations where individuals make choices versus the situations where individuals are not asked to make choices. In this study, the individuals with severe mental retardation made choices using an electrical switch system. The Dattilo studies suggest that even individuals with the lowest functional skill levels are capable of making choices.
While the Dattilo studies demonstrate that individuals with severe disabilities are capable of making choices, Mahon and his colleague describe effective strategies that enable individuals with mild disabilities to make decisions regarding their leisure. Mahon and Bullock (1992) examined an approach that taught adolescents with mental retardation in a self-contained classroom to make decisions in leisure. In this study, four students with mental retardation were observed two times a week during an eight-week leisure education program. Each session lasted approximately one hour. The leisure education program emphasized instruction in decision-making and leisure awareness. A single subject alternating treatment design was used in this study. Mahon and Bullock found that the program was successful in promoting decision-making.

Mahon (1994) studied two components of self-determination: decision making in leisure and independent leisure participation. He studied four adolescent males with mild to moderate mental retardation in a self-contained classroom. Using a single subject research design, Mahon examined how teaching decision-making skills impact self-instructed decision-making in leisure. These adolescents were observed in both a structured leisure education session and in an unstructured leisure time. Mahon found that decision-making instruction facilitates “an increase in self-instructed decision-making” (p.67). In addition to these studies, Schleien et al (1995) suggest that choice making should be a skill addressed in leisure skill development programs for individuals with mental retardation.

While we know individuals with developmental disabilities are capable of making decisions, we also know that individuals with developmental disabilities are capable of having feelings.
**Positive Emotions**

Happiness was the primary emotion discussed in the section of leisure and the “normal” society. Much has been written about how individuals with developmental disabilities are capable of experiencing happiness. Carver (2000) suggests that individuals with developmental disabilities experience joys and sorrows the same as people without disabilities. Therefore, he believes that “no one’s happiness is any more real or valid than anyone else’s. People who work with this population often describe situations like the following. Crocker (2000) writes of visiting a three-year-old boy named Brian,

who lit up our space with his spirit of joy” He had been born prematurely (with a birth weight of 800g) spent 90 days on a respirator, was initially diagnosed with serious visual impairments, and went on to have major expression of cerebral palsy (requiring surgical intervention). When we saw him many of these elements had modulated, and he clearly loved life. In this visit he was curious, social, sensitive, and warmly projecting. After he left we all felt that we had been touched by a gifted little person, and we were searching for some insight regarding his unmistakable happiness. The final interpretations were not complicated (p. 319).

Much like Crocker, Robison (2000) describes how his children with Down syndrome share their stereotypical happiness with people whom they encounter. While numerous examples are available to provide anecdotal evidence that these individuals are capable of experiencing happiness, according to Meyer (2000) several quality of life studies indices document happiness among individuals with developmental disabilities as well.

And so, based on the characteristics of leisure, it would seem as though individuals with developmental disabilities are capable of experiencing leisure. What follows then is a description of how other facets of the leisure experience pertain to this population.
The Nature of the Leisure Experience of Young Adults with DD

As mentioned previously, the nature of the leisure experience involves existential and social components. Therefore, this section describes what we know regarding the nature of the leisure experiences of young adults with developmental disabilities. We discuss this topic much as we did earlier -- focusing on the idea that leisure is an experience that occurs throughout the life course in the context of similar domain. Furthermore, the leisure experience involves concepts such as leisure participation, leisure satisfaction and leisure meaning. The social nature of this experience will also be discussed.

Leisure as Experience

For individuals without disabilities, the leisure experience is multi-faceted. The existential nature of this experience occurs throughout life in the context of other domains of life. The leisure experience involves participation, meaning and satisfaction. This section describes how the existential nature of the leisure experience has been studied among individuals with developmental disabilities.

Life Course. It was mentioned previously that studying leisure from a life course perspective involves examining leisure at different stages of an individual’s life. While much of the life span has been examined in the generic leisure literature, relatively little attention has been paid to the life span of individuals with developmental disabilities. That which has been written has focused on two areas: leisure for older adults with developmental disabilities and leisure for individuals with developmental disabilities as they transition to adulthood.

Transition services. In this study, the participants are currently transitioning from high school to adult life. As young adults with developmental disabilities, they have been
and are currently recipients of specific services which have been designed to aide in this transition. This section will describe transition services and implications related to recreation and leisure.

In 1984, transition services were brought to the forefront when Will suggested that schools should better prepare children with disabilities for adult life (Flexer, 1999; Halpern, 1985, 1993; Will, 1984). The emphasis of her transition model was placed on employment outcomes. In 1985, Halpern suggested that transition services embrace a broader viewpoint which includes the overall concept of community adjustment.

Transition services refer to those services provided by the school system that assist students in making the transition from school to adult life.

According to the Individual’s with Disabilities Education Act, IDEA (1997) transition services are a:

coordinated set of activities for a student with a disability that (a) is designed within an outcome-oriented process, that promotes movement from school to post-school activities, including postsecondary education, vocational training, integrated employment (including supported employment) continuing and adult education, adult services, independent living or community participation; (b) is based on the student’s needs, taking into account the student’s preferences and interests; and (c) includes instruction, related services, community experiences, the development of employment and other post-school objectives and when appropriate, acquisition of daily living skills and functional vocational evaluation (Section 602).

The purpose of these services is to teach the skills “needed for successful adult functioning” (Flexer, McMahan, & Baer, 2001, p. 39). Flexer et al., suggest that there are nine transition practices which have received wide-support. According to Flexer et al, these nine areas include: self-determination, ecological approaches, individualized backward planning, service coordination, community experiences, assistive technology,
post-secondary education, systems change strategies, and family involvement; and are commonly incorporated into transition curricula.

**Transition services and leisure.** Often transition services focus on developing skills associated with the living, working, and learning domains of life (Lohrmann-O’Rourke & Gomez, 2001). It is suggested, however, that the playing domain is important also (Lohrmann-O’Rourke & Gomez; Strand & Kreiner, 2001). According to Lohrmann-O’Rourke and Gomez, the playing domain involves developing the skills necessary to participate in recreation and leisure activities. According to Strand and Kreiner, “leisure skills are a critical component of the transition process because it provides many connections and relationships for common participation” (p. 476).

The idea, that recreation and leisure are important transition services, is supported by legislation that recognizes the importance of recreation and leisure in the lives of individuals with disabilities. When IDEA was reauthorized in 1997, related services were added to the transition components of the law (Flexer, 2001). Recreation is a related service that involves four components: (a) assessment, (b) leisure education, (c) therapeutic recreation and (d) recreation in school and community agencies (Bullock & Johnson, 1998). According to Bullock and Johnson, assessment involves determining the “current functional strengths of students with disabilities in terms of skills, abilities and attitudes” (p.114). Leisure education is “instruction to improve school and community involvement and social connectedness through the development of positive attitudes toward leisure, the development of skills necessary for recreation participation, knowledge of recreational resources, and recognition of the benefits of recreational involvement” (p.114). Therapeutic recreation is defined as “the purposive use of
recreation activities and experiences to ameliorate deficits in social, cognitive, and physical functioning of students with disabilities” (p.114). And, “the provision of recreation services to students with disabilities in the most inclusive setting possible” is referred to as recreation in school and community agencies (p.114).

Assessments and curriculum designed specifically for transition services also include recreation and leisure components (Brolin, 1978; Sample, 1995; Smith, 1995). Brolin’s Life Centered Career Education (LCCE) curriculum addresses 22 competencies in the areas of daily living skills, occupation guidance and preparation, and personal-social skills. These areas are supported once academic skills are developed. In this “Utilizing Recreation and Leisure” is one of competencies in the daily living skills domain of this curriculum. The subcomponents of the utilizing recreation and leisure competency embedded in the LCCE curriculum are a) participate actively in group activities; b) know activities and available community resources; c) understand recreational values; d) uses recreational facilities in the community; e) plan and choose activities wisely; and f) plan vacations.

In 2000, da Gama examined the role of recreation in five transition programs (the Transition Plus Program in St. Paul, Minnesota; Project Challenge in St. Cloud Minnesota; Community Based Services in Seattle, Washington; Transition Program in Issaquah, Washington; and the Prevocational Program in Bremerton, Washington). He interviewed nine parents, 21 program staff and six community programs associated with these programs. “There was a general consensus among all of the subjects that the role of recreation in transition so far had been minimal” (p. 121).
Transition services continue to prepare individuals with disabilities for all facets of adulthood. A consistent theme throughout this literature review has examined leisure in the context of other domains of life (e.g. school and work). Transition services connect the different domains of life, preparing individuals to work, to play and to live within the community.

**Work and Leisure Among Individuals with DD.** Working is an important facet of adult life – this is true for individuals with developmental disabilities, as well. This section will describe the role of work in the lives of individuals with developmental disabilities. A comparison between work and leisure will also be addressed.

According to Hickson, Blackman & Reiss (1995), while most adults with mental retardation are capable of working as many as 90 percent are unemployed. Fesko, Temelini and Graham (1997) surveyed 568 staff and 303 consumers from community rehabilitation providers, independent living centers, and state vocational rehabilitation agencies. They found that:

- 82% of individuals with mental retardation earned less than $5.50 an hour.
- 39% individuals with mental retardation worked 20 hours or less.
- Individuals with mental retardation were less involved with the job search process than individuals with other types of disabilities.
- Staff use more individualized job placement strategies for this population.

Individuals with mental retardation who work do so in a variety of settings ranging from competitive employment to sheltered workshops. *Competitive employment* typically refers to working in a community based facility, performing tasks the same as individuals without disabilities (Hickson et al.; Luft, Koch, Headman & O’Connor, 2001). In this setting, individuals with disabilities earn the same wages and have the same opportunities for advancement as individuals without disabilities. The literature uses the term
supported employment to describe situations where individuals with disabilities work in the community but have additional supports and training. Clustered placements and enclaves are terms that describe a small group of workers with disabilities who work with in an organization that primarily employs individuals without disabilities. Mobile crews involve taking a group of individuals with disabilities into various sectors of the community to do a specialized task. Entrepreneurial employment involves creating a small business primarily operated by individuals with disabilities but also employs people without disabilities. Sheltered workshops employ large numbers of individuals with disabilities and provide additional services to these employees.

While having a job, in and of itself, might contribute to a person’s quality of life, another contributing factor might be the degree of satisfaction associated with one’s job. According to a study by Virginia Commonwealth University (VCU, 1997) 90% of individuals with disabilities surveyed (n=110) reported liking their job. 53% of these respondents felt that their job was O.K. but that they’d rather be doing something else. They reported people, job duties, work conditions and having a job as being the aspects of the job that they liked.

Dixon and Reddacliffe (1996) interviewed young adults with developmental disabilities in Australia about their work experiences. These young adults stated that they enjoy work, because work prevents boredom, develops skills, enhances self-concept, promotes independence and provides life experiences. In the same study, Dixon and Reddacliffe report several work-related problems identified by these young adults. These problems include interpersonal difficulties, asocial behavior, qualifications and learning difficulties, rejection, time constraints, and underemployment.
It has been noted by Dixon and Reddacliffe that one of the biggest work-related problems of individuals with disabilities is their ability to interact socially with co-workers. Yet, Fesko, Temelini and Graham report that 96% of individuals with mental retardation report that they felt comfortable asking co-workers for assistance and 90% of these individuals felt comfortable asking their supervisor for help when necessary. According to Sinnott-Oswald et al (1991) leisure activities, use of leisure time, and involvement in activities were related to supported community employment.

The amount of free time associated with not working, the perceived enjoyment associated with the work experience, and the social nature of the work environment suggests that the relationship between work and leisure for this population might reveal interesting findings. Little research, however, has been done in this area.

**Operationalizing the Leisure Experience of Individuals with DD**

Most of the research about recreation and leisure of individuals with developmental disabilities examines the operationalization of the leisure experience. Efforts to understand the participation patterns, motivational properties and constraints have been a primary interest of researchers in this area. Likewise, the benefits of therapeutic recreation programs for this population have been examined thoroughly. Less attention has been granted to the areas of leisure meaning and leisure satisfaction associated with this population. This section will address the research in each of these areas.

**Participation.** As mentioned previously, the concept of leisure participation involves the behaviors associated with being engaged in an activity that is freely chosen and enjoyable. When attempting to operationalize leisure participation, scholars examine specific activity involvement, motivations, and constraints. In the area developmental
disabilities, this concept is measured most frequently in articles examining recreation participation patterns.

**Specific Activity Involvement.** As mentioned previously, specific activity involvement is measured by examining those activities that people find enjoyable. Research in this area has examined leisure preferences, actual participation patterns, and benefits associated with participation.

Individuals with mental retardation have leisure preferences. Malik (1991) and Hoge and Dattilo (1995) found that individuals with mental retardation preferred certain activities over other activities. Malik found that relationships are very important to this population. Individuals with mental retardation also prefer participating in activities with people who are like them (Neumayer, Smith, & Lundegren, 1993).

While some studies examined what the preferences of this population are, Sparrow and Mayne (1990) examined actual participation patterns. They observed 40 adults with mild intellectual disabilities and found that 49% of the participants participated in hobbies and pastimes; 35% participated in indoor recreation; 18% in health and fitness activities; 10% in team sports and outdoor pursuits; and 3% in individual sports and water activities. Hawkins (1991) found that males with mental retardation were more likely than females to watch sports and take classes. She also found that males indicated more of a desire to dish, boat or canoe, ride a bicycle, engage in pet care, and jog or run than females. Hayden et al (1996) examined two groups of individuals with mental retardation. One group lived in an institution, the other group lived in the community. Both groups tended to participate in passive leisure activities (e.g. watching or listening to TV, radio, and records).
In some cases, researchers explored the benefits of recreation participation for this population. Bedini, Bullock, and Driscoll (1993) found that individuals who participated in a leisure education program demonstrated positive changes in the areas of competence, self-esteem, communication, perceived control, social skills, feelings about leisure, life satisfaction, and feelings about life. These changes, however, were not statistically significant. Wilhite and Kleiber (1992) found that individuals with moderate to severe disabilities who were involved in sport were more likely to frequent other community locales and showed a trend towards interacting with other people to a great extent than those not involved in sport. Likewise, Mactavish and Searle (1992) found that participation in physical activity was found to have a significant and positive effect on perceived competence, locus of control and self-esteem.

And so, several researchers have studied the preferences, actual participation patterns and benefits associated with specific activity involvement. Some researchers have gone beyond this in order to understand the motivations and constraints associated with recreation participation.

Motivations. As mentioned earlier, motivations explain why people engage in specific activities. Several studies reveal different motivations related to the leisure pursuits of individuals with developmental disabilities. Some studies focus on motivations for specific recreation programs (Kleiber et al, 1990; Shapiro, 2003) while others examine the motivations for leisure on a broader spectrum.

Kleiber et al (1990) examined the reasons why people went to Special Recreation Association (SRA) programs. They found 30% referred to specific activities; 28.3 % participated because it was something to do, 21.2% reported that they enjoyed being there
and 6% reported being with friends and meeting new people as a reason why they kept going to SRA programs. Shapiro and Yun (2003) developed and tested a Sport Motivation Questionnaire for persons with mental retardation. Shapiro (2003) found that Special Olympic athletes primarily participated in order to improve their abilities and to interact with their friends.

On a more global basis, Koegel, Dyer and Bell (1987) suggest that social avoidance behavior increases after individuals with developmental disabilities experienced repeated failures in social situations. They also found that successes in child-preferred activities might serve as motivation to decrease social avoidance behavior. Malik (1990) found that participants in her study wanted to learn “adult skills.”

This literature related to individuals with mental retardation supports two areas of motivation identified by Beard and Ragheb (1980). The two types of motivation are social and stimulus/avoidance.

**Constraints** The literature has identified several constraints which limit the recreation and leisure participation of individuals with developmental disabilities. Some studies found the lack of financial resources to be a barrier to leisure participation among individuals with mental retardation (Bedini, Bullock, & Driscoll, 1993; Hawkins, Peng, Hsieh & Eklind, 1999; Hoge & Dattilo, 1995; Sparrow & Mayne, 1990). Hoge and Dattilo, Hawkins et al., and Sparrow and Mayne found that individuals with mental retardation lacked the transportation necessary to get to the leisure activities that they prefer. Furthermore, all three studies found that individuals with mental retardation often lacked the skills necessary to pursuing leisure activities. Hoge and Dattilo found that many times these individuals were unaware of leisure services. The lack of opportunities
was cited as a barrier to leisure participation in two studies (Hoge & Dattilo; Sparrow & Mayne). Bedini (2000) described the phenomenon where the society’s attitudes about individuals with disabilities limit leisure opportunities as being a stigma. Hoge and Dattilo and Sparrow and Mayne identified social stigma as being a leisure constraint for individuals with mental retardation. The lack of friendships and social support is yet another leisure constraint identified in the literature (Green & Schleien, 1991). Hawkins (1991) reported that individuals with mental retardation have low levels of perceived competence and that these low levels of perceived competence may limit an individual’s ability to participate in freely chosen leisure pursuits. The last barrier to leisure participation mentioned in the literature pertains to the concept of self-determination. Many individuals with mental retardation are not allowed to make choices about their leisure pursuits (Dattilo & Barnett, 1985; Hawkins et al, 1999). This lack of choice limits the number of leisure opportunities that individuals with mental retardation are given.

These constraints can easily be categorized into the types of constraints identified by Crawford et al., (1991). For example, constraints related to activity skill, perceived competence, self-determination, and awareness may be classified as intrapersonal constraints. The lack of friendships and social support would be consistent with interpersonal constraints. And, structural constraints might include the lack of financial resources, transportation, opportunities, and social stigma. Hawkins et al. tested the hierarchical negotiation of constraints model (Crawford et al., 1991; Jackson et al., 1993), with individuals who had developmental disabilities. Hawkins et al (1999) found that structural and interpersonal constraints were most common among individuals with mental retardation.
Satisfaction. We know little about the concept of leisure satisfaction in relation to individuals with developmental disabilities (Bedini et al., 1993; Williams & Dattilo, 1997). Bedini et al., reported that they asked individuals with mental retardation, as they made the transition from school to adult life, about leisure satisfaction. Williams and Dattilo report that individuals with mental retardation could demonstrate feelings of positive affect via smiles and vocalizations. They suggest that these gestures indicate a type of psychological and/or physiological satisfaction response. However, more research is needed regarding leisure satisfaction among individuals with mental retardation and other developmental disabilities.

Meaning. While little research has been conducted examining leisure satisfaction among this population, even less research has been conducted regarding the concept leisure meaning and leisure perception (Dattilo & Hoge, 1995; Malik, 1990). Malik interviewed 19 residents of group homes in Illinois who had mental retardation questions regarding leisure awareness, leisure perception, and leisure interests. Two of the respondents in her study were able to define leisure and did so by including a component of being by oneself. Twenty-seven percent of the respondents in the Malik study were able to define recreation. They described recreation as: activities, time and freedom, and feelings/experiences.

Dattilo and Hoge (1995) interviewed 100 individuals with mental retardation who were participants in a leisure education program. They identified three overarching themes associated with the concept of leisure perception. These were leisure preferences, benefits of leisure participation, and constraints to leisure. Both studies on leisure perception, suggest a need for further research in the area of leisure meaning.
Social Nature of Leisure Among Individuals with DD

As mentioned previously, part of the social nature of the leisure experience involves the interactions that we have with others. For individuals with developmental disabilities, friends and family are important to the leisure experience. Despite the importance of social interactions and the leisure experience, individuals with developmental disabilities are more likely to do things by themselves (Dattilo & Hoge; Sparrow & Mayne, 1990). Sparrow and Mayne found that 44% of their participants (n=40) spent time engaged in solitary activities, while 37% spent time with friends and 19% spent time with family. Therapeutic Recreation programs for this population tend to focus on the development of social skills and friendships (Dattilo & Schleien, 1991). Many of the leisure experiences of individuals with developmental disabilities involve interacting with others. This section will describe what is known about the interactions that these individuals have in relation to friends and family.

Friends

The friendships of individuals with developmental disabilities are just as important to the leisure experiences of this subpopulation as they are to the “normal” population. Individuals with developmental disabilities can benefit from friendship much like the rest of the population. Thus, friendships can help individuals with developmental disabilities live longer, happier and healthier lives. This section describes what is known about the friendships of individuals with developmental disabilities.

As previously mentioned, there is some conflict in the literature regarding friendships and social interactions as being a motivational component associated with the leisure experiences of individuals with developmental disabilities. Recall that Dattilo and Hoge (1995) report that individuals with mental retardation like to do things by
themselves. Does this necessarily mean that they prefer solitary activities? Might it mean that they prefer independence and autonomy? Malik (1990) suggests that relationships are very important to individuals with mental retardation. Kleiber et al (1990) conducted a study in a similar region of the country and found that 6% of the individuals kept attending the SRA program so they could be with friends and meet new people. Likewise, they found that 82.1% of their participants indicated that the SRA program helped them make new friends. Almost 44% of the participants in Kleiber et al’s study reported doing things with SRA friends outside of SRA.

If friendships are important to this population, how are friendships perceived by them? Neumayer, Smith and Lundegren (1993) suggest that individuals with Down syndrome prefer bowling with other individuals who have Down syndrome. Hayden et al., (1996) found that their participants primarily engaged in activities with friends who were also disabled. Kultgen and Hawkins (1992), likewise use social comparison theory to describe why people with disabilities might prefer being friends with other individuals who have disabilities.

Several researchers suggest that inclusion should encourage friendships between individuals with and without disabilities (Dattilo & Schleien, 1991; Green & Schleien, 1991; Hayden et al., 1996). In fact, many inclusive recreation programs fail in their attempts to facilitate friendships between individuals with and without disabilities. Green and Schleien suggest that adults with mental retardation who live in the community rarely develop meaningful reciprocated friendships. They further suggest that this population does not meet or make friends via recreation participation. Some researchers attribute this failure to the poor social skills of individuals with developmental disabilities and,
therefore, suggest that therapeutic recreation programs include social skill and friendship development interventions (Green & Schleien, 1991; Heyne, 1997).

While individuals with developmental disabilities may not interact fully with their peers who do not have disabilities, it is unknown as to why this occurs. It may be a reflection of an individual’s preferences or it may be a reflection of the person’s skill deficits. Likewise there is conflicting information about the role of friendships in leisure pursuits. Much more research is needed in this area in order to understand the nature of these relationships.

**Family**

As stated earlier, we can choose our friends but we cannot choose our families. Families are important to individuals who have developmental disabilities. When children with developmental disabilities are born, parents begin advocating for the rights of their children. Parents and guardians identify and seek out the best services for their children. Sometimes family decisions (e.g. where to live and work) revolve around the services that these children receive. As the children age, siblings join parents in being advocates for these individuals. Many adults with developmental disabilities live with their parents. Since families are instrumental in the lives of this population, a body of knowledge emerges which illustrates the role of family in the leisure pursuits of individuals with developmental disabilities. This section will describe the familial nature of this leisure experience.

Mactavish (1994, 1997) found that three family recreation patterns tend to exist in families who have children with developmental disabilities. She suggests that the whole family may participate in a given activity. She also found that within the familial structure small groups emerge. These small groups engage in activities together.
Mactavish also found that people alternate between doing things with the large familial group and the smaller one. In her study, the small group activities tended to dominate.

These families participate in five categories of activities which include passive activities, play, physical, social and entertainment (Mactavish, 1994, 1997; Mactavish & Schleien, 2000). Mactavish found that the level of disability affects the recreation patterns of these families. Her findings suggest that families who have children with significant disabilities tend to engage in passive, play-oriented activities, while families who have children with milder conditions tend to participate in physical activities and entertainment. Overall, she found that these families frequently participate in physical activities, passive activities and social activities.

Mactavish, Schleien and Tabourne (1997) report that 60% of the respondents in their study (n=65) believed that their family recreation occurred equally in both the home and the community. While 29% reported spending this time at home and 11% reported spending this time in the community. They found that during the summer months nearly 77% reported spending more family time in community locations.

The body of knowledge reflecting the nature of family recreation in families who have members is relatively limited in scope. Most of this literature is based on one study (Mactavish, 1994) and therefore describes the recreation patterns of families who have children with developmental disabilities in one large urban center in the upper Mid-West. More information is needed on families who include individuals (who are not children), yet have developmental disabilities.

**Summary**

While much has been written about the leisure experiences of individuals who have developmental disabilities, there are some gaps in the literature. The literature suggests
that the leisure experiences of young adults with developmental disabilities may reflect that of young adults without disabilities, thus revealing that the leisure experience might be a reflection of the normalization principle actualized. The characteristics of leisure (freedom and positive affect) have been reported to exist in both populations. Likewise, the existential and social nature of leisure appears to be present in two groups. Further research is needed to expand our understanding of the comprehensive nature of the leisure experiences of young adults with developmental disabilities. This study intends to fill that void.
CHAPTER 3
METHODS

This chapter describes the processes and procedures used in this study. Furthermore, in this chapter the unique and defining characteristics of the people and places studied in this project are described. The beginning of this chapter describes the methods used to collect data for this project. Once these procedures are described, the actual process that occurred in this study is explained. Characteristics about the research participants and the unique community in which they lived are shared.

The purpose of this study was to understand the subjective nature of the leisure experiences of young adults with developmental disabilities. In order to accomplish this task, a naturalistic perspective was adopted and qualitative research methods were used. A naturalistic research perspective embraces the idea that “an emerging propositional or theoretical understanding…is grounded in the real lives and the real worlds of the persons and the phenomenon being studied” (Bullock, 1993, p.29). As Glancy (1993) states, “to become informed about the subjective perspective, the inner way of knowing that frames the thinking and behavior of a client or group must be learned as it is known by them” (p. 259). In the context of this study, the naturalistic perspective was used to understand the leisure experience from the words of young adults with developmental disabilities.

In order to accomplish this task, a variety of qualitative research methods were used. The primary method of data collection involved in-depth interviews with individuals who have developmental disabilities. A secondary method of data collection involved follow-up interviews with the research participants and their significant others.
Additionally, participant observation was used to gather additional information about the community and the research participants.

**Data Collection**

Since the intent of this project was to understand the subjective nature of the leisure experiences of young adults with developmental disabilities, a research method which examines an experience from the perspective of the research participant was used. According to Henderson (1991), interviews are used “to find out what is on people’s minds and to access the perspective of others” (p.81). Holstein and Gubrium (1995) state “social researchers generate massive data by asking people to talk about their lives; results, findings, or knowledge come from conversation” (p.2). In an approach that Holstein and Gubrium call the “active interview,” both the researcher and the research participant guide the interview process. *Right or wrong* responses are non-existent. The process of interviewing is flexible and topics evolve throughout the conversation.

**Interviews and Developmental Disabilities**

While the importance of including the perspectives of individuals with intellectual disabilities in the research process has been noted, there have been few successful research endeavours in this area (Mactavish, Lutfiyya, & Mahon, 2000). Historically, when individuals with cognitive disabilities were interviewed, standardized, open-ended interviews have been used (Dattilo, Hoge & Malley, 1996; Malik, et al., 1991; Sigelman et al, 1983). Malik et al., stated that “yes/no and either/or questions have been found to be the easiest type of questions for persons with mental retardation to answer. Yet such questions are subject to the greatest amount of acquiescence” (p.62). In regard to multiple choice and likert type scales, “items are somewhat more difficult, but offer less chance for acquiescence” (p.62). Studies such as the one by Malik and her colleagues (1991)
demonstrated the ability of individuals with cognitive impairments to be actively involved in the research process. Malik et al. suggest that interviews should not last longer than 30 minutes at a time, in order to prevent participant fatigue. In recent years, research with this population has included more informal interviewing techniques (Dattilo, 2002b; Dattilo & Hoge, 1995; Mactavish et al., 2000; Malik, 1990; Pedlar, Haworth, Hutchison, Taylor & Dunn, 1999).

**Applying the Interview Process**

There were three phases of the interview process. The first phase involved interviewing research participants who agreed to participate in this study. The second phase involved re-interviewing these initial participants and interviewing those participants recruited during the second phase of this study. The third phase of the interview process involved interviewing an individual whom the initial research participants identified as being a member of their circle of support.

All of the interviews conducted for this study were semi-structured, in-depth and face to face. Furthermore, each interview conducted for this study was audio-taped and transcribed. Each interview was conducted at a time and place chosen by the interviewee. Therefore, these interviews occurred in bowling alleys, fitness centers, private residences, and restaurants.

The purpose of the first phase of this study was exploratory in nature. These first interviews were scheduled and conducted once participants indicated an interest in participating in this study (further information about the recruitment phase of this study and the individuals who participated is discussed later in this chapter). Once these individuals expressed an interest in this study, an acquiescence scale was used to assess
each research participant’s ability to respond appropriately to questions. The scale
described by Perry and Felce (2002) that was used involves the following four questions:
(After pointing to the person’s watch or some item of clothing)

- Does that (watch) belong to you?
- Do you make all your own clothes and shoes?
- Have you seen the people who live next door?
- Did you choose who lives next door?

According to Perry and Felce, the second and fourth response should be negative. All of
the individuals who expressed an interested in this study were deemed appropriate.

Once the research participant’s skills were assessed, an informed consent process
occurred. Parents were asked who the legal guardian of each participant was. Consent
was obtained by the legal guardian, in some cases the legal guardian was the individual
with the developmental disability. In all cases, the research participant was informed of
the research protocol via the informed consent document or the assent script approved by
the Institutional Review Board at the University of Florida.

The interviews were conducted when the informed consent process was complete.
During the first phase of this study, interviews lasted between 15 minutes to 42 minutes
depending on the participant’s ability to answer questions. A predetermined interview
guide (Appendix A) was used to initiate the conversation between the researcher and the
research participant. This interview guide was designed to understand the leisure
experiences of individuals who have developmental disabilities. Questions addressed
facets of leisure experience (e.g. constraints, motivations, perceptions, attitudes,
participation, satisfaction and meaning). Prompts and probes were used to clarify and
elaborate points made by the research participant.
The purpose of the second phase of the interview process was to verify and expand upon themes developed during the initial interview process. Therefore, during the second phase of the interview process, interviews lasted between 10 and 20 minutes. A second interview guide was used for this interview (Appendix B). The questions on this interview guide examined emerging topics (e.g., normalization, friendships, family) and verification topics (e.g., happiness, enjoyment, activities).

The third phase of the interview process involved interviews with individuals whom the primary research participant identified as being an individual trusted or felt knew them best. These individuals were considered to be a member of the primary research participant’s circle of support According to Pedlar et al., (1999) a circle of support includes those individuals in a person’s life who “reinforces his or her strengths by providing encouragement, instruction where needed, reassurance, trust, and unconditional love and caring” (p.6). This person was identified during phase one of the interview process with the questions:

- Who do you trust?
- Who knows you best?
- Would you mind if I ask them questions about you, like the ones I asked you today?

In this study, all of the participants identified their parents as the individual(s) that they either trusted the most or knew them the best. For the most part, one parent was interviewed for each participant in this study. The exception was that one mother asked her husband to help respond to the questions. In this interview the parents responded to the questions together. These interviews lasted from 15 minutes to 1 hour. The initial circle of support interview guide (Appendix C) designed for this project, was modified (Appendix D) to reflect the emerging themes in this study. These interviews discussed the
parent’s understanding of their own leisure; the parent’s understanding of their child’s leisure; information about the child’s background (e.g., diagnosis, schools, family life), friendships, and the parent’s perception of normalization.

The information obtained from these interviews served as the basis of this study. As themes emerged from the data obtained in the interviews it became apparent that an unique community was being studied. Therefore, participant observation was used to gather additional information about the community, the families, and the participants being studied.

Data Analysis

The emerging nature of the data collection process is consistent with the process of constant comparison. Constant comparison techniques were used throughout this study interviews were transcribed and analyzed continuously. As these transcriptions were analyzed, themes emerged. Initially open coding procedures were used. According to Strauss and Corbin (1998) open coding is “the analytic process through which concepts are identified and their properties and dimensions are discovered in the data” (p.101). Once open coding procedures were implemented, axial coding procedures were applied. Axial coding is the process of grouping data by means of sub themes. Once the processes of open coding and axial coding were implemented, a theory is refined and integrated through the process of selective coding. This process occurs at the point of theoretical saturation, which is “the point in category development at which no new properties, dimensions or relationships emerge” (p.143). Therefore, a grounded theory is developed.

Constant comparison was used “for raising questions and discovering properties and dimensions that might be in the data” (Strauss & Corbin, 1998, p.67). Furthermore, constant comparison was used to determine the point of data saturation, which may occur
with a sample size of eight (McCracken, 1988). Once the initial eight interviews were conducted, the interviews were transcribed and initial themes surfaced. Upon analysis of these initial themes, additional questions arose. Consistent with the constant comparison technique, a second interview guide was developed (Appendix B) to verify themes that were emerging. Likewise, the interview guide initially designed to be used with the circle of support (Appendix C) was revised (Appendix D) to reflect the emerging themes. Two additional participants were recruited for the second phase of data collection, to verify data saturation.

**Reliability and Validity**

Efforts were taken initially, to recruit individuals who were capable of providing consistent and accurate responses. Due to the nature of the study, the research participants were screened via an acquiescence scale. In order to assess the reliability and validity of these interviews, two methods were used. First, as previously mentioned, verification interviews were conducted with each research participant to determine whether initial responses were accurate and to determine whether themes were repeated. Within each interview session, several questions were repeated to determine consistency and accuracy of the responses of each participant. Likewise, several questions from the first interview were repeated with each respondent. Secondly, data from the interviews with the research participants were compared to responses from interviews with individuals in the research participant’s circle of support (Appendix C). For the most part, the responses that the participant’s gave during the first interview were consistent with the responses in the second interview. Likewise, most of the responses of the parents reflected that the initial responses of the primary research participants were accurate.
All of the interviews were conducted by the same researcher. She also transcribed each of the interviews and analyzed the data. During the initial phase of data analysis, she consulted one of the dissertation committee members who has experience conducting qualitative research. Upon consultation, the researcher and the consultant revised subsequent interview guides.

During the data analysis phase of this project, two experienced researchers independently read the transcripts of the interviews obtained in this study to check for emerging themes. These researchers both earned master’s degrees in Recreation, Parks and Tourism and have extensive research experience. These researchers independently reviewed each transcript and identified themes and sub-themes. Their findings were consistent with the primary researcher.

**Recruitment Strategies**

**Participation Criteria.** The primary research participants were young adults with developmental disabilities. The criteria used for this study was that young adults with developmental disabilities include those individuals ages 18 to 35, who are no longer enrolled as full-time students in a special education classrooms. A developmental disability was defined using the criteria identified by the National Association of Developmental Disability Councils (NADDC) which was described in Chapter 1.

Rather than expanding this sample to include a wide variety of developmental disabilities or by limiting this study to one specific type of developmental disability, (e.g. mental retardation) I focused on a variety of individuals who primarily had cognitive impairments. Therefore, my sample included individuals with mental retardation, autism, Down syndrome, and other non-specific syndromes or disorders.
**Sampling.** A combination of convenience, snowball theoretical and purposeful sampling methods were used to recruit research participants. According to Patton (1980) “purposeful sampling is used as a strategy when one wants to learn something and come to understand something about certain select cases without needing to generalize to all such cases” (p. 100). Patton suggests that purposeful sampling be used when researchers “desire in-depth, detailed information about cases” (p. 101). Lincoln and Guba (1985) described purposeful sampling strategies as having certain particular characteristics, which include a) emergent sampling design; b) serial selection of sampling units; c) continuous adjustment or “focusing” of the sample; and d) selection to the point of redundancy (p.202).

While the identity of the researcher was important throughout this study, perhaps it was most important during the recruitment phase. Whether the study is quantitative or qualitative the researcher’s subjectivities play a role. Who the researcher is, where he or she is from, who the researcher knows, and what experiences the researcher has had in the past are always reflected in the research being conducted. Qualitative research methods recognize this fact and do not attempt to hide it behind the mirrors of random sampling, outliers, or other statistical methods. The qualitative researcher brings a dimension to the research that ultimately affects the nature of the study. This is evident at every step in the research process, especially in the recruiting phase.

Initially, I targeted agencies in Alachua County, FL that serve individuals with developmental disabilities (e.g. the Association for Retarded Citizens) to recruit potential research participants. Letters describing this study were sent to these agencies seeking
permission to recruit and assistance in recruiting participants from each agency. I sought permission to make oral presentations to the participants and staff at each agency.

While visiting the agencies in Alachua county, I wore garments that indicated my involvement with a national organization serving individuals who had developmental disabilities. The reason I wore these garments was to illustrate her experience in working with people who have developmental disabilities. In one agency that I walked into, clients walked up to me and pointed to the emblem on my shirt and said “I used to do things with that organization.” They then proceeded to tell me about recent events in his or her life. Likewise, I attempted to establish rapport with the executive directors of these agencies by discussing public policy issues. Unfortunately, these attempts to establish rapport did not significantly help in recruitment. I relied upon recommendations and referrals of potential research participants and agency staff. Although several agency staff agreed to assist in the process, after three months, one out of 400 potential participants expressed an interest in this study. Numerous attempts were made to contact this potential participant but all attempts failed. I was not successful in breaking into the developmental disabilities community in north central Florida.

This was not the first time my efforts failed. Three years earlier when I first moved to the community, I attempted to become involved with a chapter of a national organization for people with developmental disabilities. It took me approximately six months to get into the organization. After a year of doing administrative tasks for the organization (e.g. planning special events, recruiting volunteers, fund-raising), I was still considered to be an “outsider” and gradually she left the organization. Perhaps this is because of the “turn-over” in a university community or perhaps it is because of the
dynamics of the developmental disability community in general. In the developmental disability community, parents band together to fight for services when the children are young. They support each other through the life course and as such they have shared life experiences.

After three months, I switched communities. I made the transition from being an “outsider” to being an “insider”. I returned to a large metropolitan area in the midwest, where I was an active member of the developmental disabilities community for 12 years prior to studying in Florida. I knew several people who worked in agencies that provided services to young adults with developmental disabilities. I was “an insider” who grew up in the physical community in which these individuals now live. I knew what schools these individuals attended, because my friends and I attended the same schools while growing up. I had worked closely with the school districts and other area agencies throughout high school and college. I attended Individualized Education Plan (IEP) meetings in the district. I knew these people and they knew me. So, the eagerness on the part of these staff and agencies to participate was of no surprise. The staff and agencies in this community invited me to attend a parent support group meeting.

This parent support group meeting was taking place at a community bowling alley and recreation center. While the parents met in the concession area, young adults with developmental disabilities from all over the metropolitan area, bowled and watched others bowl. They socialized and snacked. There were over a hundred young adults with developmental disabilities in the bowling alley that day. Some were with Special Olympics, some were just there to bowl. For others, it was a day structured by their group homes.
I initially met with the parents and staff to explain the project to them, to get an idea of which people would be appropriate participants in this study, and to obtain consent where appropriate. After meeting with the parents, I went out to the lanes and began to meet the potential participants. Several of the participants remembered me from a few years ago and were excited to see me. They ran to me and embraced me. These participants introduced me to other potential participants saying:

- “This is Kari, she used to work at << fill in the blank>>.”
- “This is Kari, she used to coach everything.”
- “This is Kari, she’d help us when we needed her.”
- “This is Kari, she used to do everything for us until she moved to Florida.”
- “This is my friend, Kari.”

They initially began telling me about their current jobs, their friends, and of course, their bowling scores. These participants had never seen me at a bowling alley before. I am not a bowler, I throw gutter balls even with bumpers and a ramp. The ability of these potential research participants to recognize me in a new environment, three years after our last encounter, demonstrates a few points. The first might be that I am “an insider”, someone with whom they are familiar. The second point is that these potential research participants are of a high skill level -- which enables them to acquire, maintain and generalize the skills to recognize certain people in their environment.

That day was the turning-point of this project. At the meeting, parents and young adults with developmental disabilities agreed to participate in this study. They then started to encourage others to participate as well. People were pulling out cell phones and scheduling interviews for me. I was home for the holidays and without a car, so members
in the developmental disabilities community began driving me from one person’s home to another. I was an “insider” and was getting the story from other “insiders.” This project had a life.

**The Physical Community**

It has been recognized that the community being studied also affects the research. In this study, the physical community in which these individuals live is unique. It is not rural. It is not inner city. It is not urban. It is suburban. It is even unique for a suburban community. It is a small town embedded in a busy metropolitan community. In this study, the researcher will call the small town Prairie View and the larger city at the heart of this metropolitan area River City.

Prairie View is a suburb of a large metropolitan area in the Heartland of the United States. Prairie View has its own mayor and city council, police department, volunteer fire department and school district. In the midst of the hustle and bustle of the large city that surrounds Prairie View on three sides, Prairie View still has a small town atmosphere. Downtown Prairie View is about five blocks, yet is home to the annual Fourth of July parade. People come from all over the state to attend this parade and other festivities such as the “firefighter’s games.” There is a gazebo in the center of town where live music is played every week during the summer. There is a community pool that is open to dues paying members. The large new public library provides access to recreational books, children’s literature and the internet. There are five public parks within the city limits and several nature trails. A private golf course and a private fitness center are also located in the small town.

Although the Prairie View is independent from River City; the small town is considered to be part of the larger city – just another borough in the larger community.
Two of the borders that join Prairie View to the larger River City are busy corridors which contain industrial parks and recreational areas. The industrial areas include: car lots, furniture stores, restaurants, and lumber yards. The recreational areas include a small par 3 golf course and driving range; a few upscale of recreational facilities such as: a small scale amusement and water park and a horseracing track; and a large River City municipal park with space available to accommodate four softball games, 15 soccer games, disk golf, tennis, skeet shooting, trail biking, soap box derby racing, and a remote control airplane strip.

On the third side where Prairie View joins River City there are several upper middle class subdivisions and apartment complexes. There are grocery stores and strip malls. Embedded within one of the subdivisions is one of River City’s community centers operated by the municipal recreation and parks department. This community center has a classroom, gymnasium, swimming pool, and game room.

The fourth side of the town borders a small town similar to Prairie View. This town is slightly smaller but also houses recreational facilities such as a large community center, private golf course and park. The homes in this town are smaller and more run down in contrast to the upper middle class properties in Prairie View. In Prairie View, the residents take great pride in remodeling homes, adding on major additions to existing properties, and pursuing massive landscaping endeavors.

Prairie View is a community of approximately 6,000 people. In December of 1998, when most of the research participants in this study were still in school, 77 students between the ages of 16 and 21 received special education services in the Prairie View School District. Of these students 13 had a diagnosis of mild mental retardation, three
were classified as having moderate mental retardation, and four were classified as having severe and/or profound mental retardation. In the Prairie View School District, the number of students with mild mental retardation ranked seconded to those with a specific learning disability (n= 42).

Prairie View is located in a state which has been recognized for innovation in the field of developmental disabilities (Schalock & Braddock, 2002). According to Wolfensberger (2002) there are major sociocultural values in the state, which lead to positive actions in the areas of advocacy, legislation, and service delivery. He suggests that people in the state value: law and order, constitutionalism, middle-church Protestantism (service oriented; guilt motivation), Protestant ethic, fiscal conservatism (non-duplication of services), rugged individualism (mutual assistance), private enterprise, frontier pragmatism, local initiatives and control. According to Wolfensberger, these values prompted the citizens of the state to act by recognizing:

- Service as a right;
- The retarded (sic) as citizens;
- A confrontation with dehumanization;
- Normalization;
- Schooling, training and work;
- Cost-benefit rationale;
- Generic agency integration;
- Citizen advocacy;
- Consumer-professional partnerships;
- Competitive institution standards;
- Realistic limits to demands;
- Dispersal of services;
- And, funding partnerships.

It was actions such as these that prompted the development of innovative programs in the state. Wolfensberger “Americanized” the normalization principle in this state. Schalock studied quality of life of individuals with developmental disabilities, in this
state (Schalock & Braddock, 2002). It was one of the first states to have advocacy groups such as the Association for Retarded Citizens (DeKraai, 2002).

**Research Participants**

Within this community there are several individuals who helped make this study possible. Without the research participants and their families, the project never would have evolved. Initially, ten interviews were scheduled and eight were conducted due to a snow storm that came into the region that weekend. Upon analyzing the initial data, the two participants not interviewed in phase one, were recruited and interviewed during the second phase of the project. Among the research participants, there are differences and similarities. The participants live in different types of residential settings and work in different types of vocational settings. Some knew “me”, others did not. Some are actively engaged in structured recreation activities, others are not. Some are males and others are females. As for commonalities, there are a few. All of the participants were from white, middle class families (as opposed to representing different racial or socio-economic groups). They are all young adults ages 21 to 32 with developmental disabilities (as opposed to being school aged or older adults). They all reside in Prairie View. All of them have tremendous support and encouragement from their families.

Of the ten interviews, two were conducted with individuals with whom I had never worked. One of the two moved to the community from another state after I moved to Florida. The other individual was from another suburb of River City. She recently became active with this group of participants. Two of the interviews were with people who are no longer participating in structured recreation programs for individuals with developmental disabilities. These individuals knew me when they were younger. The remaining research participants were individuals that I worked with in the past. These six
are still enrolled in structured recreation programs. Four of the research participants are male and six are female. At the time of the initial interviews, one was unemployed, four worked in sheltered workshops, and five worked in the community. Two of the participants lived on their own either in an apartment or house, three lived in group homes and the remaining five lived with their parents. This study is the story of ten individuals and their collective experiences. For the purposes of this study, these ten individuals will be called Danny, Diane, Becky, Carol, Jessica, Andy, Mike, Kelly, Naomi, and Charlie. A description of these ten individuals follows.

**Danny**

Danny is a rebel without a cause. Anyone who walks into a room where Danny is, will immediately be struck by the strong presence of a frail looking young boy with no ears. Danny is tall and wiry, yet his fragile body holds the heart of a gladiator. Danny’s personality and spirit are vivacious. He is full of energy, always talking and bouncing off the walls. This energy and spirit often get him into trouble. His restless temperament knows no limits. He will challenge his peers without realizing his limits. He will do what everyone else is doing just to fit in. Danny is cool, there is no doubt about that. He walks with a swagger and hangs out with the cool kids. His parents identify his social presence as one of his strengths. Where ever he is — he runs into people he knows.

He was born 22 years ago with a rare syndrome, that involves an extra tag on chromosome 21. According to Danny’s mom, “we got a big surprise when he was born because he had no ears and they were fearful that he had no kidneys and when he finally urinated, the nurses were screaming, ‘he pee-ed, he pee-ed!’” His parents were told when he was born that there was only one other person in the country with his syndrome. They were told to do the best they could with him and they did.
Danny attended Prarie View Public schools where he was primarily in self-contained classrooms as mainstreaming did not work well for him. When his sister went off to college, they sent him to a group home in the same city. When that group home shut down, Danny moved to a group home in the metropolitan area where his parents reside. He currently resides in this group home. During the first interview he was unemployed, now he works on a voluntary basis at a thrift shop and his parents pay him to mow the lawn. While Danny’s parents had little information about his syndrome other parents were given information about their child’s disability since birth.

**Diane**

Diane was born in Portland, Oregon January 1, 1981 with Down syndrome. According to Diane’s mom, they knew as soon as Diane was born that she had Down syndrome. Before they even left the hospital she had a nurse in her room with hands full of brochures on what they could do and where they could go for help. Ever since the beginning, Diane’s parents sought out the best programs for her. Diane’s mom preferred the individualized attention of small self-contained classrooms, where the teachers were speech-pathologists. Diane spent two years in a public school, which was not in her neighborhood, in an experimental mainstreaming program. This program proved to be “disasterous.” Her parents did not have a choice over Diane’s placement in this program and eventually moved her to the Metro Private Special School.

One thing obvious about Diane is that she wears her emotions on her sleeve. She smiles when she is proud of herself, when she is surrounded by her family and friends, and when she talks about her passions. When she is frustrated, sad, or just having a bad day, that shows on her face, as well. Diane thrives when she is around people like her -- when she feels accepted. Diane is creative. She is a poet, a dreamer and a romantic. She
has a rich vocabulary and the ability to describe things with much detail. She is a hard worker and seeks perfection in those activities she pursues. She lives with her parents and works at a grocery store in the community. While Diane is an easy person to read, Becky is a bit more deceptive.

**Becky**

I first met Becky when I started doing this project. At first, she appeared shy. She did not say much nor did she establish eye contact. Her parents told her that I would like to ask her a few questions, and I thought she felt obligated. But she said O.K. and we sat in the corner of a bowling alley that cold winter day. We talked for a while and her mom walked over a couple of times to see how things were going. During the course of the interview, I was repeating myself, clarifying questions and doing a lot of probing. When Becky talked about things she liked, her face lit up and she was articulate. At other times during the interview however, she seemed withdrawn. Upon questioning her father during the verification interview, I learned that Becky has a pervasive developmental disorder, or a form of autism. I was immediately surprised by this diagnosis, because during my interview with her she exhibited very few of the stereotypical behaviors that often accompany this disorder. I was impressed by her ability to communicate and to be actively engaged in the interview process. The week following my second interview with Becky, I had the opportunity to interact with her on a few occasions. During this time, it was as though I met a new friend. She knew who I was and would approach me when she saw me. One of Becky’s strengths and interests involves math calculation. Once Becky learned of my age, she calculated how old I would be in 2011, 2025, etc, then she told me whenever she saw me.
Becky was adopted by her current parents at the age of one in Boston. She has lived with this family for 21 years all around the world, Germany, New Mexico, Oregon and Prairie View. Since the third grade, Becky was mainstreamed for the non academic subjects and was in a self-contained classroom the rest of the time. She lives with her parents and works at a sheltered workshop.

Carol

Carol is the other person who I met in the course of this project. I am surprised that I have not met Carol before as she has been enrolled in area programs most of her life. Carol was born in the state capital and moved to the River City when she was five. From what I have seen of Carol, she is very much focused on the task at hand. During our interview, Carol was very attentive to each question I asked. Her answers were brief and to the point. There typically was no need to probe because she answered questions directly. I could also tell that she was not going to expand on any topic in great detail. Carol seems to take after her mom. Carol’s mom’s answers were also direct and short. Her mom describes Carol as being very smart, very caring and hurts deeply when she gets hurt. Carol lives in a group home and works at a sheltered workshop, a different one from the one where Becky works.

Jessica

Carol and Becky’s timidness was expected as neither of them knew who I was prior to this project, Jessica on the other hand has known me for about six years. Jessica is quiet. She may not say much, but her presence is felt in a room. She looks up and smiles at you when you least expect it – indicating that she knows who you are and she is happy to see you. According to Jessica’s mom, Jessica’s job coach says that her shy demeanor masks her true abilities. Her looks have always been deceiving. Jessica was born 21 years
ago, a month early, with Down syndrome. According to her mom, they did not put her on a respirator at first. Twelve hours later, the health care providers realized that Jessica was a fighter and therefore put her on a respirator. Her mom said that even in her first classroom at River City Public School 1, Jessica and another boy “were forgotten” because the other children exhibited more behaviors.

Jessica was enrolled in a pre-school program within the River City Public School District. She was then was enrolled in the River City Public Schools until first grade when her parents advocated for better services for her. She transferred to the Metro Private Special School. She stayed in the Metro Private Special School until a few years prior to graduation when there was an administrative change. At that time, Jessica transferred to Prairie View High School. While at Prairie View High School, she was primarily in self-contained classrooms. She had an aide who accompanied her to art, computer and swimming classes.

Now, Jessica lives at home with her parents. She buys her own groceries and cooks her own food. She works 20 hours a week at a Christian-based recreation facility. At this facility, she works in the maintenance department and cleans the women’s locker room. Her mom and dad continue to play a big role in her life. They encourage and support her endeavours.

Andy

Andy’s mom also supports him in his endeavours. His mom bought Andy a house in which he can live independently. This home is within walking distance to a bowling alley, church, and grocery store. Each day a bus comes and picks Andy up and transports him to a local military base where he works as a custodian with other individuals who
have either mental illness or mental retardation. Despite Andy’s relative independence, his mother has concerns about his safety.

Andy is a popular boy who appeared to be developing normally. When he did not talk by the age of three, however, his mom knew something was wrong. They found a tumor was developing in Andy’s brain. Because of this tumor, he has a very limited memory, he cannot read, and he has trouble problem-solving. Andy’s appearance belies his disability. At first glance, you would not think that Andy had any problems. He tries to mask his deficits. Sometimes people take advantage of him, getting him to drink and/or buy alcohol.

Andy is kind hearted, with a warm personality. He is a very sociable person. And befriends everybody. Most of the participants in this study identify Andy as a friend and he feels the same way about them His mom’s biggest concern is to protect him from the people who want to take advantage of him.

Andy attended Prairie View Public schools since he was five. He transfered to the Metro Private Special School during Junior High but returned to Prairie View for High School. According to his mom, he was primarily in self-contained classrooms with the exception of PE and Home Economics.

**Mike**

Mike is one of Andy’s best friends. Mike like Andy appears to be friends with everyone. He lives at home with his parents, his twin brother and four older brothers. Mike is frail. He walks with a lift in his shoe and a smile on his face. In recent years, his health has been deteriorating. He has frequent doctor’s appointments and hospital visits. When he is not receiving health care, Mike works at a local grocery store. He used to be a bagger but now works in the dining room. As Mike is getting older, he is getting
more tired. After work he reports going home and sleeping. He makes time, however, to spend with his friends; his friends and his sports keep him in high spirits.

Mike grew up attending the Prairie View Public Schools. His parents often tried to make his life as “normal” as possible. They tried to keep him in the same schools as his twin brother. He always tries his best and gives his all. He is a hard worker and a great friend to many. Although Mike’s disabilities are noticeable, his personality is much like his suave, athletic brothers who do not have disabilities. His brothers often accompany him to practice and treat him like they treat the rest of their brothers.

Mike, too, was listed by and likewise listed, most of the participants in this study as a friend. He is one of the guys who “hangs out.” A great buddy. One of his closest friends is Charlie.

**Charlie**

At first glance, Charlie looks like he has cerebral palsy. I guess literally he does -- but not from a traditional cause. When Charlie was three, a truck ran into him, shattering his brain and body. He was in the hospital and wore a body cast. When Charlie walks, he appears to be off balance and will fall. Yet, somehow, Charlie manages to stay up. Charlie is a pretty cool guy. His hair tends to be spiked and he has one ear pierced. His answers are short and to the point. You would think that Charlie is the rebel based on his outward appearances. Conversations reveal a polite young gentleman. He attended Prairie View schools with the others in this study. Therefore, like Mike, Andy, and Danny, he considers the others in this study to be his friends.

Charlie currently works at a thrift store, he lives in a duplex with two guys in their 30’s who have Down syndrome. He keeps in touch with his friends, enjoys hanging out with them, bowling with them, and talking on the phone with them.
him say “as much as he has going against him, he does not let anything bring him down.” Charlie is an optimist. He is a happy person.

**Kelly**

While Charlie has a very distinguishable disability, Kelly’s disabilities are not very noticeable. Kelly lives in an apartment by herself, she drives a car and she works at a local retail store. She attended Prairie View Public Schools and was mainstreamed into a cohort of students her same age without disabilities. Growing up, she was in Bible study and Special Olympics. She has gradually faded Special Olympics out of her life, yet hopes to resume her participation in bowling in the future. Lack of money and time are two of her biggest constraints in reference to leisure participation.

She is very close to her family. Her parents support and encourage her independence. Kelly has a best friend with whom she has much in common. They were in the same classes together at school. They go to the same church. They both drive. Kelly spends much of her free time with her friends and family. Kelly’s sister Naomi was also a participant in this study.

**Naomi**

Naomi has mental retardation. She is a big girl with big emotions. When she is happy she jumps up and down with a smile on her face. Her excitement is contagious. When she is sad you feel like weeping with her and you feel that the world has come to an end. When she is tired and sick, you definitely know that she will not be motivated that day. She lives life by following a routine.

Naomi attended Prairie View Public Schools with most of the other participants in this study and was primarily in self-contained classrooms. Right now, she lives at home with her parents, cat, and dogs. Everyday she goes to work at a sheltered workshop --
where she sees her boyfriend. She walks to the library and she watches her T.V. shows. She is interested in what others are up to. She knew that I lived in Florida and spent several minutes showing me where Florida is on the map. Naomi used to be involved in sport, but a few years ago she had some health problems and needed to quit. Now she is looking for something else to do. Yet, in talking with her, it is obvious that her life is quite busy.

**Summary**

As mentioned previously, this group of participants is made up of ten individuals. Each individual is unique, just like the rest of us are unique. Table 1 illustrates the demographic variables which describe some of the differences. There are, however, some

**Table 1: Summary of Participants**

<table>
<thead>
<tr>
<th>Name</th>
<th>Age</th>
<th>Work</th>
<th>Living</th>
<th>Diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Danny</td>
<td>24</td>
<td>Thrift store</td>
<td>Group Home</td>
<td>Rare Syndrome</td>
</tr>
<tr>
<td>Diane</td>
<td>23</td>
<td>Grocery Store</td>
<td>Family</td>
<td>Down Syndrome</td>
</tr>
<tr>
<td>Becky</td>
<td>21</td>
<td>Workshop</td>
<td>Family</td>
<td>Autism</td>
</tr>
<tr>
<td>Carol</td>
<td>32</td>
<td>Workshop</td>
<td>Group Home</td>
<td>Mental Retardation</td>
</tr>
<tr>
<td>Jessica</td>
<td>22</td>
<td>Recreation Center</td>
<td>Family</td>
<td>Down Syndrome</td>
</tr>
<tr>
<td>Andy</td>
<td>25</td>
<td>Military Base</td>
<td>Own House</td>
<td>Tumor</td>
</tr>
<tr>
<td>Mike</td>
<td>21</td>
<td>Grocery Store</td>
<td>Family</td>
<td>Unknown</td>
</tr>
<tr>
<td>Charlie</td>
<td>21</td>
<td>Thrift Store</td>
<td>Group Home</td>
<td>Brain Injury</td>
</tr>
<tr>
<td>Kelly</td>
<td>29</td>
<td>Retail</td>
<td>Apartment</td>
<td>Borderline</td>
</tr>
<tr>
<td>Naomi</td>
<td>25</td>
<td>Workshop</td>
<td>Family</td>
<td>Mental Retardation</td>
</tr>
</tbody>
</table>
similarities. Each of the participants in this study has a developmental disability. Each lives in a middle-class suburb of a large metropolitan area in the heartland of America. Each of the participants has supportive parents who have encouraged and advocated for him or her. Each is Caucasian. And each of these individual’s have preferences, values, and a desire for happiness. The next chapter will describe how these ten individuals perceive their own leisure experiences.
CHAPTER 4
RESULTS

The purpose of this study was to examine the leisure experiences of young adults with developmental disabilities. This section uses the participant’s own words to describe their perceptions of the leisure experiences. Throughout the course of the initial interviews, it became apparent that certain facets of the leisure experience were important to the participants. These facets became apparent because each of the participants seemed to refer to them with more detail and more enthusiasm than other topics. Likewise, these ideas of the leisure experience were presented in response to several different questions. These facets and ideas emerged as themes in the initial phases of data analysis. These themes indicated that my preconceived ideas of the leisure experiences of young adults with developmental disabilities were inaccurate. The themes did not reflect the ideas of participation, meaning and satisfaction to the degree that I had initially proposed.

Instead, three overarching themes emerged from the data which suggested that the leisure experiences of these individuals were more complex. The first theme involved the idea that there is a global nature of the leisure experience. In this study, the global nature of the leisure experience is comprised of community influences, mainly related to the social and work domains of life. The second theme describes the specific elements of the leisure experience. These specific elements include the ideas of leisure meaning, leisure participation and leisure satisfaction described in previous chapters. The third theme that emerged describes how leisure can be a reflection of normalcy. This chapter describes these three themes and the accompanying sub-themes that emerged from the interviews.
with the primary research participants and discusses how the interviews with the parents support these ideas.

**The Global Nature of the Leisure Experience**

As previously stated, the first theme involved the idea that there is a global nature of the leisure experience which involves a variety of community influences. In this study, the two primary community influences involved the social and work domains of life. Therefore, suggesting that the individuals participating in this study tended to identify with the nature of the leisure experience as described by Kelly (1999). The social dimensions of the leisure experience illustrated by interactions with others, while the existential dimension was signified by the hierarchy of preferences associated within the context of other life activities (e.g., work).

The two sub-themes that surfaced in the initial phases of data collected indicated that the leisure experiences of young adults with developmental disabilities can be examined in the context of work and social interactions. The social context of their leisure experience indicates that these individuals define, describe, and experience leisure via the presence or absence of others. When leisure is examined in the context of work, similarities and differences associated with these two domains of life emerge and a hierarchy of preferences evolves.

**The Social Domain**

As the data were analyzed it became evident that this group of individuals associated leisure with social interactions. These social interactions occurred within the context of friends, family, and self. The participants in this study discussed the role of friends and family in the context of the leisure experience. The role of self in the leisure experience symbolizes the absence of social interaction and, therefore, is helpful when
understanding the social paradigm associated with the leisure experience. Overall, the participants in this study indicated that they have preferences based on the social interactions that occur within the leisure experience.

**Friendship.**

Discussions about friendships were one of the more prevalent ideas that emerged in the data. “Being with friends” was one of the activities that most of the participants identified as being a source of happiness and fun. Furthermore, the responses gave the reader insight into the nature of these friendships. To these participants, friendships involved those people whom these participants enjoyed spending time with and whom these participants had shared life experiences.

**Source of Enjoyment.** As mentioned previously, “being with friends” was often identified, by these participants as being a source of happiness and fun. When they were asked “what makes you happy”; Charlie and Carol responded: “being with my friends”, Mike said “hang out with friends” and Danny responded: “seeing my best friends” and “seeing my homeboys”. When Andy was asked “what are those things that you like to do; he replied “talk on the phone”. When asked “who do you talk to”, Andy responded “… friends at work”. Likewise when Naomi was asked “what do you like to do for fun” she responded “talk to my boyfriend” “go out with my boyfriend”.

Sometimes the friendship connection was secondary to the participant’s interests. For example, when Jessica asked what she liked to do. She responded with a list of specific activities. When Jessica was asked “Who do you do those things with; she answered “um, my friends”. Diane, Charlie, Danny, Mike, and Andy all reported playing sports with their friends. Kelly, Carol, Charlie and Mike reported going out to movies,
dinner, or the mall. Since friendships appeared to be important to the leisure experiences this population, efforts were taken to understand the overall nature of these friendships.

**The Nature of Friendships.** Since friendships were associated with most of the respondents’ leisure experiences, it was essential to learn more about these friendships. The researcher often prompted the respondents to tell her more about their friendships. Several themes emerged in the data which described the nature of these friendships. As such, it became evident that these friendships evolved via shared life experiences. Furthermore, it appears as though there is a reciprocal component associated with these friendships. It is this reciprocal component which appears to be a defining quality of the friendships. An existential component also appears to be associated with the idea of a friend. Examples of these components are presented in this section.

**Shared Life Experiences:** define those events that occur in life that two or more people experience together. These events serve as the basis for friendship development and provide opportunities for commonalities to emerge. The data suggest that the participants in this study had shared life experiences with their friends. Most of the participants, who identified friendship as an important facet of the leisure experience, indicated that their friends were from Special Olympics, their group homes, their sheltered workshops, and/or school. The following dialogues illustrate this point:

Kari: Tell me about your friends.

Andy: My friends are pretty cool.

Kari: Where did you meet them?

Andy: In Special Olympics, most of them.

Jessica’s responses were similar.
Kari: Yes… Tell me about your friends.

Jessica: Um

Kari: You have a nice smile on your face when you think about them.

Jessica: (nods)

Kari: Yeah… Are they from work? From school?

Jessica: Um … Olympics (unintelligible)

Carol indicated that her friends were from Special Olympics and her Group Home.

Kari: Tell me about your friends. Where did you meet your friends?

Carol: Here (we are at a bowling alley)

Kari: At Special Olympics.

Carol: Yeah

Kari: Do you get to see those guys when you aren’t playing sports?

Carol: Yeah

Kari: What do you do with them?

Carol: Well I don’t see them very much.

Kari: Do you have other friends other than those in Special Olympics?

Carol: Yeah, my roommates.

Kari: Your roommates. What are they like?

Carol: They’re fun.

While in this exchange, Carol indicated that she did not see her friends from Special Olympics. In later discussions about her roommates, it was evident that she spends a lot of time with her roommates. Although friendships might develop through shared life experiences, it is difficult to differentiate between friendships and mere acquaintances
based entirely on point of origin. A better indicator of friendship might be the reciprocal nature of such relationships.

**Reciprocity**: is a term used to describe the reciprocal nature of the relationships that people have with friends. It implies that if I do something for a friend, they will do something for me. It also implies that if I identify someone as a friend they identify me as one. The reciprocal nature of most of these friendship emerged as being important.

One of the most obvious examples of reciprocity occurs when a person identifies someone as a friend and vice versa. The people who participate in this study identified each other as friends as demonstrated in the following examples. When Charlie was asked, “Tell me about your friends, who are they?” Charlie responded, “I hang out with Mike a lot. He’s kind of cool.” Likewise, when they were asked “Who are your friends?” Mike replied “Andy, Danny and Charlie.” Danny replied “Uh, Andy, Mike uh, uh, a lot of people.” Andy replied, “I have Mike, Charlie, almost all the people I bowl with.” These three discussions indicate that reciprocal ideas of friendships exist amongst this population.

Another indication that these individuals perceive friendships as being reciprocal emerged as they defined the term friend. Examples of this emerged in my conversations with Andy, Danny and Diane. My conversation with Andy included the following dialogue.

Kari: Have you ever heard of the word friend?

Andy: Yes.

Kari: What do you think that word means?

Andy: It means you like the person and they like you back.
While Andy’s reciprocal relationships were associated with a person’s preferences, Danny and Diane tended to focus on the helping nature of friendships.

Kari: What do your friends do for you?
Danny: Uh, they help me out to solve problems.
Kari: And what do you do for your friends?
Danny: we help them out, I help them out and they help me out.

While the reciprocal relationship of friends is important, for some of the participants the mere existence of friends is special.

**An Existential Dimension:** The mere existence of friends simply means that friends are people who exist within one's life. They are just there for you. Diane describes this dimension of friendships in the following exchange.

Kari: What are friends?
Diane: Friends are there when you have a problem, they stay with you through thick or thin and sometimes they are actually forward with you.

In the following conversation with Mike, he does not know what he does for his friends, but he knows what his friends do for him. For Mike, it means something for him just to see Andy and his other friends.

Kari: What do you do for your friends?
Mike: I don’t know.
Kari: What do your friends do for you?
Mike: They make me laugh.
Kari: What do you like best about your friends?
Mike: That I get to hang out with them, see them.
Kari: Do you have a “best” friend?

Mike: Yeah

Kari: Who?

Mike: Andy

Kari: What do you like the best about Andy?

Mike: That I get to bowl with him. I get to see him after therapy and I bowl with him. I get to be here a lot now. My mom got me a locker and I get to put my shoes and my ball in there.

Similarly Charlie reports that friends are always there.

Kari: . . . Do you have a best friend?

Charlie: Yeah, I have lots of them.

Kari: You have lots of them. What makes them good friends?

Charlie: I can call them up anytime I want to and talk to them

Although Mike and Charlie were not able to identify things that they do for friends, they were able to identify reasons why people are indeed friends. I tend to believe that due to the nature of Mike and Charlie’s personalities they probably do things for their friends. Both individuals are polite, caring young men who have several friends. They may not intentionally do things for their friends, but their friends probably find comfort knowing that they merely exist.

The friendships of these participants indicate a complex relationship. On the surface, these participants believe their friends to be “cool,” therefore; they enjoy hanging out with them. Upon further evaluation, these relationships are multi-faceted involving reciprocal and existential qualities based on shared life experiences. While Danny and
Andy’s parents indicated that these two individuals befriend everyone that they meet, Danny and Andy described their enemies to me. This indicates that they can differentiate between someone that they consider to be a friend and other people in their life. Sometimes these other people in life are considered to be family.

**The Role of Family.** Friendships are not the only relationship that these individuals value. For many, family members were important. Most of the participants in this study indicated that family was a source of enjoyment and happiness. The nature of the familial relationship, however, appears to be different than the relationships that these individuals have with their friends. While most of the respondents indicated that “being with friends” was something they liked doing and, as such, was a source of happiness; being with family was often a secondary facet of the leisure experience. Like friendships, however, family was seen as a source of happiness and trust.

**A Source of Happiness.** Some of the participants indicated that they enjoy spending time with both friends and family. For example, when they were asked “What makes you happy” Diane replied, “being with momma seeing the smiles on people’s faces makes me happy … being with mom and dad”. In Andy’s second interview, he replied “my family”.

**A Secondary Facet of Leisure Experience.** When asked “what do you enjoy doing”; few respondents replied “hanging out with family”. For the most part, the respondents mentioned family when they were telling me with whom they do things. As each of the respondents identified things that they liked to do; the interviewer often probed “who do you like to do things with”. When Becky was asked “who do you go to the movies with”; she replied “with my mom and my dad and my brother”. “Hanging
out” with his brother was an activity that Mike reported doing frequently. When Naomi was asked “who do you like to do things with” she responded “my mom and dad. And my friends ….” Naomi associated her family with specific activities such as going to Disney Land and traveling. In Naomi’s case her family was constant; it constitutes a steady source of activity, support and trust.

**Someone to Trust.** When Naomi was asked “who do you trust the most”; she responded, “my mom… my mom and dad”. Carol and Andy shared similar responses. Carol stated “my mom and dad”. Andy answered “probably, my mom”. As the issue of trust surfaced, it became evident that while friends and family are important facets in the lives of these individuals with developmental disabilities, the role of self should not be neglected.

**The Role of Self.** When examining the relationships that exist in one’s life, sometimes we need not look further than the relationship we have with ourselves. The idea of self emerged in three areas of discussion. The first involved people that the participants trusted. The second appearance indicates that these participants have a hierarchy of preferences associated with solitary activities

**A Person to Trust.** When Kelly was asked “who do you trust the most… who knows you best” she responded “me… me and my mom”. Likewise, when Danny was asked “who do you trust”, he responded “I”. The interviewer probed asking “is there somebody else that knows you well” and Danny responded “uh, no”. Not only did these respondents trust themselves, but some actually prefer participating in solitary activities.

**Solitary Activities.** When Carol was asked “do you like to do things with other people or by yourself” she responded “by myself”. As mentioned elsewhere, Diane
enjoys the solitary activity of writing; Naomi enjoys her walks to the library by herself. Much in the literature supports the idea that individuals with developmental disabilities enjoy solitary activities (Dattilo & Hoge, 1995). Yet as this study already has pointed out, most of the respondents in this study also prefer social activities.

When Kelly was asked to “tell me about some of the things you like to do by yourself”; she responded “I don’t really like to spend time by myself unless it is at night time and I am really tired or I don’t feel good. I don’t like to be by myself unless it is at night”. Likewise when Andy was asked “what are some things that you like to do by yourself” he answered “nothing. I don’t like doing things by myself. I like other people to be around.” The following dialogue with Jessica reflects a similar opinion.

Kari: O.K. Are there things that you like to do by yourself?
Jessica: um… um…
Kari: Not really … would you rather spend time by yourself or with your friends?
Jessica: Friends

The social domain associated with leisure allows for a hierarchy of preferences and opinions to be developed. As these responses indicate, the participants in this study are capable of forming these preferences and opinions. Furthermore, an understanding of each individual’s hierarchy of preferences and opinions regarding the social paradigm helps us understand the leisure experience.

Parent Perception of the Social Domain: When the parents in this study talked about the social domain, the theme of friendship was prevalent. Most of the parents indicated that their children had friends. Several of the parents have safety concerns regarding the
friendships of their children. According to the parents, friendships developed via shared
life experiences were safer and more beneficial than other friendships.

**The Nature of Friendships:** Some of the parents supported the theme that friends
were a source of enjoyment. Take for example the following exchange with Jessica’s
mom.

Kari: What does Jessica like to do for fun?

Jessica’s Mom: Um, she loves being with her friends. I mean it doesn’t matter what
that is . . . that could be uh going to class – she takes uh... after she graduated from
high school she goes to a private group, career solutions and they have classes on
socialization and that sort of thing . . . .

Kari: What makes her happy?

Jessica’s Mom: Her friends and her family make her happy. I mean she just... She
is generally always happy. I don’t know she is never... you know. She really
doesn’t ever get down or doesn’t seem to ever have any low periods. And she loves
her family and she loves her friends and she writes me notes about her family about
where they’re at or what they’re doing or what her friends said that day. She just
enjoys them.

Likewise, Andy’s mom indicated that Andy enjoys being with friends.

Kari: Um, what does he like to do for fun?

Andy’s Mom: . . . He likes being with his friends. . . .

Becky’s dad and Carol’s mom, however, do not consider Becky or Carol to have friends.

Kari: Um, Tell me about some of her friends. Does she have many, any?

Becky’s Dad: That’s been a frustration of ours. A lot of time is spent alone. If not
alone it is usually in groups or with mom and dad at something where she knows the people. But, not really individual friends, per se. She has people that she knows . . . but she does not really . . . can I go over to so and so’s house kind of thing at all.

When Carol’s mom was asked “can you tell me about some of her friends?” She responded, “she doesn’t really have any close friends, right now that she is out of school. So right now she doesn’t really have any close friends.” But, as mentioned previously, the sentiments of Becky’s dad and Carol’s mom did not reflect the statements made by most of the parents in this study.

Danny’s parents, Diane’s mom, Jessica’s mom, and Andy’s mom all indicated that their children, all met their friends through school and Special Olympics. Most of the other parents identified specific friends who their children met either at school or Special Olympics. Most of the parents indicated that there was some benefit to their children having friends who had shared life experiences. Diane’s mom highlighted these benefits by contrasting Diane’s experience with friends with shared life experience, with Diane’s experience other’s in her peer group. She describes the following scenario which occurred when Diane was transferred from a self-contained classroom to a school that was experimenting with mainstreaming.

Diane’s Mom: She was moved away from a very strong peer group that she had... so she didn’t have any really core friends. She became a little bit introverted and started exhibiting some behavior that she never had before. She had always been self-confident.

She also explained this mainstream program in the following manner.
Diane’s Mom: No. No she had little kids... but they were little token friends ...
they’re really not friends... they are little token friends that come over and sit with
you. But they are not the kids who invite you to their birthday party... she never got
invited to any birthday parties. They would sit with her in a classroom but they
weren’t friends. I mean anybody could realize that. You don’t have to be a genius.
The following is how Diane’s mom described the scenario that developed when Diane
was placed in a segregated school.

Diane’s Mom: What is good about the Metro Private Special School is that it has
that social interaction that everybody needs... its got friends, its got somebody there
that you can talk to... which she didn’t have. She was lacking that completely for
almost 2 years. She didn’t have that really good friend.

Diane’s mom describes the following reason why friendships emerge in situations where
shared life experiences occur.

Diane’s Mom: . . . we gravitate to those people that we have things something in
common with. I mean Diane is very drawn to the pretty people. She wants to be
popular. I couldn’t believe it the first time I heard that come out of her mouth. I
thought “you truly are more normal than most people will realize”. She wanted to
be “popular” like she had voiced these names. Because they are the pretty girls and
Diane will never fit in ... in that group unfortunately that is just not the pecking
order.

Kari: When she was at the Metro Private Special School, she fit in?

Diane’s Mom: At Metro Private Special School she fit in...she was one of the
“popular girls”.
Kari: Popular girls

Diane’s Mom: Yeah, so at that time her self-esteem started to blossom again. . . . yes, she was getting positive strokes... she was feeling good about herself... she had friends ... she... you know... it was more of a normal life for her because she had friends who were her equal. So then, she graduated in 2001.

While Diane’s mom reported some of the benefits associated with friendship developed during shared life experiences as being related to personal development, Andy’s mom indicated that such relationships might be safer than other scenarios.

Kari: Tell me about some of his friends.

Andy’s Mom: He has good friends and he has bad friends and you cannot tell the good from the bad. And that is another one of Andy’s problems. Everybody is like him a good person. I mean, I think most people are like that, you give everybody the benefit of the doubt until they prove you wrong but with Andy, he can be talked in to almost anything.

Andy’s mom further illustrates the differences between good friends and bad friends.

Andy’s Mom: He has been real fortunate the people the first league he got on these guys are really nice and they were there when Jim had the incident with the alcohol and I had to tell them that Andy could not drink any alcohol again Cause it will cause a seizure. And so, they even though Andy would want a beer cause they are having beers, you know they will talk him out of it. They have been real good. The second league he was on over the summer. Those kids took advantage of him. They’d make him pay for beer, they’d make him drink beer because then he would get out of control. He even got in somebody’s face he had no idea what he was
doing. It just totally messes up Andy’s whole thought process. So he was no going
to be bowling again with them this year. So he is on a different league. So that part
worries me, you know, and you don’t like to tell anybody that he can’t read so he
will make everybody believe he can which gets him into a little trouble. . . .

And so, Andy’s mom is concerned about Andy’s friendships, especially in the
community. Overall, the parents tend to support the ideas that emerged from the
conversations with the primary research participants.

**The Work Domain**

A similar pattern existed as the participants and their parents discussed leisure in
the context of the work domain. As the participants, talked about work it became
apparent that work was a source of enjoyment for many of the participants. And yet, a
hierarchy of activity preferences seemed to exist indicating that work and leisure could be
compared thus helping us understand the leisure experience.

**Work and Enjoyment.** Traditionally, it has been recognized that work is source
of pride and enjoyment among individuals who have developmental disabilities. Even in
this study, some respondents indicated enjoying their work. Becky, for example,
described the role of work in her life in the following exchange.

- Kari: Do you work…You said you work at Encore.
- Becky: Yes.
- Kari: Do you like working there?
- Becky: Yes
- Kari: Is it fun?
- Becky: Yes
- Kari: Do you like working or playing sports better?
Becky: Working

This conversation with Becky reflects the traditional idea that individuals with developmental disabilities enjoy working and in fact, prefer working over traditional leisure activities. This might suggest that work is a source of leisure for Becky. For Naomi, there was little difference between working and playing.

Kari: What do you do … where do you work?

Naomi: Martin Luther Home

Kari: What do you do at work?

Naomi: A bunch of stuff

Kari: A bunch of stuff … do you like working?

Naomi: Yes

Kari: Do you like working as much as you like camping?

Naomi: I like camping… I like both.

Kari: You like both. You don’t like one over the other.

Naomi: No

This conversation with Naomi illustrates another view in the work paradigm.

Hierarchy of Preferences. Other respondents in this study indicate that while these individuals enjoy working they prefer other activities over work. Take for example the following conversation between the interviewer and Jessica.

Kari: Do you work? Where do you work?

Jessica: Mosaic

Kari: Mosaic, What do you do there?

Jessica: Clean
Kari: Cleaning… Do you like work?

Jessica: (nods)

Kari: Yeah, is it fun?

Jessica: (Nods)

Kari: Yeah… what do you like better working or bowling?

Jessica: Bowling.

Kari: What do you like better… working or going to a movie with your mom?

Jessica: Movies

Diane describes a similar situation in her conversation with the interviewer.

Kari: Do you like working?

Diane: I love it. I love the customers… I love the employees.

Kari: Is it fun?

Diane: I think it is.

Kari: Is it as fun as writing?

Diane: Actually, I have to admit that writing is more of a passion and I like working.

Kari: You just like working. What about working and sports? What’s fun-er? Out of playing sports or working… which one do you like better?

Diane: I have to admit… I like working.

Kari: What about working and watching T.V. which do you like better?

Diane: That’s really a tough decision but I like watching TV and I like working but it’s more upscale.

Kari: So if you had to rank it you would say writing then working, then playing.
Diane: Yeah… work would be the second thing on my list.

Kari: What about going to movies and eating out with your parents?

Diane: Uh that would be up there with writing.

Diane and Jessica appear to enjoy working yet, have other passions which rank higher in their personal activity hierarchy.

While each of the respondents mentioned previously enjoy working; one of respondents indicated that he did not like working. When Andy was asked “what makes you happy”; he replied “everything except for work”. If we collectively examine the work paradigm in relation to the leisure experience. It is noticeable that a hierarchy of preferences and opinions exist which help each individual define the leisure experience.

Parent Perception of the Work Domain: As the parents talked about work, most described why their children enjoyed working. For example, Becky’s dad described some of the activities that they do at the workshop.

Kari: Um, what does she do for fun?

Becky’s Dad: She uh Special Olympics very much. She does certain things at the work setting at ENCORE. They have activities there, they do swimming, they do ceramics, and I think she is going to join in with another group too that they do seasonally. Plus, they have special events periodically at the work place like a fish fry or that kind of thing. . . .

Likewise, Danny’s parents discussed work as something that he enjoyed.

Kari: What does he like to do?

Danny’s Mom: He likes to do a lot of Special Olympics activities. And you know what? He likes to work.
She further illustrates how Danny enjoys working.

Danny’s mom: . . . He really likes to work, because there was a few days when he worked with his dad and did real carpentry stuff. He really was in hog heaven and his boss paid him money and he was happy as a lark. And that’s what they say at the group home. They don’t have a problem with Danny working. He will work.

Jessica’s mom also describes Jessica’s work habits.

Jessica’s Mom: She works... she is in maintenance at the southwest YMCA. She works 20 hours a week from 8 in the morning to noon. Monday through Friday which is like cleaning like she does the ladies locker room, changes the towels, and that type of thing. . . . She started that last June. It has been going really well. You know she uh... its part time so she doesn’t get ... her pay is based on if she works and she really works everyday. She likes to go to work. And she works everyday. The only time she has missed is when... for Special Olympics activities or she is sick or something. But other than that she really doesn’t ... she like working.

The only parent who described some of the negatives associated with work was Andy’s mom. This was not surprising, given Andy’s comments about work. Andy’s mom describes Andy’s work experience in the following quotation.

Andy’s Mom: He does, he likes the work, he doesn’t … the only thing that he really dislikes about it is that it is so early in the morning he has to get up at 5 to get on a bus to get him down at work at 6 o’clock. He gets off at 1 but doesn’t get home until 3. He has to ride this bus which is very long cause it has to drop off all of the kids. Um, he was having lots of trouble at work but we had a big meeting with all of the people that he is having troubles with and it was just a
communication problem. Um he had a supervisor that was oriental and Andy just couldn’t understand her. She talked so fast that he couldn’t understand her so when he asked her over and over again she’d get mad at him. He just couldn’t understand what she was saying cause her English was so bad. So we got that taken care of now so it’s much better. I mean yeah, they just love him down there. They’d just hate to see him leave. Cause he has learned every job in record time. You know, he has only been there two years and he knows all of the jobs that are down there. So um, you know he is a visual learner, that’s the biggest thing about Andy.

These exchanges confirm the idea that work is a source of enjoyment for these participants. It also describes some reasons why the hierarchy of preferences occurs. For example, Andy might not like working as much as other activities due to the morning community and misunderstanding. Jessica rarely misses work except for Special Olympics activities.

The Specific Elements of the Leisure Experience

As mentioned in Chapter 2, there are several elements associated with the leisure experience. These elements include: the commonly agreed upon characteristics of leisure, those facets of leisure that are commonly operationalized (e.g. participation, meaning and satisfaction) and those facets associated with the nature of the leisure experience. Although these specific elements did not emerge as global themes which describe the overall leisure experiences of the participants, sub themes surfaced which help explain how these specific elements are associated with the leisure experiences of these individuals.
Characteristics of Leisure, Leisure Awareness and Leisure Meaning

In this study, most of the participants (Jessica, Danny, Naomi, and Andy) had never heard of the words recreation and leisure. During Diane’s first interview, she told me that she had never heard of either word. Yet, after the interview with her mom, Diane insisted that she had never heard the word leisure but indicated that she had heard the word recreation. Diane then defined the word recreation as “just going out there to have fun”. Carol, Becky and Kelly recognized both terms and used them interchangeably. Carol defined the terms as “exercise”. Becky defined both as “bowling”. Kelly defined these terms as “stuff that you get to do in your spare time and things that you like to do in your leisure, things that you do in your time off work.” Since the majority of the individuals in this study did not understand the terms recreation and leisure, I defined the terms using the generally agreed upon characteristics.

The Existential Nature of the Leisure Experience

Most of the respondents in this study spoke about their favorite activities, which is consistent with the existential nature of the leisure experience. Likewise, the hierarchy of preferences that emerged when the participants spoke about leisure in the context of work represented the existential nature of the leisure experience. Yet as Chapter 2 illustrated, the existential nature of leisure involves more than these two facets. This section will describe how the leisure experiences of this population reflected additional existential properties.

Regarding leisure participation, many identified physical activity, being with friends and going to movies with family and traveling as primary leisure interests. In reference to physical activity, recall that Carol and Becky defined leisure in terms of “exercise” and “bowling.” Likewise, recall that Diane, Charlie, Danny, Mike, and Andy
all reported playing sports with their friends. Diane, Becky, Jessica all reported that they enjoy going to movies with their family.

Few leisure constraints were mentioned in the interviews. Kelly was the only one to report money as a constraint. Mike reported that he does not get to do things as often as he likes because he is always busy. Some constraints, however, were identified in the context of spending time with friends. Charlie reported that he does not see his friends as often as he would like because he is working all of the time. Most of the participants have plenty of opportunities to have fun. In fact, many report that they do things that they enjoy “all the time”, which indicates a high degree of leisure satisfaction.

**Parent Perception of Specific Elements of Leisure:** The interviews with the parents revealed a few interesting findings. The first findings confirmed many of the ideas that emerged from the conversations with the research participants especially in the area of specific activity involvement and leisure participation. The second findings reflected similarities between the leisure experiences of the parents and the leisure experiences of the primary research participant. Before describing these findings, the parents understanding of leisure is explored.

All of the parents had heard of the terms recreation and leisure. For some of the parents the terms were synonymous, other parents differentiated between the terms. Diane’s mom differentiated the terms in the following way.

Diane’s Mom: Leisure. To me, leisure tells me that I have the opportunity to do something that I enjoy at my own pace.

Kari: And what about recreation?
Diane’s Mom: It means doing something fun. Something that I enjoy. Yes, recreation!

Becky’s dad described the two concepts this way.

Becky’s Dad: I think of change of pace, getting out and doing something that you don’t normally do... And leisure would be more about having the time to do it, recreation.

According to Danny’s parents both words mean enjoyment. They further suggest that “leisure is resting” and “you have to work at recreation.” Andy’s mom and Jessica’s mom defined both terms as activity, much like the primary research participants did.

Jessica’s Mom: I think of as playing, going out with friends, playing basketball, volleyball, swimming, doing an activity that doesn’t require responding to somebody, I guess. Just having fun.

Most of the parents did not think that their children would have known what the word recreation and leisure mean, as these words are not commonly used within their households. They thought that their children may have heard the words recreation or “recreational” but for the most part didn’t think they knew what the terms meant.

These parents had diverse leisure interests. Many of the parents reported service activities with church or Special Olympics as their primary leisure interests. Other commonly reported activities that they enjoy include: physical activities, hanging out with friends, reading and working. This last list is consistent with the leisure interests of their children. Therefore, this might explain why the parents seemed to be able to identify leisure pursuits consistent with those pursuits identified by the primary research participants.
Leisure as a Reflection of “Normalcy”

The first phase of data collection and analysis revealed several similarities between the leisure experiences of individuals with developmental disabilities and the leisure experience of individuals without disabilities. Therefore, I was interested in further exploring the idea of normalization. In the second phase of data collection, some themes emerged in relation to this concept. For the most part, the individuals in my study did not perceive their lives to be all that different from either their siblings or other people their age. Those differences that surfaced were more associated with personal preferences rather than abilities. A few conversations illustrate this point.

Danny and Charlie can not identify anything that makes them different from their sisters.

Kari: How are you alike and different from your sister?

Charlie: We aren’t different at all.

Danny can, however, identify one way that he is like his sister.

Kari: …You have a sister, right?

Danny: Yes, 2 of them.

Kari: How are they different from you?

Danny: I don’t know.

Kari: You don’t know. How are they like you?

Danny: One of them has the same color of hair.

Andy, on the other hand, is able describe differences between him and his older brother

Kari: You have a brother, right.

Andy: Yeah.

Kari: How is your brother like you and how is he different from you?
Andy: That is a hard question.

Kari: That is a hard question, isn’t it? Can you think of anything?

Andy: He doesn’t like ketchup. I do. That’s about it.

Diane describes how she is similar to and different from her brother.

Kari: You have a brother, right?

Diane: Yes

Kari: Is like you at all or is he different from you at all?

Diane: Say it again.

Kari: Are you more like him or more different from him?

Diane: Probably different.

Kari: How are you different from him?

Diane: He doesn’t like chocolate that much and I do. Uh, he doesn’t drink milk but I do.

Kari: And how are you like him? Do you have anything in common?

Diane: Sports, probably. We both like sports.

My conversation with Mike, on this topic, focused on similarities.

Kari: O.K. You’ve got some brothers, right.

Mike: 5 brothers.

Kari: …how are they like you?

Mike: I don’t know they are just like me.

Kari: Are you different from them in any way or are you just like them?

Mike: I am almost just like them.
Kari: And other people your age are you pretty much the same or different from them?

Mike: Pretty much the same.

All in all, there are few perceived differences among this group of individuals and their siblings. Likewise, they report few perceived differences in relation to other people their age. Questions about normalization were difficult for them. They often did not understand what I was getting at with my first attempt. Their answers to the questions about people their own age seemed to indicate that they have constructed their own views of the world. This is most obvious in the conversations that I had with Charlie and Andy.

Kari: Tell me about how you are alike or how are you different from other people your age?

Charlie: What do you mean?

Kari: I mean, just everybody is alike and different in different ways... do you have anything that you think makes you like other people?

Charlie: Just the people I hang out with. They don’t do drugs and I don’t do drugs so I am like people in that way. I don’t like smoking that much either.

Like Charlie, Andy’s perception of the world in reference to this question focuses on similarities.

Kari: How about other people your age? Is there anything about them that you think makes you different or things about them that you think that’s the same?

Andy: Similarities. Like they are in Special Olympics and I am in Special Olympics. That kind of thing... I don’t think of anything else.
Kari: You’ve got friends who are in Special Olympics, are there any thing about them that makes them different from you. (pause) or are you pretty much like them?

Andy: I am pretty much like them.

And thus, based on these conversations, it appears as though this population believes that they are few differences between themselves and individual’s without disabilities. The world that these participants constructed focuses on similarities instead of differences.

**Parent Perception of Normalcy and Quality of Life:** As the parents discussed concepts related to quality of life, they once again supported the themes that emerged from the conversations with the primary research participants. Most of the parents identified ways in which their son or daughter is different from other people. In many instances these differences were coupled with similarities. For example, Danny’s parents discuss how his actual deficits are associated with those factors that make him like other people his age.

Kari: How is Danny like other people his age and how is Danny different?

Danny’s Dad: I think he has the same interests but he just doesn’t have the rationale to not do the things that will get him into trouble.

Danny’s Mom: I don’t know, how is he like others? He likes that stuff but he is easily influenced by anyone and he can’t make the decision about whether or not this is something that he really should pursue. He is easily led — a good follower. Becky’s dad offered a similar response.
Becky’s Dad: Well, although she is 21 in many ways she still has the teenage mentality of you know the usual parental and teenage response. Uh (laugh) like O.K. He continues to explain.

Becky’s Dad: uh, let’s see, like last night we went to a {high school} um their Jazz band they did a big band swing night and she is just like one of the kids out there the senior highers.... she is like a senior higher, you know or even sometimes a junior higher. But, anyway she’s really enjoying herself. I think in many ways she’s receptive to that sort of thing and input.

Diane’s mom, however, did not focus her attention on physical deficits.

Kari: … Are there differences between your son and Diane . . .

Diane’s Mom: Oh, well... there are huge differences. I think a lot of it too is the difference between a boy and a girl. Differences. Um Diane is very self-motivated, very articulate... um articulate in the sense that they are a lot more organized. My son just runs amuck. (laughs) but Diane is very detail oriented and has this incredible memory. I am serious. She has this incredible memory. You tell her something and she will remember it. That is why when I have so many irons in my fire, I’ll say Diane I need to do that that remind me and I ... she is going to be there and remind me and let me know. But anyway, the difference between them is that he is very bright but he is not self-motivated. He does only what he needs to do what he needs to get by. He is just happy, you know. He is a great kid but he is not going to work that hard for you. He is going to be that average C student when he is an A straight A capability student even though he did better than C’s you know
what I mean. Where Diane, she is going to do her very, very, very, best and if she
doesn’t she is going to be disappointed that she didn’t get that A or she wasn’t up
here. They are so different. But, like I said I think that is a boy/girl thing. Some
boys aren’t…. I guess I shouldn’t be so general. I know I see a lot of it.

Kari: Everybody’s different... has different strengths you know attention to detail.

Diane’s Mom: yeah... but Diane’s Brother is entirely left-brained and math is so
easy for him and Diane is so right-brained that in math she really struggles. She is
the artist also.

Jessica’s mom describes Jessica’s differences more in terms of personality traits.

Jessica’s Mom: Um, she is different in that she’s more... she’s shy-er than alot of
the kids and her, you know. She loves everybody and she doesn’t see herself as not
part of the group. She sees herself as part of the group but she is so quiet. And I
think my ... he teacher that works with her and has been her job coach told me,
“you know, to meet Jessica you would think that she is slower than some of the
other kids because she is so quiet” and he said in reality you know she is more
socially withdrawn he said in reality she is actually much smarter. But he said, you
wouldn’t know it unless you sit down in a one to one with her, you know you don’t
realize her abilities.

They also described ways that their children were like individuals without disabilities.

Diane’s Mom: She wants to be popular. I couldn’t believe it the first time I heard
that come out of her mouth. I thought “you truly are more normal than most people
will realize”. She wanted to be “popular” like she had voiced these names. Because
they are the pretty girls and Diane will never fit in ... in that group unfortunately that is just not the pecking order.

She continues.

Diane’s Mom: Oh, she is so normal in so many respects. I mean “normal” what normal is.

While Diane’s mom focuses on similarities based on Diane’s thoughts, Andy’s mom tended to focus on Andy’s physical appearance.

Andy’s Mom: Well he looks, you know. He has a mustache. You know he is built like a 24 year old, he’s not um. He does things that 24 year olds do other than driving, but he can carry on a conversation. But you know right away if you ask him to do this, this, and this. He is either going to do the first thing or the last thing. The stuff in the middle is gone. So um, But he is just, he looks you know, he looks his age.

She continues.

Andy’s Mom: Andy is the prime… I mean to look at him if he walked in nobody would know until they started talking to him. And then you’d have to … cause he … the neurologist um for the most part kids with this kind of problem, stutter a lot. They cannot hold on a conversation, they’ll put their heads down. Andy is not like that. And, I don’t and he doesn’t know how he learned not to stutter Cause he can carry on a conversation and he carries on sentences, he will make out of his talking to people.

Although the parents acknowledge their children’s limitations, they also confirmed the idea that the participants perceived their own lives as being normal. Throughout the
interview, she told me that “Andy thinks he is a normal kid.” The following dialogue elaborates on this idea.

Andy’s Mom: Yeah. And I didn’t tell him that. That was so he didn’t look like all the other people whose pants are falling down. He’s like mom why would they dress like that, don’t they know how they look, they look, you know, stupid and he does not want to look dumb. To the point to where any place he goes he will be dressed nicely. Even working out he will be dressed nicely. . . . Which is weird — that he has just picked that up himself. Cause if you dress bad you look stupid and he does not want to look stupid. Figure that out.

She is worried about what might happen if Andy’s perception of normalcy is challenged.

Andy’s Mom: . . . what if something would happen and they would bring a handicapped child into this world? How would two handicapped children deal with another handicapped child, let alone a normal child. Neither one of them can drive, neither one of them can read, how would they no what this kid is sick and if it did get sick, whose going to take it to the doctor like in the middle of the night if this child is sick? . . . I have no problem with them getting married. But children, that cannot be an option. It cannot. . . . who is going to take care of this child. And what if this child is normal? I have to go through all of the scenarios, because it is going to happen if they have a child and this child comes into this world normal and he finds out his parents are not and I know this has happened. . . . There’s paperwork and all sorts of articles and stuff on it that . . . that would hurt Andy if his child would say “you are a retard” that would just kill Andy because he prides himself on
not being one, you know. That’s why he always dresses nice, cause he never wants to be a slob like everybody else. He always dresses nice.

As mentioned previously, normalization is one of many concepts associated with the idea of quality of life. The concept of happiness was also prevalent in these interviews. Most of the parents believe that their children are happy most of the time. This perception appears to be consistent with the remarks made by the participants in this study.

**The Quality of Life Equation**

The normalization principle was one of two concepts used to examine facets associated with quality of life. The other facet was the idea of happiness. During the second phase of this study, I asked all of the participants if they were a happy person. Each one of the participants indicated that they were indeed happy and most suggested that were happy “all of the time”. Few things could make them happier. Andy reported that he could happier if he “was rich” and Danny said that he could be happier if “some people didn’t make him mad”. Since this was not a quantitative study there is no way of knowing if the perception of being “normal” plus the perception of being “happy” equals enhanced quality of life. Furthermore, there is no way of knowing whether or not the leisure experiences of these individuals contribute to these feelings of “normalcy” and “happiness”.

**Summary**

What we do know is that these feelings of “normalcy” and “happiness” emerged as these individuals discusses their leisure experiences. We also know that the leisure experiences of these young adults with developmental disabilities are similar to the leisure experiences of individuals without disabilities. These similarities are primarily
recognized in the context of the existential and social nature of the leisure experiences.

The next chapter will expand upon and explain these results.
CHAPTER 5
DISCUSSION

This project started with some idea as to the nature of the leisure experience, as more data were collected and analyzed new ideas emerged. The intent of this chapter is to summarize the evolution of the concepts studied in this project. Thus the theory that emerged from the data is described and the applications of this theory to practice and research are discussed.

Recall that the overall purpose of this study was to understand the subjective nature of the leisure experiences of young adults with developmental disabilities. I used three methods to understand this phenomenon. First, I interviewed young adults with developmental disabilities and their parents about the leisure experience. As this data emerged, a case study approach was adopted. This case study approach was used to describe the unique characteristics of the individuals and community being studied. I gathered additional data to support these case studies using participant observation.

Three broad themes emerged from the data collected via the interviews with the young adults who have developmental disabilities and their parents. These three broad themes involved the ideas that:

- There is a global nature of the leisure experience (GNL)
- There are specific elements of the leisure experience (SE_L)
- Leisure is a reflection of normalcy (LRN).

The next section of this chapter describes how these ideas contribute to and expand upon the existing body of knowledge.
The Global Nature of the Leisure Experience: $\text{GNI}_l = \Sigma \text{CI}$

The global nature of the leisure experience can be described as the sum of community influences ($\Sigma \text{CI}$). Since many leisure scholars have roots in the fields of sociology and anthropology, leisure has often been studied in the context of these community influences. Community influences, might also be called societal influences, and therefore may include those social institutions that exist within our lives. Figure 1 illustrates these community influences. Each of these domains appears to be important in the lives of individuals with developmental disabilities. It is through school that the individuals meet the friends and learn some but not all of the skills necessary for leisure pursuits. Their families support, encourage and advocate these leisure pursuits. And work is an activity similar to leisure, and may even be leisure for some of the participants in this study. Each of these domains exists within the context of a social world and therefore

![Figure 1: Domains of Life: Work, School, Family and Leisure](image-url)
produces meaningful events associated with the experience. This idea is consistent with the idea of symbolic interactionism.

These social institutions are often called agents of socialization. According to Kendall (1999) agents of socialization “are the persons, groups or institutions that teach us what we need to know in order to participate in society” (p.84). Kendall suggests that family, school, peer groups and mass media are examples of agents of socialization. For the individuals in this study, the community influences, most relevant to the leisure experience, are those associated with the work and social domains of life.

The ideas of friendships and work emerged as critical factors associated with the leisure experiences of young adults with developmental disabilities. This finding was consistent with the idea of symbolic interactionism, which guided this study. Recall that the main premise of symbolic interactionism suggests that an individual derives meaning from an experience based upon the interactions that occur within that experience. In this study, the meaning associated with the leisure experience was existential and the interactions which contributed to the understanding of this experience were social. This indicates that the existential and social nature of leisure proposed by Kelly (1999) seemed to reflect the nature of the leisure experiences of these young adults with developmental disabilities.

The existential nature of leisure experiences of these young adults indicated that the leisure that exists in the lives of these individuals takes the form of activity. These activities, in which the participants find joy and happiness, represent the idea of leisure, despite a general lack of awareness of what that term means. These activities occur within the context of other activities in their life (e.g. family, work and school).
The external dimensions which were prevalent in this study involved the ideas of work, family and friends. The leisure preferences of the individuals in this study reflected a hierarchy which included the domain of work, and preference of socializing with others. Chapter 2 examined these constructs in greater detail.

In the literature on the role of work in the lives of individuals with developmental disabilities, the concept of job satisfaction is prevalent (Dixon & Reddacliffe, 1996; VCU, 1997). Although we knew that individuals with developmental disabilities enjoy working, we did not know where work fell on a continuum of preferences. In this study, many participants reported that they enjoyed working. But, the presence of work in a hierarchy of preferences varied amongst all of the participants.

When the friendships of individuals with developmental disabilities were discussed in the Chapter 2, there were some conflicting reports. While Dattilo and Hoge (1995) reported that this population tended to prefer to do things by themselves, Malik (1990) and Kleiber et al (1990) found that friendships were important to their participants. My findings are consistent with those of Malik and Kleiber et al. In the literature review it was reported that individuals with developmental disabilities identified peers who also have developmental disabilities as being their friends (Hayden et al, 1996; Neumayer, Smith and Lundgren, 1993). The theme of shared life experience in this study illustrates consistency in this area. One area in which this study differs from the existing body of knowledge pertains to the nature of friendship. Recall that Green and Schleien (1991) suggest that adults with mental retardation rarely develop meaningful reciprocated friendships and that these individuals do not meet or make friends via
recreation participation. In this study, the themes associated with the ideas of shared life experience and reciprocity conflict with the previous studies.

Although there were no studies cited in the literature review which examined the role of family in the leisure experiences of young adults who have developmental disabilities, this study revealed that families play an important role in the leisure experience for this population. My findings resemble the findings of Mactavish (1994, 1997), however, who examined the recreation patterns of families of children with developmental disabilities. Both studies indicate that families pursue participate in recreation together. The participants tended to travel and go to movies with their families. In this study, the participants also emphasized how family supports leisure pursuits.

In many respects, individuals with developmental disabilities derive meaning from interactions associated with these community influences. Therefore, I suggest that the sum of these community influences constitute an external dimension of the leisure experience. This is one of the first studies to discuss the global nature of the leisure experience as it pertains to this population. While other studies have examined leisure in the context work, in the context of family, and in the context of friends, no studies looked at the comprehensive nature of these community influences in relation to leisure. While Pedlar et al (1999) examined each of these institutions, they did not look specifically at their relationship to the leisure experience as a whole.

**The Specific Elements of the Leisure Experience (SE₁)**

While the global nature of the leisure experience emerged as a dominant theme in this study, I initially set forth to understand the specific elements of the leisure experience. It was difficult to propose ideas a priori, which would help describe the overall leisure experience. Few studies in leisure studies, have actually studied the overall
phenomenon of the leisure experience. More often than not, researchers look at one small facet of the leisure experience (e.g. meaning or satisfaction; motivations or constraints). Therefore, finding a model that described the global nature of the leisure experience was difficult. Mannell (1999) suggested that leisure had been studied by examining three facets: participation, meaning and satisfaction. Therefore, the initial framework that guided this study included these three facets (Figure 2). For the most part these facets

Figure 2: Initial Facets of the Leisure Experience (Mannell, 1999)

of the leisure experience are internal dimensions. In Chapter 2 several concepts associated with the leisure experience were discussed. These concepts, used to operationalize the leisure experience (e.g. motivations, constraints, meaning and satisfaction), explore the internal dimensions of the leisure experience. The internal
dimensions of the leisure experience occur within the individual and include the perceptions, values, beliefs and abilities that a person has.

Recall that the literature identified several motivations for leisure participation (Beard & Ragheb, 1980). It has been reported that this population tends to be motivated by social factors (Kleiber et al, 1990; Shapiro, 2003). This population is also motivated by a desire to develop new skills (Malik, 1990; Shapiro). In this study, the participants were motivated by doing activities “cause it is fun” and “to hang out with friends”.

The literature also identified common constraints associated with this population. While the individuals within this study did not report many constraints, those constraints mentioned were consistent with those constraints mentioned in the literature. Several studies suggested that a lack of money is a constraint for this population (Bedini, Bullock & Driscoll, 1993; Hawkins et al, 1999; Hoge & Dattilo, 1995; Sparrow & Mayne, 1990). In this study, Kelly cited money as a barrier to participation. The other constraints mentioned in the literature (e.g. transportation, lack of knowledge, lack of opportunity, lack of social support, stigma, and competence) were not mentioned by the participants. Mike and Charlie identified “being too busy” as a constraint. This constraint was not mentioned in the literature about leisure and individuals with developmental disabilities. The constraints of time and money mentioned by the participants more accurately reflect the structural constraints of individuals without disabilities identified by Crawford and Godbey (1987).

Prior to this study, two studies reported examining leisure satisfaction among individuals with developmental disabilities. Bedini et al (1993) merely asked individuals about developmental disabilities about leisure satisfaction, but they did not report any
results. Williams and Dattilo (1997) said that the smiles and vocalizations of this population could reflect psychological or physiological satisfaction. In this study, the most of the participants reported doing things that they enjoy “all the time” when asked if they would like to do these more or less frequently, most appeared to be satisfied with their current level of participation.

When leisure meaning and leisure perceptions were studied in the past, the authors suggested that this idea be explored further in future research. Malik (1990) found that few of her participants understood the terms recreation and leisure. This study revealed similar results. While her participants identified leisure time as time spent alone and recreation as activities, time and freedom and feelings/experiences, the participant identified the terms as being synonymous with each other. The participants tended to define these terms much in the same way Malik’s participants defined recreation. Dattilo and Hoge (1995) found that the concept of leisure perception involves leisure preferences, benefits of leisure participation and constraints to leisure. The only theme from their study, reflected in this study was the idea of leisure preferences. The leisure preferences and meaning identified in this study appear to have been influenced by interactions with the external dimensions of the leisure experience.

The Leisure Experience (LE = GN_L + SE_L)

As this project emerged, it became evident that the early conceptualization (focusing on the specific elements of the leisure experience) did not reflect some important elements associated with the leisure of young adults who have developmental disabilities. So, upon the initial phases of data analysis additional trips to the library were made to find a model, a theory, or a framework that reflected the themes that were emerging in the data. Although symbolic interactionism is commonly used to describe the
interaction between an individual (SEₗ) and the community influences (GNₗ) this framework tends to focus on one element of the specific elements of the leisure experience — meaning. And yet, the premise that experience involves primarily internal dimensions minimizes the role of the community influences. Therefore, the model that emerged from this project fills a gap in the literature — explaining the leisure experience in terms of internal and external dimensions. Figure 3 illustrates the leisure experience described by the participants in this study. The arrow indicates the internal dimensions of the leisure experience. This is the dimension of the leisure experience that involves the Self (the Self’s experiences and the Self’s perceptions). This dimension is depicted by an arrow which indicates that the experience occurs throughout the course of the Self’s life (Kelly, 1987, 1990; Kleiber, 1999; Rapoport & Rapoport, 1975). As the Self develops, he or she encounters people, places and things along the way (Kelly,
1987). These people, places, and things influence the opportunities that the Self experiences (Kelly, 1983, 1987; Rossman & Schlatter, 2000; Samdahl, 1986, 1988). For example, the Self may live in Florida and have the opportunity to go to the beach versus living in Nebraska where a large body of water is non-existent. Likewise, the Self may have parents who enroll him or her in a variety of activities. In contrast, these community influences may hinder the ability for the Self to engage in leisure pursuits (Crawford, Jackson, & Godbey, 1991; Jackson, Crawford & Godbey, 1993; Raymore, Godbey, Crawford & von Eye, 1993). For example, society might have attitudes which stigmatize an individual (Bedini, 2000). Some of these experiences may elicit positive emotions while other experiences may be negative. If the Self enjoys an activity he or she might be motivated to participate in similar activities, likewise, the Self may feel satisfied these pursuits (Mannell & Kleiber, 1997). If the Self does not enjoy these activities he or she may seek or desire more.

Therefore, the leisure experience involves internal and external dimensions. This study suggests that the leisure experience occurs within the self and involves perceptions related to participation, meaning and satisfaction all of which are influenced by factors such as family, friends, and work. The internal and external dimensions of the leisure experience, alone, do not fully explain the concept of leisure of the participants in this study.

Leisure as a Reflection of Normalcy (LRN)

As the community and society influenced the leisure experiences of the individuals in this study, the participants in this study developed perceptions of the world based on their leisure experiences. These participants look at their world, their
friendships, and their experiences in the context in which they live. They identify niches that they fit then distinguish similarities and differences.

The world in which these participants live is the same world that we all live in. Six of the ten participants in this study work in the mainstream community, they bowl in the mainstream community, they live in the mainstream community and they went to school in the mainstream community. They know people without disabilities, yet, they prefer segregated activities and their parents prefer segregated activities.

Their perceptions of the world may differ from the rest of society. But we all have different perceptions of the world. We are republicans or democrats. We are artists or scientists. To the participants in this study, the segregated activities that they participate in are “normal”. These activities, interactions, and experiences represent “normal” — whatever “normal” may be. Figure 4 illustrates how the leisure experience reflects normalcy.

Figure 4: Leisure as a Reflection of Normalcy
Figure 4 shows the Self looking into a mirror which represents society, the community, or the world. In this study, the Self represents the young adults with developmental disabilities who were participants in this study. These individuals look into the world when they work in the community, when they “hang out” with their siblings, when they go to the community bowling alley. What the Self sees in this mirror is a reflection of who the Self is? There are few differences and many similarities. This image is similar to the idea of Cooley’s *looking-glass self*. The *looking-glass self* refers to the way in which the Self perceived him or herself based on the interactions that the Self has had with society (Kendall, 1999). This idea is consistent with symbolic interactionism. Based on the interactions that the participants have had in their community, it appears as though they perceive themselves to be “normal” — having more perceived similarities with members of society than perceived differences.

Furthermore, the participants in this study appear to live a life similar to most people without disabilities in society. Their friendships are reciprocal and are based on shared life experiences. Their leisure constraints involve not having enough time or money to do the things that they enjoy. These individuals have preferences just like other people. The participants do not see themselves as being different from the rest of society. Physical differences may exist which impair their abilities to read or to problem-solve. These differences, however, do not prevent them from living life. They make friends, work and play just like the rest of us.

**Quality of Life**

In Chapters 1 and 2, the concept of quality of life was discussed. It was mentioned that the concept of quality of life is abstract, but there are certain elements that are measurable. Recall that Schalock et al.,(2002) stated that quality of life:
• Is composed of those same factors and relationships for people with intellectual disabilities that are important to those without disabilities;

In Chapter 1 it was mentioned that quality of life is characterized by feelings of happiness, life satisfaction, and psychological well-being (Iso-Ahola; Dennis et al., 1993). According to the research participants and their parents, for the most part these young adults with developmental disabilities are happy.

• Is experienced when a person’s needs and wants are met and when one has the opportunity to pursue life enrichment in major life settings;

It is my belief that the individuals in this study had the opportunity to pursue life enrichment in major life settings. As mentioned previously, 6 of the 10 participants in this study work in the mainstream community, they all bowl in the mainstream community, and they all live in the mainstream community.

• Has both subjective and objective components but is primarily the perception of the individual that reflects the quality of life he/she experiences;

If perceived normalcy and perceived happiness reflect quality of life. The idea presented in this statement is reflected in the grounded theory that emerged from the data gathered in this study.

• Is based on individual needs, choices, and control; and

Most of the respondents in this study indicated that they are satisfied with their leisure experiences. They are given opportunities to engage in those activities that they enjoy.

• Is a multidimensional construct influenced by personal and environmental factors, such as intimate relationships, family life, friendships, work, neighborhood, city or town of residence, housing, education, health, standard of living and the state of one’s nation (p. 460).

The participants in this study have friends, supportive family, and significant others. All of the participants in this study are employed. They live in community that supports their
values. If these criteria are indeed a measure of quality of life, it appears as though each participant in this study lives a life that is high on the quality of life scale.

**Implications for Professional Practice**

It was stated in previous chapters, that many human service professions strive to enhance the quality of life of individuals who have developmental disabilities. As such, this study has several implications for the practice of recreation and therapeutic recreation.

First, this study once again suggests that individuals are unique but also similar; therefore, it is important to assess the unique needs, interests and preferences of each individual within a recreation program. In this study, it was evident that the participants had preferences regarding specific activity involvement and social interaction. Many participants enjoy working; therefore, recreation programs should be offered in the evenings and the weekends to accommodate individual work schedules. Many of the participants enjoyed physical activities, but several also enjoyed passive activities such as writing, reading, and listening to music. Recreation programs therefore, should offer a variety of programs and should consider the preferences of the participants.

Secondly, this study suggests that individuals with developmental disabilities prefer activities that involve opportunities for social interaction. Therefore, when programming, it is suggested that recreation professionals provide opportunities for this population to “hang out with friends”. Since friends tend to include people who are similar, some segregated programs may be advisable.

Family programming also appears to be appropriate for this population as many participants are “happy” when they are with family. Parents interviewed in this study
have found organized recreation programs to be beneficial for themselves as well since these programs provide them with respite and a support system.

Although leisure education does not seem as though it would have enhanced these participants’ ability to participate in structured recreation. It might be beneficial when exploring how an individual uses his or her alone time. For the most part, the participants listed few solitary activities in which they participate (i.e., writing, reading, and word games).

**Implications for Future Research**

The scope of this study can be expanded in various ways. Additional studies could enhance our understanding of the leisure experience and quality of life from the perspectives of young adults with developmental disabilities.

Within this community, further exploration of these ideas from the perspectives of other individuals (e.g. staff, teachers, siblings, co-workers) could provide further insight into the unique nature of this community. By examining similarities and differences from the different perspectives we would have a better understanding of how these individuals are perceived by their community.

The models that emerged from this data could be tested with other populations. For example, are these models reflective of the leisure experiences of young adults without disabilities? When examining these phenomena further, it is suggested that other types of communities (e.g. inner city and rural) be studied. The impact of race, gender and socio-economic status should be examined in order to determine the generalizability of the model and to determine whether these factors influence the perceptions of the leisure experience. For the same reasons, comparisons among disability groups might want to be explored as well.
It might be helpful to develop quantitative measures based on these models. The quantitative measures can be used with a large number of participants can could determine correlations. Such indices might help determine whether quality of life is related to leisure, number of friends, self-determination and hours worked.

The interviews with the parents of these young adults suggested that the amount of parent involvement might be an indicator of the amount of leisure involvement within this population. The parents’ perception of the leisure experiences and friendship yielded some interesting insight into why parents have encouraged and discouraged their children’s involvement in different activities.

Ecological studies with this population, including interviews with the participants, parents, teachers and other human service providers might provide insight into some of the historical events that occurred within the lives of these participants. Furthermore, a longitudinal study with this population might help us understand the leisure experiences of these individuals throughout the life course.

Finally, comparative studies between the parents and participants perceptions of life events might be useful when determining the amount self-determination that occurs within an individual’s life. These suggestions will only help expand upon the body of knowledge in the area of developmental disabilities and can enhance service delivery practices.

**Conclusion**

Leisure experience is a complex phenomenon. Prior to this study, the overall nature of the leisure experience had not been examined. The data that emerged in this study suggest that the leisure experience \( LE = GN_L + SE_L \) is made up of two components. The first component, called the global nature of the leisure experience
(G\textsubscript{N\textsubscript{L}}), describes an external dimension which involves the sum of the community influences (\(\Sigma CI\)). In this study the primary community influences involved work and social domains. The second component, called the specific element of the leisure experience (SE\textsubscript{L}) involves internal dimensions such as leisure participation, leisure meaning and leisure satisfaction.

The leisure experiences of the participants in this study reflected an idea of normalcy. This idea emerged as a theme called leisure as a reflection of normalcy. This theme suggests that the individuals in this study perceive their lives as being “normal”. These individuals live, work, and play within the physical community of Prairie View. They have co-workers, siblings, and co-recreators who do not have disabilities. These participants and their parents prefer segregated activities. The participants in this study have shared life experiences and reciprocal friendships with other individuals who have developmental disabilities. They do not perceive these friendships or experiences to be abnormal. The parents suggest that segregated activities are beneficial. As a whole, these segregated activities are perceived as being “normal”.

APPENDIX A
INITIAL INTERVIEW GUIDE

1. Have you ever heard of the word *leisure*? (Malik, 1991)

   **Probes:**
   What do you think the word means? (Malik, 1991)
   Have you ever heard of the words “free time”?

2. Have you ever heard of the word recreation? (Malik, 1991)

   **Probes:**
   What do you think the word means? (Malik, 1991)

3. What do you do for fun (Dattilo & Hoge, 1995)?

   **Probes:**
   What do you like to do (Dattilo & Hoge, 1995)?
   What do you like about these things?
   What other things do you like to do?
   What makes you happy? (Malik, 1991)

4. How often do you do these things?

   **Probes:**
   Would you like to do them more often?
   Why don’t you?
   How do you pay for these things?
   How do you do this/How do you get there?

5. When did you start doing these things?

   **Probes:**
   How old were you?
   Where did you learn how to do these things?
   Did you learn them at school?
   Who taught you?

6. Why do you like to do these things?
**Probes:**
Are you good at these things?
How does doing this make you feel?

7. Do you do these things with other people or by yourself?

**Probes:**
Whom do you do these things with?
Tell me about your friends.
Tell me about your family.

8. Tell me about some of the things you like to do by yourself.

**Probes:**
Are you good at these things?
How does doing this make you feel?

9. What is your current job?

**Probes:**
Where do you work?
What do you do?
Do you like it?
Is it fun?
Is there anything else that you’d like to/rather do?

10. What do you do when you aren’t working?

**Probes:**
Do you like it?
Is it fun?
Is there anything else that you’d like to/rather do?

11. Is there anything that you haven’t done that you think might be fun?

**Probes:**
Why haven’t you done it?

12. Who do you trust the most?

13. Would you mind if I ask them a few questions, like the ones I asked you today about you?
APPENDIX B
FOLLOW-UP INTERVIEW GUIDE

1. What makes you happy?

2. What do you enjoy doing?

3. Do you have any brothers or sisters?

   **Probes:**
   
   If so, please tell me about them.
   
   How are they like you?
   
   How are they different from you?

4. Please tell me about other people your age.

   **Probes:**
   
   How are they like you?
   
   How are they different from you?

5. Have you ever heard of the word friend?

   **Probes:**
   
   What do you think that word means?
   
   Who are your friends?
   
   Do you consider your parents to be your friends?
      
      Why? Why not?
   
   Do you consider your brother or sister to be your friend?
      
      Why? Why not?
Do you consider your case worker or job coach to be your friend?

Why? Why not?

6. How often do you do things with your friends?

7. How often do you talk to your friends?

8. Do you see your friends as often as you want?

9. How often do you feel lonely?

10. Are you a happy person?

11. What do your friends do for you?

12. What do you do for your friends?

13. What do you like best about friends?

14. Do you have a best friend?

15. Do you have a “best friend”?

16. What do you like best about him or her?
APPENDIX C
CIRCLE OF SUPPORT GUIDE

1. Have you ever heard of the word *leisure*? (Malik, 1991)
   
   **Probes:**
   What do you think the word means? (Malik, 1991)

2. Have you ever heard of the word recreation? (Malik, 1991)
   
   **Probes:**
   What do you think the word means? (Malik, 1991)

3. What do you do for fun (Dattilo & Hoge, 1995)?
   
   **Probes:**
   What do you like to do (Dattilo & Hoge, 1995)?
   What do you like about these things?

4. Does the <<research participant>> know what the word recreation and leisure mean?

5. In your opinion, what does he or she do for fun?
   
   **Probes:**
   What does he or she like to do (Dattilo & Hoge, 1995)?
   In your opinion, what does he or she like about these things?
   How does he or she do this/How does he or she get there?
   What makes him or her happy? (Malik, 1991)
   How does he or she pay for these things?

6. When did he or she start doing this?

7. How often does he or she do this?

8. Who does he or she do these things with?
   
   **Probes:**
   Tell me about some of his or her friends.

9. In your opinion, why does he or she like to do these things?

10. What are some things that he or she does by his or her self?
11. Does he or she work?

   **Probes:**
   Where?
   What does he or she do?

12. What does he or she do when he or she is not working?
APPENDIX D
REVISED CIRCLE OF SUPPORT INTERVIEW GUIDE

2. Have you ever heard of the word *leisure*? (Malik, 1991)

**Probes:**
What do you think the word means? (Malik, 1991)

2. Have you ever heard of the word recreation? (Malik, 1991)

**Probes:**
What do you think the word means? (Malik, 1991)

3. What do you do for fun (Dattilo & Hoge, 1995)?

**Probes:**
What do you like to do (Dattilo & Hoge, 1995)?
What do you like about these things?

4. Tell me about <<research participant>>

**Probes:**
When was he/she born?
Where was he/she born and raised?
What is his/her diagnosis?
When was he/she diagnosed?
Where did he/she go to school?
What types of classes did he or she take?

5. Does the <<research participant>> know what the word recreation and leisure mean?

6. In your opinion, what does he or she do for fun?

**Probes:**
What does he or she like to do (Dattilo & Hoge, 1995)?
In your opinion, what does he or she like about these things?
How does he or she do this/How does he or she get there?
What makes him or her happy? (Malik, 1991)
How does he or she pay for these things?

7. When did he or she start doing this?
8. How often does he or she do some of these things?

9. In your opinion, why does he or she like to do these things?

10. Who does he or she do these things with?

   **Probes:**
   Tell me about some of his or her friends.

11. What are some things that he or she does by his or her self?

11. Does he or she work?

   **Probes:**
   Where?
   What does he or she do?

12. What does he or she do when he or she is not working?
LIST OF REFERENCES


The Education of All Handicapped Children’s Act of 1974, Public Law No.94-142.


BIOGRAPHICAL SKETCH

Kari Kensinger, Ph.D., CTRS, earned both her bachelor’s and master’s degrees in therapeutic recreation from the University of Nebraska at Omaha. She recently earned a Doctorate of Philosophy in therapeutic recreation from the University of Florida.

Ms. Kensinger has worked in the field of therapeutic recreation for over 15 years, with clients ranging in age from 2 to 106. She has worked in a variety of settings, including nursing homes, hospitals, schools, and human service agencies. Her primary interests have been in the areas of developmental disabilities and geriatrics.

Ms. Kensinger has been an active member and leader within the field of therapeutic recreation. Kari served as president of the Nebraska Association of Recreation Therapists, and has been a team leader for several committees of the American Therapeutic Recreation Association. Upon graduating, Ms. Kensinger will be an assistant professor of therapeutic recreation, at Grand Valley State University in Grand Rapids, Michigan.