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# A Phenomenological Study of Participation in Specialized and Inclusive Recreation Programs

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**A Phenomenological Study of Participation in  
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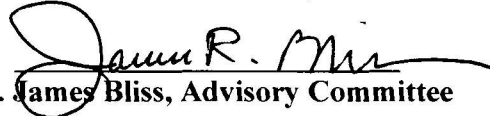
by

**Charles K. Mullins**

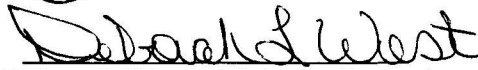
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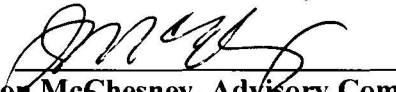
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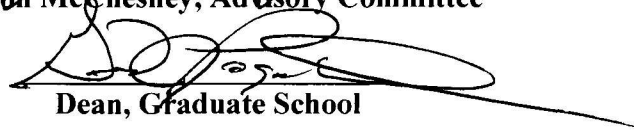
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A Phenomenological Study of Participation in  
Specialized and Inclusive Recreation Programs

by

Charles K. Mullins

A Dissertation

Submitted in Partial Fulfillment of the Requirements  
For the Doctorate in Education

College of Education  
Department of Educational Leadership and Policy Studies

Doctoral Committee:

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Richmond, Kentucky

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## **DEDICATION**

I lovingly dedicate this dissertation to my wife, Lashé, and my children, Gabriel and Haven, who have inspired and encouraged me throughout the pursuit of this advanced degree. Without their love and understanding, I would not have been able to finish this work.

## ACKNOWLEDGMENTS

I would first like to acknowledge my mother, Brenda Watts, for all her love and encouragement throughout my educational pursuits. In addition, this dissertation would not have been possible without the love and support of my wife, Lashé Mullins. I wish to acknowledge my doctoral committee members who were more than generous with their expertise and time on my dissertation despite their already heavy loads of responsibility. I give special appreciation to Dr. Charles Hausman, my committee chair, for his invaluable direction and leadership throughout the dissertation process. Thank you Dr. James Bliss and Dr. Jon McChesney for your sagacious guidance in my research, including manuscript revisions. Thank you Dr. Deborah West for assisting me with final edits and teaching me about qualitative field research. I would like to express my sincere appreciation to Dr. Michael Bradley and Dr. Caelin Scott for their advice and friendship during this process. Furthermore, I am thankful that I made a few new friends along this journey. I would like to extend my sincere appreciation to doctoral candidates, Vicki Jozefowicz and Tara Rodriguez for being my group partners in many class projects and for numerous peer-to-peer discussions outside the classroom. Finally, I would like to acknowledge my research participants as their excitement and willingness to take part in my study made the completion of this dissertation as enjoyable as recreation itself.

## ABSTRACT

The purpose of this qualitative study was to understand whether participation in specialized recreation programs, which are designed for individuals with disabilities, increases opportunities for participation in inclusive programs, which are designed for both individuals with and without disabilities. Regardless of the popularity and growth of inclusive services, specialized programs persevere in numerous recreational service settings and continue to be used by individuals with disabilities and their families. This study helps to clarify why individuals with disabilities and their families choose to participate or not participate in these programs. The research questions focused on the connection between participation in specialized and inclusive recreation programs. The International Classification of Functioning, Disability and Health for Children and Youth (ICF-CY), a classification of the health components of functioning and disability, provided the conceptual framework for the study and facilitated the interpretation of the findings. This study should help recreational service providers and educators create and develop programs, both specialized and inclusive, and promote the concept of choice in recreation. The research participants were selected using purposive sampling wherein individuals who possessed specific characteristics of importance to this study were selected by the researcher. The findings as well as the implications and conclusions from this study provide understandings that could have a direct impact on participation in specialized and inclusive recreation programming.



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## CHAPTER I

### INTRODUCTION

As a doctoral student, I am familiar with research on the promotion of inclusive education, and the rights of children to be included in mainstream education as well as the proposition that inclusive education is more effective. For example, Tremblay (2013) compared two instructional models for students with learning disabilities with regard to their effect on academic achievement and class attendance. Although the results of the study revealed no considerable difference between the two models in terms of target population and objectives, significant differences were observed in the effects of student outcomes in reading, writing and attendance, with the inclusion model being more effective when compared to the specialized education setting (Tremblay, 2013, p. 256).

On a Sunday afternoon in the summer of 2014, I was reviewing Tremblay's (2013) article for a class assignment while visiting a community playground with my two children. The outdoor facility, which happens to be one of the largest playgrounds in the community, includes a play area containing adaptive equipment for children with special needs. My children were inquisitive and began to ask me several questions pertaining to the adaptive equipment. I explained that some children have disabilities that may prevent them from playing on certain types of equipment, but thankfully this playground was designed for children and families of all abilities to enjoy the fun. As I played with my children, I realized the importance of playgrounds that are truly inclusive for all. I began to think beyond commercial playground equipment and look at the big picture within inclusive recreation. What did this term mean to me? I thought how inclusive recreation

could be anything an individual with a disability likes to do, activities that occur in the natural environments at school, in the community, or in recreation service agency settings, alongside people without disabilities. At that moment, it was apparent to me that inclusive recreation was as important to quality of life as inclusive education. That afternoon, on the drive home from the playground, I realized that I had found the subject of my dissertation. Everyone should have the option to participate fully in leisure without discrimination. Inclusive recreation breaks down the barriers that separate individuals with disabilities from those without disabilities or at least, it should if it is planned and delivered correctly. The reality is that individuals with disabilities are often faced with far too many barriers to inclusive recreation program participation.

Having worked closely with Special Olympics for several years, I have observed how the organization, although mostly segregated in programming, can co-exist with inclusive recreation programs. Furthermore, I have observed individuals who participate in both specialized and inclusive recreation. In this study, it is revealed that Special Olympics has made great strides to participation in inclusion by adding inclusive recreation programs to their roster of events and activities. Moreover, Special Olympics appear to be expanding into inclusive recreation as never before. Stumbo, Wang, and Pegg (2011) wrote: “It has been widely acknowledged that leisure experiences and participation provide unique and valuable opportunities that may result in numerous physical, social, and psychological benefits, as well as enhance overall quality of life” (p. 92). After all, inclusive recreation should truly be inclusionary by making certain that no individual is deprived of the ability to grow and to flourish through participation in leisure.

While engaged in leisure participation over the past several years, I began to observe an increasing number of recreation service agencies placing an emphasis on supporting adults and children with disabilities in a wide range of programs. As a recreation programmer in higher education, I have worked for many years with certified therapeutic recreation specialists and other recreation professionals to develop multiple strategies to create, develop, and implement inclusive recreation programs. As Carter (2015) explains, a certified therapeutic recreation specialist (CTRS) is a professional who works to improve the mental, emotional, and physical welfare of sick or disabled individuals. As a CTRS, you improve the welfare or well-being of individuals who have illnesses or disabilities through treatment services and inclusive recreation service delivery. Therapy methods help to build confidence and may utilize sports, arts and crafts, dance, music, theatre, and other techniques to reduce stress, and improve functioning in individuals with disabilities (p. 17).

In addition, I have worked directly with Special Olympics in the development and delivery of their Summer Games among other annual events, observing first-hand that the organization is truly comprised of individuals who want to improve the lives of people with intellectual disabilities. It was because of my background in Special Olympics, that I decided the participant pool in my study would be comprised of parents of children with intellectual disabilities rather than merely physical disabilities. After I was encouraged by my departmental advisor to take a phenomenological approach, I realized a first-person viewpoint along with relevant conditions of experience was ideal for my study. After conducting my interviews, I realized that each of my participants strongly felt that Special Olympics is a program that excels in meeting the necessary support needs of its

audience, and that, generally speaking, other specialized recreation programs aspire to if not achieve the same results.

As Miller, Schleien, and Lausier (2009) observed, there has been expanding growth in the number of recreation agencies implementing inclusive service delivery (ISD) practices. However, while many of these agencies are experiencing success with these inclusive initiatives, many are not. Why? Although, the field of recreation and leisure studies has been introduced to inclusive services, curricula, and evidence-based practices to serve individuals with disabilities, there is still need for further research and knowledge to better understand how to increase the implementation of these best practices and eliminate all barriers to inclusion.

### **The Meaning of Leisure and Importance of Inclusive Recreation**

Leisure is commonly described by scholars in the field as free time, as recreational activity, or as an attitude (Anderson & Kress, 2003). The perspective used in this study is that leisure is a social experience designed through interaction in social situations (Iso-Ahola, 1999; Samdahl, 1988). The responsibilities of work-life balance can obscure the meaning of “freely chosen” or “free choice,” in leisure or at least make it more difficult to understand (Samdahl, 1988, p. 30). The idea of freedom has been a vital component of leisure since mankind first pondered the meaning of leisure (Rossman & Schlatter, 2011). Most importantly, the notion of freely choosing anything can only be determined from the perspective of the individual making the choice (p. 9). Therefore, in terms of leisure participation the notion of freedom is a matter of individual perception.

Rossmann and Schlatter (2011) explain that programming is the central focus of the leisure service profession and the most essential component of leisure service

agencies. Moreover, “Programming is designing, staging, and delivering leisure opportunities by intervening in social interaction; that is, by manipulating and creating environments in a manner that maximizes the probability that those who enter them will have the leisure experiences they seek (p. 6). “As the National Recreation and Park Association (NRPA, 2015) proclaim, “programming is not only the heartbeat of park and recreation departments’ community outreach; it is also the largest single source of most agencies’ annual revenue. Furthermore, these two faces of recreational programming can create problems for budget-challenged agencies about whether to channel resources into lower-revenue programs” (p. 14). Being the heartbeat of park and recreation agencies, means that staff must be qualified and ready to meet the challenges that makeup inclusive practices. As Rossman and Schlatter (2011) explain, “Programmers, better than any other professional group, should understand the phenomena of leisure, how humans engage in and experience leisure, the results of this experience, and how to facilitate an individual’s experience of leisure” (p. ix). Overall, research has shown that participation in recreation and leisure programming is important for overall happiness and is directly related to quality of life (Gladwell, 2000; Iso-Ahola, 1999; Kelly, 1990; Rossman & Schlatter, 2011).

Historically, individuals with disabilities have had fewer opportunities for engaging in recreation and leisure programs than individuals without disabilities (Anderson & Kress, 2003). A common approach to recreation for individuals with disabilities is through specialized recreation programs where individuals with disabilities participate alongside others with special needs (Devine, 2004; Friend & Bursuck, 2011; Watcher & McGowan, 2002). Individuals with disabilities were once thought to need



segregated programs to accommodate differing skill levels and special needs. As Zabriskie, Lundberg & Groff (2005) observed, specialized recreation may not be the popular method of recreation program delivery today, however, segregated programs have been shown to provide benefits for participants nonetheless.

Today, research has shown us that the concept of inclusion, where individuals with and without disabilities participate in recreation programming together has become the widespread dynamic in recreation programming (Anderson & Kress, 2003; Devine, 2004; Friend & Bursuck, 2011; Godbey, 2008; Mayer & Anderson, 2014). Society has evolved in that inclusive recreation is considered the optimal environment for social relationship development between people with and without disabilities (Devine & Kotowski, 1999). Again, everyone should have the option to participate fully in leisure without discrimination, and when planned and delivered correctly, inclusion breaks down the barriers that separate individuals with disabilities from those without disabilities.

As Renzaglia, Karvonen, Drasgow, and Stoxen (2003) explained, “inclusion is a philosophy that urges schools, neighborhoods, and communities to welcome and value everyone, regardless of differences” (p. 142). Additionally, “Central to the philosophy of inclusion are the beliefs that everyone belongs, diversity is valued, and people can all learn from each other” (p. 140).

From an educational perspective, inclusion is different from the educational practice of mainstreaming as Renzaglia, Karvonen, Drasgow, and Stoxen (2003) noted, “Mainstreaming implies that individuals with disabilities have a separate placement and enter the mainstream only for the activities that they can perform at the level needed to succeed. Inclusion is also different from integration.

Integration implies bringing an individual back into a unified system; the physical act of bringing people back does not necessarily create an inclusive environment. Building a system that meets the needs of everyone from the onset creates an inclusive environment, and inclusion extends beyond the K-12 school boundaries to people of all ages with disabilities” (p. 147).

Research has established that inclusion in recreation and leisure is the philosophy that individuals with and without disabilities have the opportunity to participate together (Devine & Lashua, 2002; Godbey, 2008; Mayer & Anderson, 2014; Rossman & Schlatter, 2011; Smith, 2002). Research has identified positive outcomes for individuals without disabilities that engage in recreational programs with individuals with disabilities such as experiencing personal growth and a greater awareness of people with special needs (Anderson, Schleien, Germ, & McAvoy, 1996; Godbey, 2008; Schleien, McAvoy & La). Other benefits to inclusive recreational programming for individuals with and without disabilities have been revealed throughout research over the years, and these will be contained in my Review of the Literature (Chapter II). Inclusive recreation programs can help participants without disabilities gain a far better understanding of the strength and skills of individuals with disabilities, by focusing on the recreational activity, instead of on the disability (Rossman & Schlatter, 2011; Schleien & Green, 1992; Schleien, Germ, & McAvoy, 1996; Schleien, Miller, & Shea, 2009). Individuals with disabilities find that inclusive program settings provide diverse opportunities for developing friendships and increasing self-

esteem (Dattilo, 2002; Dattilo, 2013; Skulski, 2007; Shank & Coyle, 2002; Taylor, 2004).

### **An Introduction to Specialized Recreation**

Mayer & Anderson (2014, p. 156). In my professional experience as a recreation programmer, I have observed many agencies and schools providing specialized programs that offer recreational and social opportunities for individuals with physical or intellectual disabilities such as Unified Sports and after-school programs. Other examples include municipal recreation agencies, YMCAs or youth centers, such as the Boys and Girls Club, which all function as good resources for specialized programs (NRPA, 2015). Today, research has shown that recreation agencies located throughout the United States offer a variety of specialized programs from community enrichment classes that include fun, hands-on learning activities such as cooking, dance, drama, music, and pottery to team sports like baseball, basketball, bowling, golf, and soccer (Bendini, 2012; Dattilo, 2013).

Portland Parks and Recreation located in Portland, Oregon maintains a program, formerly known as Disabled Citizens Recreation, now aptly titled the Adaptive and Inclusive Recreation (AIR) program, which began in 1964 (Portland Parks and Recreation, 2015). Today, AIR is considered one of the top specialized community recreation programs in the United States. AIR serves individuals of all ages and variations of intellectual disability at various sites throughout the city of Portland, including community recreation agencies and schools.

In 1997, the Autism Society of North Carolina opened Camp Royall, a 133-acre facility near Pittsboro (Autism Society of North Carolina, 2011). Camp Royall is the

oldest and largest summer camp program in the United States specifically for people on the autism spectrum. Camp Royall offers several options of programs and services throughout the year for individuals with autism (para. 2). Camp Royall provides a hands-on approach to recreation participation and learning as well as an accepting atmosphere that celebrates the individuality of campers ages 4 to adult (para. 4).

What began as a backyard summer camp for people with intellectual disabilities was transformed to a global movement as Special Olympics has been changing lives and attitudes for 45 years (Special Olympics, 2015). Bueno (1994) explains the origin of Special Olympics, which began in the 1950s and early 1960s, when Eunice Kennedy Shriver observed how unfair society was to people with intellectual disabilities. Shriver then planned and implemented a summer day camp for children with intellectual disabilities in her own backyard. Throughout the 1960s, Shriver continued her work to help individuals with special needs, whether it was in her backyard or as part of John F. Kennedy's White House panel on people with intellectual disabilities, or as the director of the Joseph P. Kennedy Foundation (p. 21). Eventually, Shriver's dedication for helping individuals with disabilities grew into the Special Olympics movement and in 1968 Shriver organized the first International Special Olympics Games at Soldier Field in Chicago, Illinois.

From my own professional field observations, I can attest that the mission of Special Olympics remains as vital today as it did when the movement was founded in 1968. I was fortunate enough to work alongside Special Olympics for a decade by coordinating and facilitating campus space and other event resources every June when the organization brought their annual Summer Games to the university. Siperstein, Hardman,

Harda, Parker and McGuire (2006) observed that Special Olympics endeavors to create a better world by fostering the acceptance and inclusion of all people. As Special Olympics is the world's leading voice in elevating awareness of the needs and abilities of people with intellectual disabilities, I thought it would unquestionably be the ideal organization in which to find my study participants. Widaman and Siperstein (2005) explained that recreation and sports are at the heart of Special Olympics, but their ultimate goal is to use the stories of their participants' achievements to help educate the world on the amazing capabilities of individuals with intellectual disabilities. Furthermore, Special Olympics desires to use the stories of its participants to engage and ultimately change attitudes toward people with intellectual disabilities on a global scale. From a research point-of-view, I desired to use their stories as well. As former Senior Vice President with Special Olympics and current Senior Advisor to the National Inclusion Project, Corbin (2015) said,

“While progress has been made, there is still a long way to go before people with disabilities have equitable access to opportunities for productive lives, vocationally, socially, and culturally. Laws can be passed, but changing minds and hearts is a slower and more gradual process.”

Through the eyes of the research participants I hoped to learn whether participation in specialized recreation programs, which are designed for individuals with disabilities, increases opportunities for participation in inclusive programs, which are designed for both individuals with and without disabilities. Research has overwhelmingly identified barriers to inclusive recreation programs remain in our communities (Bendini, 2000; Devine, 2004; Schleien, Germ, & McAvoy, 1996; Schleien,

Miller, Walton, & Pruett, 2014; Scholl, Glanz, & Davison, 2006; Stumbo, Wang, & Pegg, 2011), however, I wanted to conduct my own qualitative study as a critical researcher and as a result, listen to and learn from the perceptions and stories of the participants of the study. If everyone should have the option to participate fully in leisure without discrimination, why do barriers to participation in inclusive programs remain?

### **The Concept of Individual Choice in Leisure**

In review of specialized and inclusive recreation programs, it is important to note that the concept of individual choice is central to leisure, as all people must be free to choose programs of specific interest. In other words, leisure must be freely chosen from the perspective of the participant making the choice (Rossman & Schlatter, 2011). In addition, program participants must perceive they have options and choices in construing the leisure experience (Csikszentmihalyi & Kleiber, 1991; Guralnik & Simonsick, 1993; Iezzoni, 2011). For example, although inclusive recreation programming may be more ideal considering the benefits for people with and without disabilities, some individuals with disabilities may choose to participate in specialized recreation programs (Anderson & Kress, 2003). Not all participation in specialized programs, however, is due to simply a lack of choices (Austin & Youngkhill, 2013). Many individuals with disabilities may elect to engage in both inclusive and specialized recreation depending on their interests or the particular type of activity (Mayer & Anderson, 2014). Recent research indicates the demand for inclusive recreation programming will be increasing exponentially in the next few years as baby boomers continue to retire from the work force, war veteran's return from service overseas with physical and intellectual disabilities and, as children with disabilities grow and freely choose recreational options (Austin & Youngkhill, 2013).

## **The Purpose of the Study**

The purpose of this study was to understand if participation in specialized recreation programs, which are designed for individuals with disabilities, increases opportunities of participation in inclusive programs, which are designed for both individuals with and without disabilities. As Mayer and Anderson (2014) have examined, specialized programs are segregated and do not consistently lead to inclusion within recreational settings. More research in the field is needed to determine if participation in specialized recreation programs increases opportunities for participation in inclusive recreation programs, or if specialized recreation unintentionally enables barriers to inclusion. Shields, Synnot, and Barr (2012), noted that personal, social, environmental, and policy and program-related barriers and facilitators influence the amount of recreational activity children with disabilities undertake (p. 991), while “the barriers to such inclusive recreation programs have been studied more comprehensively than the facilitators” (p. 992).

The study participants consist of parents of children with intellectual disabilities that actively participate in Special Olympics among other specialized programs. In addition, the participants engage in inclusive recreational programs within their communities. In order to examine the understanding of participation in specialized and inclusive recreational programming, I chose to use the International Classification of Functioning, Disability and Health for Children and Youth (ICF-CY) as a unifying framework, and study the barriers that often inhibit participation in inclusive recreational programs. The ICF-CY is derived from the International Classification of Functioning, Disability and Health (ICF) and “is designed to record the characteristics of the

developing child and the influence of its surrounding environment” (WHO, 2007, p. vii).

Furthermore,

The ICF-CY was developed in response to a need for a version of the ICF that could be used universally for children and youth in the health, education and social sectors. The manifestations of disability and health conditions in children and adolescents are different in nature, intensity and impact from those of adults. Such differences must be taken into account so that classification content is sensitive to the changes associated with development and encompasses the characteristics of different age groups and environments (WHO, 2007, p. vii).

The growth and development of children with disabilities constitute central themes guiding the identification and adaptation of the content for the ICF-CY (WHO, 2007). In developing the ICF-CY, particular attention was given to four key issues: the child in the context of the family, developing delay, participation, and environments. The domains of the ICF-CY are defined by two umbrella terms (p. xviii). *Functioning* is a term including all body functions, activities and participation (p. xviii). *Disability* is a term including impairments, activity limitations and participation restrictions (p. xviii). With the diverse ICF-CY functioning as my theoretical framework in this study, I also realize that in qualitative research, the ongoing process of questioning in research is a critical part of understanding the phenomena of the study (Creswell, 2007).

### **Research Questions**

1. How does previous participation in specialized recreation programs influence participation in inclusive recreation programs?



2. Why do some parents of children with intellectual disabilities choose to pursue specialized recreation programs instead of inclusive recreation programs?
3. Why do some parents of children with intellectual disabilities choose to pursue inclusive recreation programs and specialized recreation programs?
4. For those parents of children with intellectual disabilities who have participated in both inclusive and specialized recreation programs, how do they describe their various experiences?
5. What are the barriers that inhibit participation in inclusive recreation programs?

### **Assumptions**

It was assumed that the criteria of the interview questions are appropriate and, therefore, assures that the participants have indeed experienced identical or similar phenomenon within the study. Additionally, it was assumed that the research participants, all of whom care for family members with intellectual disabilities and have had varied experiences with both specialized and inclusive programs, valued recreation as significant to their overall quality of life. It was also assumed that as participants actively participate in specialized or inclusive recreation, that the value placed on recreation allowed them to openly discuss recreation and leisure as a significant part of their quality of life.

### **Delimitations**

The scope of this study was delimited to individuals with an intellectual disability who have had experience in specialized recreation programs, but also have participated in inclusive recreation programs. Specifically, the participants were chosen based on their affiliation and participation in Special Olympics. Qualitative methods of inquiry

including field experience observations, interviews, and a focus group were utilized to collect participant information. Research subjects, both male and female, were parents of individuals with various intellectual disabilities, ranging in age from nine to seventeen years, that included Apert Syndrome, Autism Spectrum Disorder, Cerebral Palsy, Down Syndrome, and Fragile X Syndrome.

Intellectual and developmental disabilities are disorders that are typically present at birth and that negatively affect an individual's physical, intellectual, and/or emotional development (National Dissemination Center for Children with Disabilities, 2011, para. 1). Many of these developmental conditions affect multiple body parts or systems (Scott & Haverkamp, 2014). Each of the children of the study participants had one of five disabilities (refer to Table 3), which are: Apert Syndrome, Autism Spectrum Disorder, Cerebral Palsy, Down Syndrome, and Fragile X Syndrome. These disabilities are defined as follows:

### **Apert Syndrome**

Forrest and Hopper (2013) define Apert Syndrome as a genetic disorder characterized by the premature fusion of certain skull bones (p.93). The unfortunate physical result is that the head is unable to grow normally, which creates a sunken appearance in the middle of the face, with bulging eyes, a beaked nose, and an underdeveloped upper jaw leading that usually leads to various dental issues (p. 94). The premature fusion of the skull bones also affects the development of the brain, which results in normal to mild or moderate intellectual disability (p. 94). Additionally, individuals with Apert Syndrome have webbed fingers and toes among other physical abnormalities (p. 96).

### **Autism Spectrum Disorder**

The American Psychiatric Association (2013) defines Autism Spectrum Disorder (ASD) as a serious neurodevelopmental disorder that affects a child's ability to communicate and socially interact with others (para. 2). Children with ASD do not observe typical models when developing social and communication skills (para. 2). Attempting to diagnose ASD can be difficult as there is no medical test, such as a blood test, to diagnose the disorder. Medical specialists observe the child's behavior and development to make a final diagnosis (para. 5).

### **Cerebral Palsy**

The National Institute of Neurological Disorders and Stroke (2013) define Cerebral Palsy as a disorder of movement, muscle tone or posture that is caused by an immature, developing brain. Signs and symptoms of Cerebral Palsy appear during infancy or preschool years and cause impaired movement accompanied by exaggerated reflexes, irregular posture, involuntary movements, or some combination of these abnormalities (para. 8). Although, there are individuals that exhibit normal to near normal intellectual function, others may have intellectual disabilities in addition to epilepsy, blindness or deafness (para. 11).

### **Down Syndrome**

The National Down Syndrome Society (2013) define Down Syndrome as a chromosomal condition that is linked with intellectual disability, a distinct facial appearance, and weak muscle tone in infancy (para. 1). Individuals with Down Syndrome experience cognitive delays, but the intellectual disability is generally categorized from mild to moderate (para. 1). Individuals with Down Syndrome may have various birth

defects, and almost half of all affected children are born with a heart defect (para. 2). A small percentage of individuals with Down Syndrome are also diagnosed with autism spectrum disorders, which affect social behavior and communication (para. 4).

### **Fragile X Syndrome**

Martin, Ausderau, Raspa, Bishop, Mallya, and Bailey (2013) inform that Fragile X Syndrome is the most common form of inherited mental retardation in males and is a significant cause of mental retardation in females (p. 844). Boys with Fragile X are likely to be affected more severely than girls as boys have only one X chromosome (p. 844). Children with Fragile X have a large head size, a long face, and prominent or protruding forehead, chin and ears (p. 845). Boys affected with Fragile X may have behavioral problems such as hyperactivity, temper tantrums and autism (p. 847).

### **Limitations**

The validity of the research may be limited because the presence of the researcher may have affected how the participants answered the questions and the significance they placed on various subjects. There are limits regarding the effectiveness of the questions participants were asked. The interview questions are based on my review of the literature and correlate back to the aforementioned research questions.

Conducting research both on and with the ICF-CY may provide another limitation. The limiting factor was restricting the theoretical basis for the research to one conceptual framework. It may have resulted in a narrow perspective, although the classification reflects a systems theory perspective, taking into account how parents intervene and care for how children grow and develop and how the environment around them influences parent and child participation in inclusive recreation setting.

## **CHAPTER II**

### **REVIEW OF THE LITERATURE**

#### **Introduction**

This review of literature focuses on research concerning recreation and leisure programming for individuals with intellectual disabilities. The review includes research conducted on specialized and inclusive recreation programs, including those practices related to assessment, planning, implementation, and evaluation strategies for individuals with disabilities. The literature will set the stage for discussion of the study, including methodology, reporting of findings related to recreational programming practices, and implications and recommendations for future research and practice.

The following sections are included in this chapter: (1) U.S. Census Bureau Americans with Disabilities Report; (2) Federal Legislation; (3) Leisure Defined; (4) Recreation Defined; (5) Analysis of Specialized Recreation Programs; (6) Analysis of Inclusive Recreation Programs; (7) Barriers to Participation in Inclusive Recreation Programs; (8) International Classification of Functioning, Disability and Health for Children and Youth (ICF-CY); and (9) Summary of Review of the Literature.

#### **U.S. Census Bureau Americans with Disabilities Report**

The U.S. Census Bureau Americans with Disabilities: 2010 (United States Census Bureau, 2014) is the most current report at the time of this study, which presents estimates of disability status and type and is the first such report to be published since the Census Bureau released statistics in a report about the 2005 population of people with disabilities. The U. S. Census Bureau collects data on disability through the American Community Survey (ACS) and the Survey of Income and Program Participation (SIPP).

The U.S. Census Bureau Americans with Disabilities: 2010 (United States Census Bureau, 2014), explains the total number of people with a disability increased by 2.2 million over the review period, yet the percentage remained statistically unaffected. However, it is relevant to note that both the number and percentage with a severe disability increased (p. 5). Likewise, the number and percentage of people with a severe disability needing assistance both increased as it is estimated that one in five Americans has some form of physical or intellectual disability or impairment that significantly limits a major life activity (p. 6).

As indicated in Table 1, (United States Census Bureau, 2014) approximately 56.7 million people living in the United States had some kind of disability in 2010. This accounted for 18.7 percent of the 303.9 million people in the civilian non-institutionalized population that year (p. 4). About 12.6 percent or 38.3 million people had a severe disability (p. 4). The total number of people with a disability increased by 2.2 million from 54.4 million people in 2005, when disability was last measured in the SIPP, while the percentage remained statistically unchanged (p. 5). Both the number and percentage with a severe disability increased over that time period.

**Table 1**

**Prevalence of Disability for Selected Age Groups: 2005 and 2010**

Category	2005 Number	2005 Percent	2010 Number	2010 Percent	Difference Number	Difference Percent
<b>All Ages</b>	<b>291,099</b>	<b>100.0</b>	<b>303,858</b>	<b>100.0</b>	<b>**12,760</b>	<b>(X)</b>
With a Disability	54,425	18.7	56,672	18.7	*2,247	-
Severe Disability	34,947	12.0	38,284	12.6	*3,337	*0.6
<b>Aged 6 and Older</b>	<b>266,752</b>	<b>100.0</b>	<b>241,682</b>	<b>100.0</b>	<b>*11,469</b>	<b>(X)</b>
Needed Personal Assistance	10,996	4.1			*1,353	*0.3

**Table 1 (Continued)**

Category	2005 Number	2005 Percent	2010 Number	2010 Percent	Difference Number	Difference Percent
<b>Aged 15 and Older</b>	<b>230,391</b>	<b>100.0</b>	<b>241,682</b>	<b>100.0</b>	<b>**11,291</b>	<b>(X)</b>
	49,069					
With a Disability	32,771	21.3	51,454	21.3	*2,385	-
Severe Disability		14.2	35,683	14.8	*2,912	*0.5
	7,793					
Difficulty Seeing	1,783	3.4	8,077	3.3	284	-
Severe		0.8	2,010	0.8	*228	0.1
	7,809					
Difficulty Hearing	993	3.4	7,572	3.1	-237	*-0.3
Severe		0.8	1,096	0.5	103	-
<b>Aged 21 to 64</b>	<b>170,349</b>	<b>100.0</b>	<b>177,295</b>	<b>100.0</b>	<b>*6,945</b>	<b>(X)</b>
With a Disability	28,141	16.5	29,479	16.6	*1,338	0.1
Employed	12,838	45.6	12,115	41.1	*-723	*-4.5
Severe Disability	18,705	11.0	20,286	11.4	*1,581	0.5
Employed	5,738	30.7	5,570	27.5	-167	*-3.2
Non-Severe	9,436	5.5	9,193	5.2	-243	*-0.4
Disability						
Employed	7,100	75.2	6,544	71.2	*-556	*-4.1
No Disability	142,208	83.5	147,816	83.4	*5,607	-0.1
Employed	118,707	83.5	116,881	79.1	*-1,826	*-4.4
<b>Aged 65 and Older</b>	<b>35,028</b>	<b>100.0</b>	<b>38,599</b>	<b>100.0</b>	<b>**3,571</b>	<b>(X)</b>
With a Disability	18,132	51.8	19,234	49.8	*1,102	*-1.9
Severe Disability	12,942	36.9	14,138	36.6	*1,196	-0.3

- Represents or rounds to zero.

(X) Not applicable.

\* Denotes a statistically significant difference at the 90 percent level.

\*\* Denotes a difference between two controlled estimates. By definition, the difference is statistically significant.

Source: U.S. Census Bureau, Survey of Income and Program Participation, June – September 2005 and May – August 2010, p. 16.

Because recreation service agencies among other professionals and advocates use the same term in different contexts, disability does not often refer to a single definition (Brault, 2012). Medical models view disability as an extension of a physiological

condition that requires treatment or therapy. Moreover, social models view disability as the result of society's view on impairment and suggest that changes to social norms and practices, such as inclusion be implemented. Rather than a dichotomous concept, disability is a gradient on which each individual function at different levels due to personal and environmental factors (WHO, 2001).

The U.S. Census Bureau Americans with Disabilities: 2010 (2014) report indicated that cognitive, mental and emotional difficulties could manifest in the kinds of activity limitations described in Table 2 (United States Census Bureau, 2014). As shown in Table 2, approximately 15.2 million adults (6.3 percent) experienced difficulty with some kind of cognitive, mental, or emotional functioning (p. 9). Nearly 10.6 million adults (4.4 percent) had a condition that limited mental or cognitive functioning, such as a learning disability (3.9 million or 1.6 percent), or dementia (2.4 million or 1.0 percent) (p. 9). Roughly 1.2 million adults (0.5 percent) had an intellectual disability and 944,000 (0.4 percent) had other intellectual disabilities, like Cerebral Palsy or Autism, while nearly 4.7 million adults (1.9 percent) had some other mental or emotional condition (p. 9). The types of functional and activity limitations defined in the U.S. Census Bureau Americans with Disabilities: 2010 (2014) report are categorized into three domains: communicative, mental, or physical (p. 9). As shown in Table 2, of the 51.5 million adults with a disability, 30.3 million had a disability or disabilities in only one domain; 15.8 million had disabilities in two domains; and 4.0 million had a disability in all three domains (p. 9). About 15.7 million adults had disabilities in the communicative domain (alone or in combination with other domains); 16.8 million adults had disabilities in the mental domain; and 41.5 million adults had disabilities in the physical domain (p. 9).



Table 2

## Prevalence of Specific Measures of Disability with Individuals 15 Years and Older:

2010

Category	Aged 15 Years and Older: Number	Aged 15 Years and Older: Percent	Aged 65 Years and Older: Number	Aged 65 Years and Older: Percent
<b>Total</b>	<b>241,682</b>	<b>100.0</b>	<b>38,599</b>	<b>100.0</b>
<b>Disability Status</b>				
With a Disability	51,454	21.3	19,234	49.8
Severe	35,683	14.8	14,138	36.6
Not Severe	15,770	6.5	5,096	13.2
No Disability	190,228	78.7	19,365	50.2
<b>Seeing/Hearing/Speaking</b>				
With a Disability	14,924	6.2	6,909	17.9
Severe	3,288	1.4	1,705	4.4
Not Severe	11,636	4.8	5,203	13.5
Difficulty Seeing	8,077	3.3	3,782	9.8
Severe	2,010	0.8	1,050	2.7
Not Severe	6,067	2.5	2,731	7.1
Difficulty Hearing	7,572	3.1	4,152	10.8
Severe	1,096	0.5	666	1.7
Not Severe	6,475	2.7	3,485	9.0
Difficulty with Speech	2,818	1.2	843	2.2
Severe	523	0.2	158	0.4
Not Severe	2,295	0.9	685	1.8
<b>Walking/Using Stairs</b>				
With a Disability	30,550	12.6	15,201	39.4
Severe	20,132	8.3	11,191	29.0
Not Severe	10,418	4.3	4,010	10.4
Difficulty Walking	23,879	9.9	11,883	30.8
Severe	13,118	5.4	7,186	18.6
Not Severe	10,761	4.5	4,697	12.2
Difficulty Using Stairs	22,262	9.2	11,043	28.6
Severe	7,698	3.2	4,530	11.7
Not Severe	14,564	6.0	6,513	16.9
Used Wheelchair	3,637	1.5	2,014	5.2
Used	11,584	4.8	7,012	18.2
Cane/Crutches/Walker (Used) for 6 Months or Longer	9,385	3.9	5,803	15.0

**Table 2 (Continued)**

Category	Aged 15 Years and Older: Number	Aged 15 Years and Older: Percent	Aged 65 Years and Older: Number	Aged 65 Years and Older: Percent
<b>Selected Physical Tasks</b>				
With a Disability	19,890	8.2	9,205	23.8
Severe	8,617	3.6	4,486	11.6
Not Severe	11,273	4.7	4,719	12.2
Difficulty Lifting	17,186	7.1	8,171	21.2
Severe	8,076	3.3	4,270	11.1
Not Severe	9,110	3.8	3,901	10.1
Difficulty Grasping	6,712	2.8	2,875	7.4
Severe	893	0.4	334	0.9
Not Severe	5,819	2.4	2,541	6.6
Difficulty Pushing/Pulling	23,319	9.6	11,045	28.6
Severe	13,603	5.6	6,822	17.7
Not Severe	9,717	4.0	4,224	10.9
Difficulty Standing	24,170	10.0	11,526	29.9
Difficulty Sitting	10,120	4.2	3,528	9.1
Difficulty Crouching	27,367	11.3	12,897	33.4
Difficulty Reaching	12,185	5.0	5,763	14.9
<b>Activities of Daily Living</b>				
With an ADL Limitation	9,442	3.9	4,639	12.0
Needed Assistance	4,994	2.1	2,668	6.9
Did Not Need Assistance	4,449	1.8	1,971	5.1
Difficulty Getting Around	4,552	1.9	2,345	6.1
Needed Assistance	2,452	1.0	1,391	3.6
Did Not Need Assistance	2,100	0.9	954	2.5
Difficulty Getting In Bed	6,151	2.5	3,011	7.8
Needed Assistance	3,008	1.2	1,578	4.1
Did Not Need Assistance	3,142	1.3	1,433	3.7
Difficulty Bathing	5,499	2.3	2,916	7.6
Needed Assistance	3,475	1.4	2,039	5.3
Did Not Need Assistance	2,024	0.8	877	2.3
Difficulty Dressing	4,264	1.8	2,142	5.5
Needed Assistance	2,806	1.2	1,523	3.9
Did Not Need Assistance	1,458	0.6	619	1.6
Difficulty Eating	1,845	0.8	927	2.4
Needed Assistance	1,031	0.4	578	1.5
Did Not Need Assistance	813	0.3	349	0.9
Difficulty Toileting	2,846	1.2	1,468	3.8
Needed Assistance	1,880	0.8	1,058	2.7
Did Not Need Assistance	996	0.4	411	1.1

**Table 2 (Continued)**

Category	Aged 15 Years and Older: Number	Aged 15 Years and Older: Percent	Aged 65 Years and Older: Number	Aged 65 Years and Older: Percent
<b>Instrumental Activities of Daily Living</b>				
With an IADL Limitation	15,513	6.4	7,449	19.3
Needed Assistance	11,566	4.8	5,869	15.2
Did Not Need Assistance	3,947	1.6	1,580	4.1
Difficulty Going Out	10,094	4.2	5,365	13.9
Needed Assistance	7,983	3.3	4,497	11.7
Did Not Need Assistance	2,110	0.9	867	2.2
Difficulty Managing Money	5,901	2.4	2,881	7.5
Needed Assistance	4,996	2.1	2,550	6.6
Did Not Need Assistance	905	0.4	331	0.9
Difficulty Preparing Meals	5,817	2.4	3,035	7.9
Needed Assistance	4,718	2.0	2,528	6.6
Did Not Need Assistance	1,098	0.5	506	1.3
Difficulty Doing Housework	7,708	3.2	3,804	9.9
Needed Assistance	5,892	2.4	3,101	8.0
Did Not Need Assistance	1,817	0.8	703	1.8
Difficulty Taking Medication	4,994	2.1	2,485	6.4
Needed Assistance	3,928	1.6	2,108	5.5
Did Not Need Assistance	1,066	0.4	377	1.0
Difficulty Using Phone	2,886	1.2	1,771	4.6
Needed Assistance	1,039	0.4	592	1.5
Did Not Need Assistance	1,847	0.8	1,180	3.1
<b>Need For Assistance</b>				
<b>Number of ADLs or IADLs</b>				
One or More	12,049	5.0	6,051	15.7
One	4,333	1.8	2,049	5.3
Two	2,139	0.9	993	2.6
Three or More	5,577	2.3	3,009	7.8
<b>Number of ADLs</b>				
One or More	4,994	2.1	2,668	6.9
One	1,709	0.7	859	2.2
Two	844	0.3	429	1.1
Three or More	2,441	1.0	1,380	3.6
<b>Number of IADLs</b>				
One or More	11,566	4.8	5,869	15.2
One	4,717	2.0	2,311	6.0
Two	2,201	0.9	951	2.5
Three or More	4,648	1.9	2,607	6.8

**Table 2 (Continued)**

Category	Aged 15 Years and Older: Number	Aged 15 Years and Older: Percent	Aged 65 Years and Older: Number	Aged 65 Years and Older: Percent
<b>Mental</b>				
With Disability	15,155	6.3	3,024	7.8
With One or More Selected Conditions	10,614	4.4	2,184	5.7
A Learning Disability	3,896	1.6	286	0.7
Alzheimer's, Senility, or Dementia	2,427	1.0	1,661	4.3
Intellectual Disability	1,239	0.5	76	0.2
Other Developmental Disability	944	0.4	63	0.2
Other Mental/Emotional Condition	4,707	1.9	395	1.0
With One or More Selected Symptoms	8,916	3.7	1,729	4.5
Depressed or Anxious	7,012	2.9	1,098	2.8
Trouble Getting Along w/ Others	2,684	1.1	309	0.8
Trouble Concentrating	5,140	2.1	1,047	2.7
Trouble Coping w/ Stress	5,936	2.5	910	2.4
<b>Working At A Job Age 16 to 64 Years</b>	<b>199,036</b>	<b>100.0</b>	<b>(X)</b>	<b>(X)</b>
With Disability Related Problems	25,333	12.7	(X)	(X)
Has Difficulty Remaining Employed	14,371	7.2	(X)	(X)
Limited in kind or amount of work	23,535	11.8	(X)	(X)
Prevented	14,558	7.3	(X)	(X)
Not Prevented	8,977	4.5	(X)	(X)
<b>Working Around the Home Age 16 years and older</b>	<b>237,635</b>	<b>100.0</b>	<b>38,599</b>	<b>100.0</b>
Limited in kind or amount of housework	19,328	8.1	7,450	19.3
Prevented	5,715	2.4	2,537	6.6
Not Prevented	13,613	5.7	4,913	12.7

**Table 2 (Continued)**

Category	Aged 15 Years and Older: Number	Aged 15 Years and Older: Percent	Aged 65 Years and Older: Number	Aged 65 Years and Older: Percent
<b>Disability Domains</b>				
With a disability in 1 domain	30,343	12.6	11,096	28.7
Communicative	2,841	1.2	768	2.0
Physical	22,444	9.3	10,044	26.0
Mental	5,058	2.1	284	0.7
With a disability in 2 domains	15,799	6.5	6,328	16.4
Communicative + physical	8,061	3.3	4,729	12.3
Communicative + mental	791	0.3	111	0.3
Physical + mental	6,947	2.9	1,488	3.9
With a disability in 3 domains	4,028	1.7	1,677	4.3
Domain(s) not identified	1,284	0.5	132	0.3

- Represents or rounds to zero.

(X) Not applicable.

Source: U.S. Census Bureau, Survey of Income and Program Participation, May – August 2010, p. 17-19.

### **Federal Legislation**

Recreation and leisure experiences are an essential part of being human (Anderson & Kress, 2003). It is important that all human beings with and without disabilities be free to participate in recreation and leisure experiences. Recreational programming is beneficial to individuals with disabilities for the same reasons that all people benefit from leisure and recreation; however, individuals with disabilities generally have fewer opportunities for such experiences (Taylor, 2014). Consequently, individuals with disabilities regularly participate less in recreation and leisure experiences. Fortunately, the Americans with Disabilities Act (ADA) in 1990, has helped recreation programmers and service providers develop more inclusive programs over the years (Datillo, 2013; Devine & Lashua, 2002; Fisher, Pumpian, & Sax, 1998;

Krahn & Drum, 2006; Riley, Rimmer, Wang, & Schiller, 2008; Schleien, Germ, McAvoy, 1996).

According to the U. S. Department of Justice, Civil Rights Division (2006), people with disabilities rely on various government interventions to maintain their participation in the community. For managers and administrators in recreation agencies, it is critical that they understand the characteristics, needs and legislative mandates necessary to successfully include and accommodate 20 percent of their park visitors and program participants (p. 3). Many recreation agencies have made impressive strides over the last decade to remove barriers and implement greater access for people with disabilities (Austin & Youngkhill, 2013; Datillo, 2002; Devine & McGovern, 2001; Heyne & Schleien, 1997; Schleiem, Miller, Walton, & Pruett, 2014). However, even with the plethora of positive strides made to improve access in recreational agencies, more notable are the situations when public agencies have not efficiently planned and implemented comprehensive accessibility programming (Anderson & Heyne, 2000; Anderson & Kress, 2003; Datillo, 2013; Mullick, 2013). These mishaps in accessibility programming are unfortunate and may place recreation agencies and other service providers in the middle of a public relations crisis.

As Skulski (2007) explained, legal milestones such as the Architectural Barriers Act of 1968, Section 504 of the Rehabilitation Act as amended in 1978, and the Americans with Disabilities Act of 1990 have raised expectations that individuals with disabilities have access to public recreational facilities and services. When public services are inaccessible, complaints and litigation may lead to allegations of discrimination based on disability (para. 3). For example, in 2005, the California

Department of Parks and Recreation settled two class action lawsuits agreeing to make more than \$10 million in accessibility improvements and renovations over the next 11 years (Skulski, 2007, para. 7). According to the U.S. Department of Justice (2006), from the year 2000 to 2005 the federal enforcement agency entered into more than 90 settlement agreements with local governments concerning improved access to park and recreation facilities. The Waukegan (Illinois) Park District was an example of such an agency of which the Justice Department investigated an ADA-related complaint and entered into a settlement agreement under its Project Civic Access Program (Skulski, 2007, para. 7). The settlement (U.S. Department of Justice, 2004) mandate for the park district to make accessibility improvements at its large regional parks, nature preserve, golf course, administration building, museum and other facilities (para. 7). In addition, the terms of the settlement agreement mandate the park district to employ a new hire or appoint an existing staff person to oversee ADA responsibilities and assure Waukegan Park District complies with and implements its responsibilities under the ADA (para. 7). These examples could represent any recreational agency, state or municipal, anywhere in the continental United States. Skulski (2007) argues,

The lessons to be learned from these or any of the other Department of Justice settlements is that settlements is that the provision and maintenance of programs, activities, services and facilities that are accessible to people with disabilities is an ongoing responsibility and one that is only effective through the administration of a comprehensive accessibility management program (para. 7).

It is only in the last 40 years that accessibility, inclusion, and equal opportunity have emerged as a basic civil right for the more than 52 million Americans with

disabilities (Anderson & Kress, 2003). Nevertheless, there have been numerous examples of litigation due to consistent failure in improving facilities, services and programs to meet the needs of people with disabilities (Austin & Youngkhill, 2013; Riley, Rimmer, Wang, & Schiller, 2008; Skulski, 2007).

According to Skulski (2007), the majority of recreational programmers, view inclusion of people with disabilities as more than a federal mandate as inclusion of all people, of all backgrounds and abilities, are considered a founding principle for building healthy communities (para. 6). In 1999, as a testament to the organization's stance on inclusion, the National Recreation and Park Association (NRPA) issued an inclusion policy statement that states, "To encourage all providers of park, recreation, and leisure services to provide opportunities in settings where people of all abilities can recreate and interact together" (Skulski, 2007, para. 6).

### **Leisure Defined**

According to Russell (2013) "To have leisure is one of the earliest dreams of human beings: to be free to pursue what we want, to spend our time meaningfully in pleasurable ways, to live in a state of grace" (p. 4). Leisure is a concept that may seem like a simple idea, but as research indicates, it is difficult to define (DeGrazia, 1962; Godbey, 2008; Kelly, 1990; Rossman & Schlatter, 2011; Russell, 2013; Samdahl, 1988). Contemporary definitions of leisure used by scholars in the field include the ideas of leisure as free time, as recreational activity, or as an attitude (Anderson & Kress, 2003). Moreover, Russell (2013) outlines how leisure may be defined through its reflections in the humanities: literature, art, dance, music, and theatre. Russell (2013) also examines some of the original meanings of leisure in history, and summarizes leisure's



contemporary connotations, arguing that leisure has multiple, and even contradictory, meanings.

One idea is the definition of leisure as time, which simply defines leisure as time not spent on work or maintaining home and self (Kelly, 1990). However, this definition means any time not spent at work or in basic essential functions could be construed as leisure, which is not always true. Kelly (1990) also discusses role determined leisure that encompasses those activities and times spent in an apparently discretionary way, but while fulfilling personal obligations such as spending time with family or friends while not at work. Kelly and Godbey (1992) define recreation as “voluntary non-work activity that is organized for the attainment of personal and social benefits including restoration and cohesion” (p. 21).

Leisure defined as recreational activity describes leisure as activities or hobbies not associated with work (Anderson & Kress, 2003). The problem with this definition is that this may place certain obligations on the individual during leisure activity. Kelly (1990) philosophized that playing a particular sport or game is indeed a leisure experience when an individual freely chooses to participate, but could be non-leisure when that same individual feels obligated to participate.

Lastly, a common definition of leisure discussed is the concept of leisure as an attitude, or state of mind. Anderson and Kress (2003) describe leisure as the feelings and perceptions an individual may experience while participating in freely chosen activities. Feelings that arise from leisure experiences include self-worth and happiness. DeGrazia wrote, “Leisure refers to a state of being, a condition of man, which few desire and fewer achieve” (DeGrazia, 1962, p. 5).

Regardless of how it is defined, leisure is an integral part of being human (Anderson & Kress, 2003) and a consistent theme in the research literature is that leisure must have certain humanistic qualities to be construed as a true leisure experience. Anderson and Kress (2003) discuss the components required to implement leisure. First, individuals must be permitted to freely choose how and when they experience leisure (p. 32). Also, adding diversity to the overall experience, individuals must be able to select from various opportunities in pursuing leisure (p. 34). The final element of a true leisure experience is the concept of challenge and participation outside an individual's normal routine (p. 36). Thus, individuals need to experience the feelings and perceptions of using their own skills and abilities to experience the true nature of leisure.

### **Recreation Defined**

As Russell (2013) explains, defining recreation and leisure provides leisure professionals with a strong foundation for the programs and services that are provided. While recreation professionals may disagree on the standard definitions of recreation and leisure, scholars in the field have established distinctions between the two. According to Godbey (2003), leisure is defined in three primary ways, which are: leisure as free time, leisure as activity and leisure as a state of mind or attitude, while recreation is usually thought of as activity chosen to experience leisure. Whereas, Pigram (1983) defined recreation as activity voluntarily taken, primarily for pleasure and satisfaction, during leisure time. Kelly (1990) defined recreation as "voluntary non-work activity that is organized for the attainment of personal and social benefits including restoration and social cohesion" (p. 27).

Rossmann and Schlatter (2011) explained, "Recreation is leisure that is engaged in

for the attainment of personal and social benefits” (p. 12). Recreation has always been distinguished itself as being socially purposeful and moral; as there are both good and bad types of recreation, morality has always been associated with recreation in society (p. 13). For example, drug abuse is considered morally degenerative in society.

Therefore, from the viewpoint of a recreation professional, the idea of “recreational drug use” is something that is not possible (p. 13). Hurd and Anderson (2013) discussed that recreation has a connotation of being morally acceptable not only to the individual seeking recreation but also to society as a whole. While recreation activities can take many forms, they must contribute to communities in a way that society deems acceptable (p. 10). Moreover, recreation is viewed as a social instrument due to its contribution to society. Hurd and Anderson (2013) further elaborated by stating, “That is, professionals have long used recreation programs and services to produce socially desirable outcomes, such as the use of free time, physical fitness, and positive youth development” (p. 10). Moreover, “The organized development of recreation programs to meet a variety of physical, psychological, and social needs has led to recreation playing a role as a social instrument for well-being and, in some cases, change” (p. 10). Such a role has been the incentive for the development and implementation of many recreation programs from municipalities to nonprofits such as the YMCA, YWCA, Boy Scouts of America, Girl Scouts of the USA, the Boys and Girls Clubs of America, and the Special Olympics.

Another important factor in defining recreation is that recreation has always been viewed as restoration from the labor of work (DeGrazia, 1962; Godbey, 2008; Kelly, 1990; Kelly & Godbey, 1992; Rossman & Schlatter, 2011; Russell, 2013). Moreover, recreation creates social significance by relating it to the work environment and is

influential to work because it allows individuals to recuperate and restore themselves in order to achieve more work (DeGrazia, 1962; Rossman & Schlatter, 2011). DeGrazia (1962) assumed this point-of-view when he stated, “Recreation is activity that rests men from work, often by giving them a change (distraction, diversion), and restores (re-creates) them for work” (p. 233).

The research has proven that recreation provides benefits such as physical and mental health, stress management, and increases self-esteem (Anderson & Kress, 2003; Russell, 2013), while leisure is important for people with disabilities, not only for physical and mental benefits, but research shows the most important benefit may be the social aspects of recreation participation (Godbey, 2008; Kleiber, Walker, & Mannell, 2011). Schleien, Ray, and Green (1997) and Schleien, Fahnstock, Green, & Ryders (1990) found that social relationships are developed and maintained in recreation programs. While studying social acceptance, Devine and Lashua (2002) found that when participating in inclusive recreation programs, individuals with disabilities reported feelings of happiness and belonging, however, when participants with disabilities did not experience social acceptance by peers and others they described feelings of sadness and rejection. Hammel, Magasi, Heinemann, Whiteneck, Bogner, and Rodriguez (2008) found that individuals with disabilities experience social acceptance in participation as a complex and dynamic phenomenon, which is dependent upon personal choices and environmental influences.

### **Analysis of Specialized Recreation Programs**

Historically, an individual with a disability has been limited in recreation participation by means of specialized activities where people participate in programs

based on disability, not specific interest (Datillo, 2013; Olkin & Howson, 1994; Scholl, Dieser, & Davison, 2005; Watcher & McGowan, 2002). The most well known example of organized specialized recreation programs is Special Olympics (Siperstein, Hardman, Harda, Parker, & McGuire, 2006). Special Olympics is the worldwide leader in providing high-quality sports training and competition opportunities for individuals with intellectual disabilities, offering almost 1.4 million athletes from more than 150 countries the opportunity to participate in 26 Olympic-type summer and winter sports (Special Olympics, 2015, para. 7). Special Olympics programs also promote social competence and self-esteem, acceptance, and improved health (Siperstein, Parker, Norins-Bardon, & Widaman, (2007).

Siperstein, Hardman, Harda, Parker & McGuire (2006) completed a study that researched the motivation of athletes to actively pursue and then leave Special Olympics programs. The comprehensive study found that Special Olympics athletes typically become involved through program housed in or associated with school and actively participate in activities for over 11 years. The findings also found that athletes have improved self-esteem and self-confidence, social relationships, and sport skills as a result of their participation in Special Olympics.

In a study that provides examples of benefits to specialized recreation, Duvdevany (2002) examined the self-concept and adaptive behaviors of individuals with intellectual disabilities in both specialized and inclusive recreation programs. The research found that the physical self-concept of individuals with intellectual disabilities who participated in specialized programs was more positive than those counterparts that participated in inclusive community activities (p. 423). The findings also indicated that satisfaction with

the whole self-concept was higher among those participating in the inclusive community center programs.

In a study by Zabriskie, Lundberg, and Groff (2005) outcomes were examined on the quality of life of individuals with disabilities who participated in specialized recreation programs. The specialized programs selected for the study included community-based therapeutic recreation and adaptive sports programs (p. 323). The findings presented that a majority of individuals with disabilities experienced significant increases in several areas pertaining to quality of life (p. 324). The findings presented significant impacts of specialized programs, particularly in adaptive sports, which demonstrate positive outcomes on the quality of life of participants.

### **Analysis of Inclusive Recreation Programs**

Inclusion in leisure is the philosophy that individuals with and without disabilities should participate in recreation programs together (Austin & Youngkhill, 2013). No one is under any illusions that inclusive recreational programming is easy, as successfully including all participants requires effort, creativity, and a unique commitment to the success of each participant in a program (Devine & McGovern, 2001; Iezzoni, 2011; Malone, Barfield, & Brasher, 2012). Inclusive recreation programming occurs when programs welcome all individuals, and accommodations are made for those in need (Dattilo, 2002; Miller, Schleien, & Lausier, 2009; Mullick, 2013).

The origins of inclusion can be traced back to the Normalization Principle, which Nirje (1972) defined as “making available to the mentally retarded patterns and conditions of everyday life, which are as close as possible to the norms and patterns of the mainstream of society” (p. 181). Nirje (1972) explained that The Normalization

Principle reflects several perspectives as follows: 1) People with disabilities ought to have lives that are similar to the lives of people without disabilities. Thus, the Normalization Principle is rooted in the concept of equality. 2) People with disabilities ought to have the opportunity to create and pursue good lives that are related to their own personal situations. Thus, the principle is rooted in the concept of quality of life. 3) The Normalization Principle is grounded in the concept of human rights as people with disabilities should be valued and have the same rights as those without disabilities (Renzaglia, Karvonen, Drasgow, & Stoxen, 2003, p. 142).

The normalization principle provides the framework for inclusion by stating that individuals with disabilities “should participate equally in the normal routines of community life, including having a home to live in, access to school or a job, self-selected and self-directed leisure time, and the opportunity to establish social network which include individuals without disabilities” (Renzaglia, Karvonen, Drasgow, & Stoxen, 2003, p. 144).

According to Godbey (2008), the least restrictive environment (LRE) has been a vital component for inclusion practices. The LRE looks at a continuum of environments an individual can participate in ranging from very restrictive to least restrictive (Taylor, 2004, p. 221). The LRE concept was first developed for use in education, specifically within the school systems, but is often utilized in community and municipal recreation and leisure settings (p. 224). The LRE are the most inclusive factor, and the most restrictive environments are the most segregated factor. While practicing LRE theory, an individual should ideally be in an environment that is the least restrictive as possible,

depending on their disability as the outcome is meant to provide a greater understanding and acceptance of individuals with disabilities.

Individuals without disabilities have reported that they experience increased social acceptance of individuals with disabilities when participating in inclusive recreation programs (Anderson & Kress, 2003). In terms of social acceptance, research has shown that inclusion in an educational or learning setting does not interfere in the learning experience of children without disabilities (Causton-Theoharis & Theoharis, 2008; Fisher & Meyer, 2002). Schleien, Hornfledt and McAvoy (1994) found that children without disabilities were not negatively impacted after participating in a study that was set in an inclusive outdoor recreation program that integrated children with disabilities.

Scholl, Dieser, and Davison (2005) developed an ecological method to implementing inclusive recreation in community recreation programming. The researchers conducted a case study that concentrated on the efforts of a multi-agency coalition to meet the needs for inclusion in the Cedar Valley region of Iowa, where the community was severely lacking in inclusive recreation programming (p. 307). The coalition identified that employees of existing recreation programs in the community lacked the necessary skill sets and training to successfully deliver inclusive recreation programs. In addition, the coalition determined that the community lacked the necessary infrastructure for inclusive program delivery, including a gross shortage of qualified personnel to successfully facilitate inclusive programming.

The case study research by Scholl, Dieser, and Davison (2005) offered a solution to a community that desperately needed to adopt inclusive services, that was later



developed into the Together We Play (TWP) program. The TWP program is a service delivery model where one certified therapeutic recreation specialist (CTRS) is hired to improve upon and increase an agencies ability to offer inclusive recreation programs (Scholl, Dieser, & Davison, 2005, p. 299). TWP established a successful ecological approach in order to provide successful inclusive recreation, proving that we must be mindful of barriers that may prevent inclusion from transpiring (p. 304).

Causton-Theoharis & Theoharis (2008) informed us that inclusion is not merely an experience supported by positive anecdotes and stories, but it is also an established recreational practice supported by research. Inclusion increases the rates of learning when children are placed in a setting comprised of students with and without disabilities (p. 27). Research indicates that children with and without disabilities benefit both socially and academically from inclusive recreation service delivery (Kleiber, Walker, & Mannell, 2011; Mactavish & Schleien, 2004; McDonnell, Mathot-Bucker, Thorson, & Disher, 2001; McGregor & Vogelsberg, 1998; Rimmer, 2011). Furthermore, in schools systems, research has consistently shown the academic and social benefits of placing students with and without disabilities together in the classroom setting (Fischer, Pumpian, & Sax, 2000; McDonnell, Thorson, Disher, & Mathot- Buckner, 2001).

In 2007, the National Center on Health, Physical Activity and Disability (NCHPAD) and the Rehabilitation Engineering Research Center on Interactive Exercise and Recreation Technologies and Exercise Physiology for People with Disabilities, which has been funded by the National Institute on Disability and Rehabilitation Research (NIDRR) since 2002, created a partnership with the American College of Sports Medicine (ACSM) to activate a national initiative to promote physical activity inclusion

(Rimmer, 2014, p. 7). The resulting initiative would be titled the Inclusion Fitness Coalition (IFC) and its key purpose is to address policy, environmental, and societal issues often related to the lack of inclusion for individuals with disabilities. Rimmer (2014) explains that “The IFC is charged with promoting equitable access to, and safe use of, fitness and recreation equipment, facilities, and programs, to help reduce debilitating secondary conditions associated with disability and a sedentary lifestyle” (p. 7).

The mission of the IFC (Figure 1) is “to facilitate an expanded coordination of organizations and individuals to address the complexity of personal, social, cultural, political, and economic factors that influence, positively and negatively, the participation of people with disabilities in physical activity, fitness, sports, and recreation” (Rimmer, 2014, p. 7).

<b>Framework for Action</b>	<b>Vision: Create a unified effort to increase access to and participation in physical activity for youth, adults, and seniors with physical, cognitive and sensory disabilities.</b>
Policy	No child, youth or young adult with a disability left on the sidelines.
Health and Fitness	No person with a disability left out of health and fitness clubs due to lack of access.
Inclusive Play	No child with a disability being left indoors due to lack of inclusive play environments.
Veterans	No veteran with a disability left to re-engage in society without being served through inclusive sport and recreation.

Figure 1. The Inclusive Fitness Coalition’s Framework for Action.

Source: Developed by the Inclusive Fitness Coalition (IFC) (Rimmer, 2014, p. 8).

## **Barriers to Participation in Inclusive Recreation Programs**

While including individuals with disabilities in inclusive recreation programming, several types of barriers have been established in the literature (Bendini, 2000; Devine, 2004; Schleien, Germ, & McAvoy, 1996; Schleien, Miller, Walton, & Pruett, 2014; Scholl, Glanz, & Davison, 2006; Stumbo, Wang, & Pegg, 2011). Barriers may include physical as well as social barriers (Schleien, Miller, Walton, & Pruett, 2014, pg. 65). They are physical barriers in reference to the design of a building or lack of accessible transportation, or they may be social barriers perceived by the individual, such as feeling unwelcomed (p. 66). Various reasons individuals with disabilities have reported for engaging in recreation is fun, exercise, meeting others, entertainment, challenge, occupying the mind, or a change in environment (Stumbo, Wang, & Pegg, 2011, p. 95). When individuals with disabilities are not participating in their desired recreational activities and experiencing these benefits, it may be due to a variety of traditional barriers.

For example, Lieberman & Stuart (2002) identified in varied studies of inclusive recreational programming and individuals with physical and intellectual disabilities, the following barriers to participation: perceived perception of others; inadequate transportation; lack of self-confidence; the disability itself; lack of knowledge; lack of appropriate programming and/or staff; attitudes of people offering activities; communication obstacles; time or money constraints; accessibility problems; and unavailability of others with whom to participate (p. 724). Another study by Rimmer, Riley, Wang, Rauworth, & Jurkowski (2004) identified that there are ten major categories of barriers for individuals with disabilities aimed to engage in participation in fitness and recreation programs: built and natural environment, cost/economic issues; emotional and

psychological barriers; equipment barriers; interpretation of guidelines, codes, regulations, and laws; information-related barriers; education and training issues; perceptions and attitudes of individuals who are not disabled; policies and procedures; and availability of resources (p 421).

Scholl, Smith and Davison (2005) examined inclusive recreational programs and found that individuals with disabilities that continue to experience many barriers to participation. This study focused on the views of key players that participated in the aforementioned multi-agency inclusion program called TWP, which was specifically created to provide inclusive services to individuals with disabilities. The findings revealed that each of the key player groups supported inclusion, however, they reported that they would have preferred more training in inclusive service delivery, specifically in dealing one-on-one with individuals with disabilities (p. 60). Thus, the findings in this study indicate that a major barrier to inclusive service delivery in recreation agencies is the lack of personnel who have professional knowledge and experience with inclusion.

Evaluating a 1996-97 study of recreation programs, an article by Devine and Kotowski (1999) identifies accommodations used and barriers encountered in providing inclusive recreation services. In addition, this study identifies training needs as specified by the respondents. The findings of this study indicated that the most frequently identified training needs are disability awareness and sensitivity toward individuals with disabilities (p. 63). The findings suggest a possible willingness on the part of the employees to include individuals with disabilities; however, staff appears to lack knowledge and skill sets to include individuals with disabilities in programs.

Anderson and Heyne (2000) found attitudes, lack of awareness, inaccessible facilities and programs, ineffectively trained staff, lack of administrative support, and lack of social networks and resources as common barriers to inclusive recreational programming. Anderson and Kress (2003) determined that the recurrent use of specialized recreation programs could also inhibit inclusion. Research has primarily examined barriers from two viewpoints: barriers individuals with disabilities could face while participating in inclusive recreational programming, as well as barriers that agencies could confront in providing inclusive recreational programming (Devine & Lashua, 2002; Devine, 2004; Malone, Barfield, & Brasher, 2012; Schleien, Miller, Walton, & Pruett, 2014).

Bendini (2000) conducted research on the negative experiences that individuals with disabilities may have when participating in inclusive recreation programs within the community. The study determined that individuals with disabilities reacted to barriers to inclusive recreation in one of three ways. Individuals with disabilities may be rendered helpless, oppose the negative stigma, or concede and embrace the situation. The third group, those who concede or embrace the situation, was a new concept found in the research. Bendini (2000) found that this particular group was distinctive in that they viewed themselves as equal to others in society, both with and without disabilities, and that the attitudes of others was the result of ignorance (p. 297).

As stated previously, research has primarily examined barriers from two viewpoints: barriers individuals with disabilities could face while participating in inclusive recreational programming, as well as barriers that agencies could confront in providing inclusive recreational programming (Devine & Lashua, 2002; Devine, 2004;

Malone, Barfield, & Brasher, 2012; Schleien, Miller, Walton, & Pruett, 2014). In terms of barriers faced by agencies, Schaumleffel and Payne (2010) explained that parks and recreation programs are often the first to be cut in tough economic times, particularly those municipal programs located in rural areas of the United States. In contrast, wealthier urban cities may experience broad-based support for parks and recreation funding to meet resident demands, increases property values, and promotes development. Furthermore, though some state grants often target low-income cities; they fail to equalize gaps in municipal funding. To complicate issues further, application processes often require detailed proposals and matching funds, leaving low-income communities at a disadvantage.

NRPA's 2015 Field Report (NRPA, 2015) indicates that although parks and recreation department responsibilities have expanded well beyond traditional park-related functions in recent years, agencies have not seen corresponding increases in budget. Moreover, survey results of both operating and capital budgets have remained largely stagnant during the past four years. Total operating expenditures for agencies surveyed stayed flat in 2014 as they have since 2011, regardless of agency size (NRPA, p. 4). More importantly, agency budgets across the board have not returned to 2010 levels. Yet, as the laws of supply and demand would have it, recreation departments across the nation have seen no corresponding decrease in the demand for their services.

Organizations like Kids Included Together, Schools of Promise, and the National Inclusion Project stand at the ready with best practices, inclusive activities, suggestions, and consulting to help programs navigate the paths to successful inclusion more effectively and efficiently. Programs like the National Inclusion Project's Let's ALL

Play initiative provide support, funding, and training for recreational programs committed to inclusion in recreation (Fisher & Meyer, 2002). Let's ALL Play and similar initiatives include inclusive modifications that work for programs, including inclusive games and activities that benefit all participants (Siperstein, Parker, Norins-Bardon, & Widaman, 2007). For example, camp counselors have reported that Let's ALL Play modifications and games have made an overwhelmingly positive difference in the recreational experience for all participants (p. 447). As an example, in February 2015 the National Inclusion Project partnered with Girl Scouts of the Northwestern Great Lakes to create an inclusive environment where children with and without disabilities can play together (Lee, 2015). As part of the partnership, the National Inclusion Project provides the Let's ALL Play program training, expertise, and a wide network of inclusion professionals ready to engage in inclusive recreation games and activities, and share best practices on ensuring that each child with a disability has the choice of participation with no barriers.

### **International Classification of Functioning, Disability and Health, for Children and Youth (ICF-CY)**

The International Classification of Functioning, Disability and Health (ICF) describe disability as the interchange of person-level characteristics within the social context or environmental setting (World Health Organization, 2001). The principle measurement unit is not the individual with a disability, but rather the specific interaction with his or her environment. The ICF is an ideal theoretical framework for health and recreation research because it isolates four critical areas that may affect an individual's program participation: 1) body functions, which encompasses body structures as the anatomical parts of the body impairments as problems in body functions or structures, 2)

activity, is the demonstration of a task or action, 3) participation is involvement in a life situation, and 4) environmental factors, which comprise the physical, social, and attitudinal contexts in which people live (WHO, 2001, p. 17). Each of these components could help professionals break down the barriers in ISD for individuals with disabilities (Rimmer, 2006).

Between 2002 and 2005, a WHO Work Group conducted meetings and research groups to review existing ICF codes and identify new codes to describe characteristics specific to children and youth (WHO, 2013). The end result was the publication (2007) of the International Classification of Functioning, Disability and Health for Children and Youth (ICF-CY). WHO explains that, “the ICF-CY is derived from the International Classification of Functioning, Disability and Health (ICF) and is designed to record the characteristics of the developing child and the influence of its surrounding environment” (WHO, 2007, p. 14). WHO (2013) understands that the manifestations of disability and health conditions in children and adolescents are different in nature, intensity and impact from those of adults and such differences should be taken into account while conducting research. The ICF-CY is, therefore, sensitive to the changes associated with development and includes the characteristics of children and youth along with their environments. In this study, the ICF-CY components of Activities and Participation and Environmental Factors provided a conceptual framework to better understand the barriers to inclusive program participation faced by parents of children with cognitive disabilities (WHO, 2007). In addition, to understand whether participation in specialized recreation programs increases opportunities for participation in inclusive programs.



The family dynamic is frequently where the majority of a child's recreation happens, therefore, parents of children with disabilities engage in specialized and inclusive programs to enhance the quality of family life (Mactavish & Schleien, 2004). In addition, research suggests that individuals with disabilities enjoy participating in recreation with their family members (Hammel, Magasi, Heinemann, Whiteneck, Bogner, & Rodriguez, 2008; Heyne & Schleien, 1997; Kleiber, Walker, & Mannell, Mayer & Anderson, 2014; 2011; Mactavish & Schleien, 2004; Zabriskie, Lundegren, & Groff, 2005). For example, Zabriskie, Lundegren and Groff (2005) learned that the majority of participants in adaptive horseback riding and alpine skiing programs strongly agreed with the statement, "Participation with family members had a positive impact on meaning of my experience" (p.184). Schleien, Miller, Walton, & Pruett (2014) explained that parents who have children with disabilities, including intellectual and related developmental disabilities, have several ideas about their children's participation in community recreation. For the recreation programmer involved in ISD, these same parents could provide valuable information about a child's preferences, personality, abilities, needs, learning styles, and idiosyncrasies.

### **Summary of Review of the Literature**

There is a massive amount of literature in the field in regards to recreation and leisure for individuals with disabilities with much research based in developmental and intellectual disabilities. Overall, the structure of recreation programming has changed dramatically over the past few decades and the literature reflects those changes in an optimistic way that has brought inclusion to the forefront. The research in this study focuses on the importance of recreation for individuals with intellectual disabilities while

examining specialized programs as well as inclusive programs and their barriers.

Without program opportunities to foster social inclusion and the exercise of freedom of choice in recreation, the quality of life for individuals with disabilities weakens. Many individuals with intellectual disabilities and their families, support inclusion and access to community recreation programs.

Inclusion is the most popular philosophy for participation in recreation programs for individuals with disabilities, however, research has proven benefits of participation in specialized recreational programming exists as well. Special Olympics, for example, have grown into a worldwide movement that supports individuals with intellectual disabilities. Research has also proven that some individuals with disabilities simply choose to participate in specialized recreation programs instead of inclusive recreation programs. Choice is a vital component in recreation as individuals should be free to choose what types of recreational programming in which they want to participate. Although research indicates that some individuals with disabilities may choose to participate in specialized recreation programs, the literature has yet to determine if participation in specialized recreation programs may increase opportunities for participation in inclusive programs or inadvertently create more barriers.

## **CHAPTER III**

### **METHODOLOGY**

#### **Introduction**

In this chapter, I discuss the methodology utilized in my study. This methodology plays a critical role in implementing this research study accordingly. The sections of this chapter include: (a) Study Design; (b) Research Participants; (c) Data Collection; (d) Data Analysis; (e) Positionality; (f) Trustworthiness; and (g) Summary of Methodology. In addition, a rationale for choosing a qualitative phenomenological study will be outlined, and detailed emphasis on the researcher's positionality and ethics will be shared. I chose to approach this study as a critical researcher and truly learn from the participants of the study. As a critical researcher, I ventured into this study with substantial experience in specialized and inclusive recreational programming. However, as a parent, I knew little about the difficulties of raising and caring for a child or adult with intellectual disabilities. Therefore, this study was more than an education, but a life-changing experience for me as both a recreation professional and a father.

#### **Study Design**

To fully understand the research questions contained in this study, I chose to utilize a qualitative approach, as this method is suited for analyzing a particular social situation, event, or interaction (Creswell, Henson, Plano, & Morales, 2007). Given the nature of this study, I felt strongly that a qualitative research approach offered advantages over a quantitative design. Qualitative research attempts to explain how events happen and the meanings that human beings ascribe to them (Silverman, 2012), whereas,

quantitative design uses statistical calculations to arrive at broad conclusions in research (Creswell, Henson, Plano, & Morales, 2007).

Creswell, Henson, Plano, and Morales (2007) define phenomenology as a form of study that focuses on the commonality of a lived experience within a particular group. In recreation programming, phenomenology can enable the identification of the underlying dimensions on various perspectives of specialized and inclusive experience. Specifically, the parents of individuals with intellectual disabilities were interviewed in terms of their child's participation in both specialized and inclusive recreation programs. The focus of the questions will be the participant's feelings in regards to specialized recreation programs, inclusive recreation and whether direct involvement in specialized recreation helped the participants to pursue inclusive recreation programming.

Approval from the Institutional Review Board (IRB) and permission from Special Olympics was obtained prior to data collection. After all necessary approvals were confirmed, I contacted the prospective research participants identified to me by Special Olympics to request their participation. As with any research, participation was voluntary and all participants were given the opportunity to withdraw at any time throughout the course of the study. The research questions that guided the interviews and focus group were:

- 1) How long have you participated in Special Olympics?
- 2) Do you participate in other recreation programs? If so, can you tell me about them?
- 3) What's it like for you to be involved in the Special Olympics program? Just tell me everything you can remember about being involved in Special Olympics.

- 4) Talk about your Special Olympics goals as a parent or legal guardian of a Special Olympics athlete?
- 5) Describe a typical day of preparing for a Special Olympics program or activity?
- 6) What obstacles do you face as a parent of a Special Olympics athlete?
- 7) What is most satisfying about participating in Special Olympics?
- 8) What is most frustrating about participating in Special Olympics?
- 9) How does participation in structured specialized recreation programs influence participation in inclusive recreation programs?
- 10) What do you find to be the main benefits gained from participating in specialized programs?
- 11) What characteristics of specialized/inclusive recreation programs do you prefer?
- 12) How do you benefit from participating in specialized/inclusive recreation programs?
- 13) If you have previously participated in inclusive recreation, and presently only participate in specialized programs, what led you to withdraw involvement in inclusive recreation?
- 14) What are the reasons and benefits for participating in inclusive programs?
- 15) If you have previously participated in specialized recreation, and presently only participate in inclusive programs, what led you to withdraw involvement in inclusive recreation?
- 16) If you have participated in both inclusive and specialized recreation programs, how do you describe your two experiences?

- 17) What is the difference between participating in specialized recreation programs and inclusive recreation programs? How has this difference affected you?
- 18) Who chooses which recreation programs you participate in?
- 19) When you have had a new recreation interest, how have you followed through with that idea?
- 20) What factors helped encourage your participation in recreation, either specialized or inclusive?
- 21) What things have hindered your participation in recreation, either specialized or inclusive?
- 22) Is there anything else you would like to share about specialized or inclusive recreation that I did not ask but could help me understand more about being a Special Olympics participant?

### **Research Participants**

Eight research participants were selected using purposive sampling, where individuals who had the specific characteristics of importance to this study were intentionally selected. Purposive sampling leads to “information rich cases” (Patton, 1990, p. 169). Lichtman (2011) explained the goal in qualitative research is to describe and interpret instead of generalize, and there are no specific rules about how many participants you should study. Therefore, most qualitative research studies use a small number of individuals, and it is quite common to see studies with as few as ten participants, and, at times, only one person is studied (Lichtman, 2011). The eight participants were selected in order to obtain a variety of males and females of different age levels, recreational backgrounds, who parent a person with an intellectual disability.

Parents who have children with disabilities, including intellectual developmental disabilities, have several ideas about their children's participation in community recreation (Schleien, Miller, Walton, & Pruett 2014). These same parents could provide valuable information about a child's preferences, personality, abilities, needs, learning styles, and idiosyncrasies.

Recreation involvement of children with disabilities is greatly dependent on the efforts of their families (Schleien, et al., 2009). The family dynamic is frequently where the majority of a child's recreation happens. Also, it has been suggested that a best practice for inclusive recreational programming for children is to team up with parents. Parents may provide valuable information that can help recreation professionals provide services to their children (Heyne & Schleien, 1997). Parents of children with disabilities perceive recreation as a tool to enhance the quality of family life and prove development of skills and interests (Mactavish & Schleien, 2004). In addition, research suggests that individuals with disabilities enjoy participating in recreation with their family members. Zabriskie, Lundegren and Groff (2005) learned that 79.3% of participants in adaptive horseback riding and alpine skiing programs strongly agreed with the statement, "Participation with family members had a positive impact on meaning of my experience" (p.184).

The study participants (see Table 3) were delimited to participants of Special Olympics Kentucky because of the geographic location of the researcher and logistical constraints pertaining to the interviewing process. In terms of location, all of the participants are residents of Kentucky. Four of the participants are native Kentuckians, two of which have lived and thus, engaged in recreation programs with their children, in

other states prior to moving back to Kentucky less than five years ago. The remaining four participants are transplants to the Commonwealth that previously engaged in recreation programs with their children in other states. These four relocated to Kentucky from cities in Indiana, Ohio, and Virginia less than seven years ago. Six out of the eight participants have consistently lived and participated in recreation programs in rural communities, although seven out of eight participants have participated in recreation programs in urban communities. All participants have actively engaged their children in both specialized recreation (in addition to Special Olympics) and inclusive recreational programs within their communities.

**Table 3**

**Demographics of Interview and Focus Group Participants**

Participant's Name	Participant's Gender	Participant's Age	Child's Gender	Child's Age	Child's Disability
Ms. Drew	Female	35	Male	11	Autism Spectrum Disorder
Mrs. Jones	Female	29	Female	10	Down Syndrome
Mr. Lang	Male	28	Male	10	Fragile X Syndrome
Dr. McCoy	Male	52	Male	16	Down Syndrome
Mr. Parker	Male	30	Female	9	Cerebral Palsy
Mr. Rand	Male	44	Male	12	Apert Syndrome
Mrs. Walker	Female	47	Female	17	Down Syndrome
Ms. Walters	Female	37	Female	13	Autism Spectrum Disorder



The semi-structured interviews were conducted using open-ended questions based on the review of the literature. Although there are limits in regards to the trustworthiness of the questions that participants were asked, the interview questions were my best calculation to obtain accurate, trustworthy answers. Based on the responses and initial analysis, I held succeeding interviews with research participants to follow-up and clarify particular points that were made in previous discussions.

A focus group was conducted with the research participants to explicitly utilize group interaction as part of the research method. The participants were encouraged to talk to one another, ask questions, exchange anecdotes and comment on one another's experiences and points of view.

### **Data Collection**

The data collection consisted of initial meetings with the President and CEO of Special Olympics Kentucky as well as observations made by the researcher at the Kentucky Special Olympics Summer Games in June 2014 to gain direct, first-hand experience in the research and develop a better understanding of the research participants and their program participants. While conducting fieldwork at the Kentucky Special Olympics Summer Games, no interviews were conducted. Instead, careful observation notes were taken and informal interactions were made with program participants and Special Olympics staff and volunteers, which essentially laid the groundwork for this phenomenological study.

After nearly six months of conducting research and writing my literature review, I directed my focus toward my methodology. The organization that I selected to help provide me with participants for my research was Special Olympics Kentucky. Because

of my job responsibilities at the university, I had established a previous professional working relationship with the staff of Special Olympics Kentucky that spanned over a decade of recreation programming, I was able to locate eight individuals willing to participate in my study. I began my interviews in December 2014, recording the audio of each session with an individual who was a parent of a Special Olympics program participant or athlete, as they are called, with an intellectual disability. As the interviews were conducted, I listened attentively, made careful notes, and generally transcribed responses the following day. I conducted a total of eight (8) participant interviews during the months of December 2014, January 2015 and February 2015 that ranged from 45 – 60 minutes in length. All interview responses were transcribed, coded, and analyzed to determine developing themes. Each research participant was asked the same set of questions to help expedite validity and organization in the overall data collection process. In addition, I made attentive deliberations to triangulate the variables compatible with participant responses to data.

Although group discussions had a dynamic character with lively exchanges among group members, as a researcher I was particularly attentive to allowing everyone to express their views and to share their experiences on the issues discussed. As a facilitator, I was vicarious and encouraged the participation of parents who were hesitant to talk amongst the group. The focus group session was held at Eastern Kentucky University in a private conference room over a period of 2 hours. The first hour of the session was to stimulate and foster open communication and discussion among group members. The second hour of the session took on the role of interpreting and framing the parents' experiences. The focus group discussions were audio-recorded and transcribed

the week that followed the live session. The transcripts were codified in order to ensure the consistency of the data collected.

My study resides on the assumption that the very intimate nature of the focus groups could allow parents to express their experience of parenting, therefore, offering me their “personal narrative” on the individual, family, educational, and social parameters related to their child’s participation in recreational programming. With this objective in mind, I established relationships based on trust and intimacy with the parents, highly encouraging them to express themselves freely during the focus group process.

### **Data Analysis**

The data were analyzed using transcribed audio recordings, notes, and coding of themes and patterns from the data. In his book, *Qualitative Inquiry and Research Design: Choosing among Five Traditions*, Creswell (2007) suggests six (6) stages for phenomenological studies, which are:

1. Organizational system – the researcher creates a system of organization for the data.
2. Reading and memoing – the researcher reads the interview transcripts and other data while coding and making preliminary notes.
3. Making meaning – the researcher examines the notes and codes searching for meaning and themes in the data.
4. Connecting the dots – the researcher examines the meaning and forms a classification system for the individual meaning.

5. Interpretation – after the individual meanings have been grouped into a collective classification system, the researcher endeavors to form a collective meaning capturing the essence of the data collected.
6. Representation – the last stage of data analysis requires the researcher to translate his/her interpretation into something understandable. Examples include a flow chart, a table, a figure, a narrative text or any other type of representation, which captures the essence of that interpretation.

As a qualitative researcher, the system described above is the approach that I used while analyzing the data accurately and effectively. Furthermore, audio recordings of interviews and ample observation field study notes provided various opportunities to identify themes that aligned with the focus of the research questions.

### **Positionality**

I arrived at this study as a person who is passionate about leisure and recreation, and more specifically, recreation programming. Working in higher education, I not only engage with students but with the local community as well as a myriad of stakeholders. From the perspective of a recreation programmer, I sympathize with the struggles municipal recreation agencies face in connecting all members of the community together by attempting to build innovative, inclusive programs. Glesne (2006) states, “typically, qualitative research is not explicitly driven by theory, but it is situated within theoretical perspectives” (p. 29). I find this accurate of my positionality and how it relates to the many theories of qualitative research. I love qualitative research because it reveals the truth behind the story, the perspective of a human being, which is ultimately their truth and perceived reality. What interested me most about my positionality was the clarity I

received from a parental perspective. As a recreation professional, I am well versed in specialized and inclusive programming. However, as a parent, I had no concept of the difficulties of raising and caring for a child or adult with intellectual mental disabilities.

The essence of my research and my hope in completing my dissertation was to analyze specialized recreation experiences and learn if by participating in such programs increases opportunities for participation in inclusive recreation activities within the community. Today, recreation professionals are not only expected to understand the fundamentals of programming, but to meet recreation demands resulting from expanding populations, increased leisure time, greater mobility and changing social attitudes. As my study indicates, I observed the need for further inclusion of individuals with disabilities as part of program development. Having this understanding, I wanted to carefully listen and observe the research participants as an outsider as much as possible. I wanted to explore the similarities and differences of being responsible for the welfare of a child with and without intellectual disabilities and learn what issues and barriers present themselves in terms of program development and delivery in recreation and leisure service settings.

### **Trustworthiness**

The primary focus of this qualitative study was to understand whether previous participation in specialized programs, which are designed for individuals with disabilities, increases opportunities for participation in inclusive programs, which are designed for both individuals with and without disabilities. Perspectives came from parents of children with intellectual disabilities who actively participate in Special Olympics. These same parents currently participate or have participated in inclusive programs at school or

in recreation agencies in their communities. Other examples of inclusive recreation in which my participants have engaged in include organizations like Kids Included Together, Schools of Promise, and the National Inclusion Project.

In terms of other specialized recreation program examples in which my participants have engaged in include, local school programs that provide recreational and social opportunities for individuals with physical or developmental disabilities such as Unified Sports and after-school programs. Additionally, participants have engaged in specialized programs with local recreation agencies, YMCAs or youth centers, such as the Boys and Girls Club. Recreation agencies located throughout the United States offer a variety of specialized programs from community enrichment classes that include fun, hands-on learning activities such as cooking, dance, drama, music, and pottery to team sports like baseball, basketball, bowling, golf, and soccer (Bendini, 2012; Datillo, 2013).

I assured my participants that their confidentiality would be protected and their actual names would not be included in my dissertation. Most participants had no problem having their names included in my dissertation; however, I felt strongly that some of the information they provided could implicate others within their communities. Therefore, I opted to use pseudonyms for each of my participants. Throughout the research process, I tried my best to let the participants understand my position and intent at the initiation of every contact, and I also let them know that they were not under strict obligation to continue participating in my interviews.

Many researchers suggest the use of a minimum of two procedures to ensure trustworthiness of the study (Creswell, Henson, Plano, & Morales, 2007). As a qualitative researcher, I employed triangulation by using prior literature research, field

experience observations, participant interviews, and a focus group. In addition, I employed member checks to ensure I accurately transcribed and coded the interview data correctly. Member checks or interview feedback gave each participant an opportunity to review transcripts, thus verifying that the data collected were accurate reflections of their thoughts, feelings and ideas (Glesne, 2006).

In order to minimize the effect of researcher bias, the selection of participants within the Special Olympics organization were chosen based on specific criteria (outlined in prior sections of this chapter), which coincide with the goals of the study. Because the researcher is not employed by or an active volunteer for Special Olympics and, thus, is removed from the organization studied, the impact of research credibility, and/or trustworthiness was immensely enhanced.

### **Summary of Methodology**

As mentioned previously, the primary focus of this qualitative study was to understand whether participation in specialized programs, which are designed for individuals with disabilities, increases opportunities for participation in inclusive programs, which are designed for both individuals with and without disabilities. By studying numerous viewpoints, I endeavored to convey clarity to the issues and find a consensus among the research participants involved. This qualitative approach to conducting a research study is manifested through observations, interviews and focus groups. Additionally, I chose to utilize a phenomenological approach within my qualitative study. Because this study sought to learn about specific barriers to participation in inclusive recreation programs, this study has commonality within the field of phenomenology.

The results from this study (presented in Chapters IV and V) will optimistically provide recreation professionals and educators with understandings that could have a direct impact on participation in specialized and inclusive recreation programming. More importantly, it is my hope that the results of this study point toward a bright future for inclusive recreation programming. Particularly noteworthy in my review of the literature is that inclusive recreation appears to be more widely embraced, reflective of a growing inclusive recreation movement. Despite the expanding inclusive recreation movement, specialized programs are still being widely used by individuals with disabilities, such as my research participants. Chapter IV presents the descriptive stories of these eight participants.



## CHAPTER IV

### FINDINGS

#### **Introduction**

The purpose of this study was to understand if participation in specialized recreation programs, which are designed for individuals with disabilities, increases opportunities for participation in inclusive programs, which are designed for both individuals with and without disabilities. The research questions focused on the connection between participation in specialized recreation and inclusive recreation. The study was conducted with parents that have children with intellectual disabilities that participate in Special Olympics Kentucky based in Frankfort, Kentucky. Specialized recreation programs, such as Special Olympics, are primarily segregated and do not consistently lead to inclusive recreation programs.

The findings in this chapter is presented in the following manner: (a) Introduction; (b) Presentation and Analysis of the Data; (c) The Interviews; (d) The Focus Group; and (e) the Summary of Findings. The findings of the data are organized and discussed according to the categories and themes that emerged from the data in relation to the research questions of the study. The interviews and focus group session are discussed in the context of relevant literature that helped clarify the meaning of the data.

#### **Presentation and Analysis of the Data**

Parents of children with disabilities have many reactions to their children's special needs, and these reactions may focus on positive or negative factors. Some parents go through several emotions roughly in a sequence, whereas others may experience only one or several discrete reactions. In discussing participation in

specialized and inclusive recreation, for some, the reactions may be minor and their approach pragmatic. For others, their child's disability might affect their entire family structure and life (Friend & Bursuck, 2011). A series of interviews and a focus group session was conducted to try to establish a pattern of understanding to explain this phenomenon. The research questions of this study are connected to participant responses below:

### **The Interviews**

**How does previous participation in specialized recreation programs influence participation in inclusive recreation programs?** Mrs. Walker, who has a daughter that participates in both the Special Olympics among other programs, both specialized and inclusive, explained:

Being a mom to a child with Down syndrome is just like being a mom to any other kid. There are good days, and even amazing days, but also there are difficult ones that leave you frustrated and discouraged. Parenting is hard in general; being a mother is being a mother. With my daughter, it simply means a little more patience, extra hours spent on homework, and more research on things such as therapies and leisure time.

**Why do some parents of children with intellectual disabilities choose to pursue specialized recreation programs instead of inclusive recreation programs?**

Mr. Lang, has a son that competes in Special Olympics, however, participates in inclusive community programs infrequently, explained:

The day-to-day struggles of caring for a child with Fragile X syndrome can be physically and mentally exhausting. As a parent, it can be difficult at times to

find motivation for recreational activities after hours or on weekends. Although I often feel fatigue after a hard day at work, I can't allow that to dampen my son's growth and development. When Robin participates in Special Olympics events with other kids like her, she's so happy and energized. Her happiness then energizes me.

**Why do some parents of children with intellectual disabilities choose to pursue specialized recreation programs instead of inclusive recreation programs?**

Mrs. Jones, who has a daughter that participates in both Special Olympics and occasionally engages in inclusive community programs, explained:

The truth is that our lives very much center around Danielle's disability. At least, it feels that way to me. I see everything in our family revolving around Danielle and her needs. Community recreational activities that had once been fun for the entire family became inappropriate as Danielle and the other kids grew older.

There came a point when we were left with very few recreational options for the entire family when Danielle's developmental stage did not fit the standards of the cultural norm. Fortunately, we made the decision to give Special Olympics a try. The focus is still on Danielle, but when he is positively impacted, so is the family.

**Why do some parents of children with intellectual disabilities choose to pursue inclusive recreation programs and specialized recreation programs?** Ms.

Drew, who has a son that participates in both Special Olympics as well as various inclusive recreation programs, explained:

Because of the age gap between our children, I feel as though we have had two different families. Clint, now eleven, is eight years younger than his sister. Then

five years ago we took in my younger sister's daughter who is now seventeen. We chose to do it that way because of the different interests and ability levels. I've met other families that have similar arrangements when it comes to leisure time and community recreation programs. I've also met other parents who I know don't agree with it. They feel that I should put my foot down and make the other children participate in Special Olympics or whatever I am doing with Clint. I've never felt like that was a necessary course of action because we are all individuals and there is nothing wrong with my family choosing to take part in activities as individuals. It doesn't mean that we all don't love and respect one another. Everyone makes an attempt to come out and watch Clint when he competes in the summer games (with Special Olympics), but with other commitments and schedules, we can't all take part in everything Clint does throughout the year.

**Why do some parents of children with intellectual disabilities choose to pursue specialized recreation programs instead of inclusive recreation programs?**

Dr. McCoy, who has a son that competes frequently in Special Olympics but seldom participates in inclusive recreation programs, explained:

In addition to caring for Bobby, the continuous effort necessary to maintain and supervise the social situations between him and individuals outside our immediate family is also a challenge. For example, my wife and I have to repeatedly explain Bobby's disability and support needs to people we meet in the community. From my perspective, the experience of public judgement and uncomfortable attention can have a discouraging psychological effect on the recreation environment. Special Olympics alleviates this because I know everyone involved in the games

understands Bobby's behavior and needs. I know there are great community programs out there that are trying to include everyone and I appreciate that, but I think those programs have a long way to go before they can truly meet the special needs of participants with a cognitive disability.

**Why do some parents of children with intellectual disabilities choose to pursue specialized recreation programs instead of inclusive recreation programs?**

Mr. Parker, who has a daughter that participates in both Special Olympics and occasionally engages in inclusive community programs, explained:

I would be lying if I said that I didn't have periods of anxiety and stress when my daughter and I venture out in public or participate in programs outside Special Olympics. I mainly worry about Lauren's unpredictable behavior. Before we moved to Kentucky, we lived in New York and I remember taking Lauren on a two-day camping trip with Project Fit America. I was not only worried about my daughter's unpredictable behavior interfering with the other campers, but also worried about how to protect her from potential danger. Lauren is just so unpredictable. We were in a canoe on the lake and Lauren was becoming extremely hyperactive. I was very afraid she was going to capsize the canoe. Fortunately, we made it back to the shore safely.

**For those parents of children with intellectual disabilities who have participated in both inclusive and specialized recreation programs, how do they compare their various experiences? Why do some parents of children with intellectual disabilities choose to pursue specialized recreation programs instead of inclusive recreation programs?** Mr. Rand, who has a daughter that participates in

Special Olympics, but infrequently participates in inclusive community programs, explained:

My wife and I have to repeatedly explain Luke's disability and support needs to people we meet in the community. From my perspective, the experience of public judgement and uncomfortable attention can have a discouraging psychological effect on parents participating in recreation programs. Special Olympics alleviates this because I am confident that everyone involved in the games understands Luke's behavior and needs. I know there are great community programs out there that are trying to include everyone and I appreciate that, but I don't think those agencies can succeed in meeting the special needs of every participant with a disability.

**For those parents of children with intellectual disabilities who have participated in both inclusive and specialized recreation programs, how do they compare their various experiences? What are the barriers that inhibit participation in inclusive recreation programs?** Ms. Walters, who has a daughter that participates in Special Olympics, and frequently engages in inclusive community programs, explained:

I try to be a responsible and engaged community member and I support our local parks and recreation programs. I'm on a first name basis with the parks and recreation staff and I volunteer for the events they offer to our community. I think the staff do the best they can considering the limited amount of resources allocated for programming. Our legislators certainly need to accept responsibility to help parks and recreation agencies with funding and other important issues that affect programs in our communities. I think the real problem is a lack of disability

awareness overall in our communities. The men and women who staff our parks and recreation agencies can't possibly do it alone, yet they are the ones often charged with creating community events and activities. It is the responsibility of everyone in our communities to generate disability awareness and champion equal access and participation in parks and recreation.

### **The Focus Group**

**Why do some parents of children with intellectual disabilities choose to pursue inclusive recreation programs and specialized recreation programs? For those parents of children with intellectual disabilities who have participated in both inclusive and specialized recreation programs, how do they compare their various experiences?** Participant Walker explained:

When we lived in Cincinnati my husband and I participated in an inclusive day camp program for Joshua. This was a month long camp and Joshua attended the program three days per week. Joshua's Cerebral Palsy affects his right side and causes weakness in his arms and legs. Joshua is ambulatory, although his gait is unsteady. Therefore, even something like stairs were a concern for us. To accommodate this safety concern, a railing was added to the right side of the stairwell. There was already a hand rail on the left side of the stairwell. Joshua was also able to use a wagon when ambulating long distances such as going from one side of a large gymnasium to the other or walking to the swimming pool. On that note, Joshua's aquatic instructors were trained in techniques to adapt his swim instruction. My son increased his socialization skills that summer and

developed friendships with other kids that he still maintains even though we moved to Kentucky.

**Why do some parents of children with intellectual disabilities choose to pursue inclusive recreation programs and specialized recreation programs? For those parents of children with intellectual disabilities who have participated in both inclusive and specialized recreation programs, how do they compare their various experiences?** Participant Lang explained:

Last summer during some science camp activities, Robin operated as class “checker.” He was the only student in his class with an intellectual disability. Students showed him their completed assignments, and he accompanied the teacher when students explained the activity, keeping a record of which groups had earned extra credit. Robin not only assisted the teacher, but he also developed appropriate skills for the world of work. As a result of his inclusion, Robin began greeting his peers before class. He also took responsibility for completing class tasks and practiced motor and number recognition skills. Robin’s inclusion also affected nondisabled students, who, prior to this experience, didn't talk much with other students during classroom activities. After initiating cooperative learning groups and teaching collaborative learning strategies, Robin’s teacher noted that the on-task behavior of all students increased and that they began to interact with each other across ethnic groups.

**Why do some parents of children with intellectual disabilities choose to pursue inclusive recreation programs and specialized recreation programs? For those parents of children with intellectual disabilities who have participated in both**



**inclusive and specialized recreation programs, how do they compare their various experiences?** Participant Jones explained:

Danielle participated in a theatre arts camp last summer and students spent a majority of their time reading plays. The camp consisted of about 65 students and only Danielle and two other students had disabilities. Danielle's fellow campers read to her, she listened to audiotapes of plays, and she interviewed other campers about plays they had read. Danielle made bulletin boards about the plays the class were studying by looking up appropriate photographs online. In the process, she developed general theatre knowledge, research skills, and other work-related skills of photocopying, designing, and compiling information about specific topics.

**Why do some parents of children with intellectual disabilities choose to pursue inclusive recreation programs and specialized recreation programs? For those parents of children with intellectual disabilities who have participated in both inclusive and specialized recreation programs, how do they compare their various experiences?** Participant Drew explained:

Clint sometimes has difficulty making friends. He frequently tries to join in conversations by asking, "Did you know Scooby Doo is a Great Dane?" Then, he repeats the question several times regardless of how the other child answers. Clint's autism also affects his ability to write essays and to answer inference questions. His peers had primary responsibility for teaching Clint to engage appropriately in conversations, although they required some instruction to do so. While participating in an after-school program at Parks and Recreation his

counselor taught all of the students in Clint's classes about inclusion and friendships. She also talked about how Clint needed to learn to make friends. She taught the kids how to redirect Clint to join their conversations with the same topic and gave them permission to tell Clint when they didn't like what he said or did. Previously, students had ignored or avoided Clint when he tried to talk with them. Once they understood how to talk to him, however, his skills improved, and students included Clint in their social groups more often.

**For those parents of children with intellectual disabilities who have participated in both inclusive and specialized recreation programs, how do they compare their various experiences? What are the barriers that inhibit participation in inclusive recreation programs?** Participant McCoy explained:

Recreation service providers should recognize the importance of rigorous program evaluations. I see no better way of improving these programs. Parents need to be involved in this process to evaluate perceptions of the inclusion process, accommodations provided, program outcomes, etc. Service providers have to continuously make changes to ensure the advancement of inclusive programs because a person with a disability has specific needs.

**Why do some parents of children with intellectual disabilities choose to pursue specialized recreation programs instead of inclusive recreation programs? What are the barriers that inhibit participation in inclusive recreation programs?**

Participant Parker explained:

The greatest concern for me when considering an inclusive program at an agency I am unfamiliar with is inadequately trained staff or that the facility itself does not

have sufficient supports to allow my daughter to effectively participate. Also, if the behavior of the typical students is not well monitored by staff this may result in Lauren being ostracized in subtle ways that could have a very negative effect on her self concept. Of course, I speak from experience when I say this. This has happened before.

**Why do some parents of children with intellectual disabilities choose to pursue specialized recreation programs instead of inclusive recreation programs? What are the barriers that inhibit participation in inclusive recreation programs?**

Participant Rand Explained:

The biggest barrier to including a child with a disability or other special need seems to be fear. A good friend of mine has been a director in a municipal park and recreation agency for over a decade and he agrees with me on this. Service providers are afraid of physically hurting a child, of not meeting perceived needs, and of having to tell a parent, “I don’t know how to take care of your child.” It isn’t easy to run these programs. I realize that funding support for staff and facilities isn’t solid for many agencies either, yet they are fully expected to provide high quality services and experiences to people like my son and I. I think it would be unfair for me to completely fault an agency unless they are not making an attempt to provide better inclusive services. At least by making an attempt we are facing the fear.

**How does previous participation in specialized recreation programs influence participation in inclusive recreation programs? Why do some parents of children with intellectual disabilities choose to pursue specialized recreation programs**

**instead of inclusive recreation programs? What are the barriers that inhibit participation in inclusive recreation programs?** Participant Walters Explained:

When it comes to parks and recreation services, I have observed that while parents often have questions about supervision, medical issues, meals and communication, the most important thing they look for is reassurance about their child's health and safety. This doesn't change when you are the parent of a child with a cognitive disability. A good staff is crucial in establishing this reassurance of safety. Parents want to know how experienced staff members are with their child's particular disability and that the staff knows what to do if a problem arises. It's important to know who will be with your child every day, socializing with and helping care for them. In my experience, it takes time to build this reassurance and overall trust of the agency. I fully support their efforts to create programs for children with and without special needs, but if the program isn't designed exclusively for children with disabilities such as Special Olympics then I need that reassurance.

**How does previous participation in specialized recreation programs influence participation in inclusive recreation programs? Why do some parents of children with intellectual disabilities choose to pursue specialized recreation programs instead of inclusive recreation programs? Why do some parents of children with intellectual disabilities choose to pursue inclusive recreation programs and specialized recreation programs?** Participant Walker explained:

I know several parents who are hesitant about inclusive services because of negative past experiences. I have always encouraged my friends and any new

parents that I meet against that way of thinking. We've all got to work together. For the community agencies, it means taking on new roles and responsibilities, and actually shifting to an inclusion model but it needs to be done. It can be frustrating for parents, but we are the ones most capable of helping to promote inclusion in our community parks and recreation programs as well as in our schools. A good friend of mine worries that her son will have nothing in common with peers without disabilities. Some kids with disabilities have difficulty communicating ideas about potential interests and it can be exhausting on parents since exploration of interests takes time. I know first hand how it takes time to explore new interests and programs. This is why better collaboration between parents, schools, and community agencies and other organizations is important.

**How does previous participation in specialized recreation programs influence participation in inclusive recreation programs? Why do some parents of children with intellectual disabilities choose to pursue specialized recreation programs instead of inclusive recreation programs? Why do some parents of children with intellectual disabilities choose to pursue inclusive recreation programs and specialized recreation programs? What are the barriers that inhibit participation to inclusive recreation programs?** Participant Lang explained:

We've all been there. We have all observed inadequate supports and accommodations, at times. It is frustrating when the support is expected to come from the parent. I think what most of us want is to know there is someone on staff that functions as support for a participant with a disability. It can be as simple as helping my son to be part of an activity or help him communicate with

other children and make friends. It can be more involved by helping Robin acquire new skills or competencies. But the important thing is that the support person is a permanent fixture. You know they will always be there at every program and every activity. This is probably the best way to put me at ease. I dare say most of the parents in this room would agree with me on this. Children with cognitive disabilities especially need this support and when the parents realize that your agency doesn't have it then they are going to go back to segregated programs because they know the support is there.

**How does previous participation in specialized recreation programs influence participation in inclusive recreation programs? Why do some parents of children with intellectual disabilities choose to pursue specialized recreation programs instead of inclusive recreation programs? What are the barriers that inhibit participation in inclusive recreation programs?** Participant Jones explained:

One of my personal observations from engaging in many inclusive programs is the verbal and non-verbal behaviors of staff. For me, this will have the biggest influence on whether efforts at having inclusive programs are successful. Staff may be "theoretically" supportive of inclusion but unsure of the logistics and impact that a person with an intellectual disability may have on their program. No one would argue that staff training and support isn't critical, but the face-to-face, personal assistance provided Danielle and I by staff may be the most important gesture an agency can make to ensure that I return. I completely agree that overall access to many programs is still far too limited. Still, when I walk into a building where a program is being held, I can quickly identify whether this

is an agency that is trying to make things better or not. It is important to remind staff that for some people who have a disability, a bit of human kindness and support is all that may be needed to create a positive, inclusive environment that makes parents want to come back.

**How does previous participation in specialized recreation programs influence participation in inclusive recreation programs? Why do some parents of children with intellectual disabilities choose to pursue specialized recreation programs instead of inclusive recreation programs? What are the barriers that inhibit participation in inclusive recreation programs?** Participant Drew explained:

Changing how an activity or game is done can offer a tremendous amount of assistance to parents and lead to fuller participation. I've seen inclusive programs that use the "buddy system" as an adaptation. The idea is that a buddy or peer steps in to perform the tasks that my child cannot. I think this idea is a good one providing the buddy is someone well trained and experienced in working with children with disabilities. I agree with Scott in that it is very hard on the parent when the support is put back on us all the time. I once took part in a day camp program that fully expected me to stay with Clint by his side the entire time. I was shocked by this expectation, particularly when it was being advertised as an inclusive recreational camp with highly trained staff. I was told that funding for the agency's summer programs had taken a severe cut, which limited their seasonal staff for the camps. Although I feel partial participation is a reasonable accommodation in parks and recreation programs, when I am paying a fee to allow my son to participate in a camp then I expect the program to deliver what is

being advertised. Not to mention that my son doesn't always want me being his "buddy" at camp. It is far better for his social development to engage with other children, staff and volunteers without his mother around all the time.

**How does previous participation in specialized recreation programs influence participation in inclusive recreation programs? Why do some parents of children with intellectual disabilities choose to pursue specialized recreation programs instead of inclusive recreation programs? What are the barriers that inhibit participation in inclusive recreation programs?** Participant McCoy explained:

My experiences with inclusive programs for the most part have not been positive. We participated in a few programs in Tennessee where we used to live that were fairly accommodating, but I haven't found a program yet that is both welcoming and fully equipped to the standards needed. As far as we've come with the idea of inclusion, we still have a long way to go. I would like for it to be less of a fight. I don't think we as parents should always be the ones fighting for access. We run non-stop, 24-7, 365 days a year. One thing I've observed over the past few years is that while the other parents are sitting on the sidelines watching their kids play, we're out on the field. We're running up and down the field to constantly monitor our kid so we never get to simply sit down and enjoy the game. Students with severe disabilities need supports and adaptations, and agencies need trained staff to be able to implement effective approaches.

**How does previous participation in specialized recreation programs influence participation in inclusive recreation programs? Why do some parents of children with intellectual disabilities choose to pursue specialized recreation programs**



**instead of inclusive recreation programs? What are the barriers that inhibit participation in inclusive recreation programs?** Participant Parker explained:

When I find that I'm running on fumes, I utilize the supports that I already have in place or seek new ones. This can mean calling on grandparents, friends, or babysitters to provide me with a little respite from the kids every so often to recharge. But not every parent may have such a support system. Their support system may come parks and recreation. The fatigue that can come from parenthood is a reality for any of us, but it is a legitimate daily struggle when caring for a nine-year-old daughter with Cerebral Palsy. (Gesturing to Dr. McCoy) I understand what you're saying about running non-stop, 24-7, 365 days a year. I think a good inclusive program should help alleviate fatigue and stress whether a parent opts to actively participate or sit on the sidelines and watch. This is made possible by the presence of experienced and dedicated staff that are skilled at structuring game play, facilitating interactions in non-structured settings, and encouraging the development of our children's interests and skills. Of course, safety is always a concern for us so we want staff to make us feel comfortable by knowing that the individuals supervising my child know everything about using adapted equipment and that they know how to safely modify games and activities.

**How does previous participation in specialized recreation programs influence participation in inclusive recreation programs? Why do some parents of children with intellectual disabilities choose to pursue specialized recreation programs instead of inclusive recreation programs? What are the barriers that inhibit**

**participation in inclusive recreation programs?** Participant Rand explained:

Physical exhaustion can take a toll on the parents of a child with an intellectual disability. Logic would dictate that the degree of this is usually relative to the amount of care needed. Feeding, bathing, moving, clothing and diapering an infant is much easier physically than doing the same tasks for someone who weighs 80 pounds. The child, much like my son, may have more health-care appointments than a typical child and may need close medical monitoring.

Therefore, I don't allow my son to be placed into the care of anyone that is not prepared and equipped to handle his disability and any emergencies that may arise. I am very cautious when it comes to choosing a new inclusive program. In fact, I have a tendency to shy away from any new programs. It can be a wearisome and daunting task to find new programs and I am more likely to stick with those in which I am already involved. Does that sound bad? I'm just being honest.

**How does previous participation in specialized recreation programs influence participation in inclusive recreation programs? Why do some parents of children with intellectual disabilities choose to pursue specialized recreation programs instead of inclusive recreation programs? What are the barriers that inhibit participation in inclusive recreation programs?** Participant Walters explained:

Well, I understand wanting to stay within your comfort zone in terms of inclusive programs, but I would feel guilty if I didn't give new programs a try. I'm very loyal to the parks and recreation program in my town, but I want to continue to pursue new interests too. Don't get me wrong. I do understand how exhausting it

all can be. Sometimes, I have participated in a program and even being in a room with fifty other people I felt very alone and isolated. No other parents would even talk to me. I felt very invisible. Finally, after several minutes of standing alone in the back of a gymnasium, a staff member noticed I was alone and invited me to sit and have some refreshments with a small group of parents. So it isn't easy finding a good inclusive environment for a child with a cognitive disability, yet it should be. It should not be too difficult to create a welcoming, inclusive environment for all children to play. I recall going back home and crying one time because I didn't feel my child and I were welcomed at a community program. I strongly feel that support from family, friends, the community or paid caregivers is essential to maintaining a healthy balance in the home. I think it is crucial for us to remember that we must care for ourselves as well as our children. If we ignore our personal needs, it can result in even more trips to the doctor's office, as we face exhaustion, depression, feelings of isolation and a host of ailments.

**How does previous participation in specialized recreation programs influence participation in inclusive recreation programs? Why do some parents of children with intellectual disabilities choose to pursue specialized recreation programs instead of inclusive recreation programs? What are the barriers that inhibit participation in inclusive recreation programs?** Participant Walker explained:

No parent of a child with a disability, whether it is intellectual or physical, is under an illusion that inclusion is easy. To successfully include all children requires creativity and a strong commitment to the success of each child. Some of

the limitations to inclusion are very practical like staff, training, facilities and equipment, and then others are less tangible such as public awareness and shifts in personal beliefs. If community leaders work effectively with parents, schools, local non-profits, and other community service programs we can address both the practical and philosophical nature of creating a world where all people with disabilities are included.

**For those parents of children with intellectual disabilities who have participated in both inclusive and specialized recreation programs, how do they compare their various experiences? What are the barriers that inhibit participation in inclusive recreation programs?** Participant Lang explained:

Well said. I agree. We need to educate every single person in the community to understand that inclusion is not a place, a program, or a fad, but rather it is a state of being and, as pertaining to our discussion here, a way of operating your services that says “all are welcome.” Also, as critical as public awareness and educating the community is, we need to focus on how we overcome the practical barriers of resources and accessible facilities.

**For those parents of children with intellectual disabilities who have participated in both inclusive and specialized recreation programs, how do they compare their various experiences? What are the barriers that inhibit participation in inclusive recreation programs?** Participant Jones explained:

One thing that has come up several times during our discussions is what is arguably the biggest barrier to creating an inclusive recreation program, which is not the lack of resources and accessible facilities. Although those are problems

that need to be solved, the biggest barrier is actually one of attitude. Nearly all of us in this room have spoken about this today. In order to provide a recreation program that is authentically inclusive, we must understand that inclusion is first and foremost a philosophy. It is a strong belief that everyone has value and something to contribute. It is an understanding that what our programs really provide at their heart is the opportunity to build relationships and develop skills. To put it simply, it is the belief that all children can participate, make friends, and be successful.

**For those parents of children with intellectual disabilities who have participated in both inclusive and specialized recreation programs, how do they compare their various experiences? What are the barriers that inhibit participation in inclusive recreation programs?** Participant Drew explained:

Last week I was having lunch with a friend of mine whose 11-year-old son has a cognitive disability and we were actually talking about barriers that relate to policies and regulations within parks and recreation programs. She was telling me about a few negative experiences she and her son had with their community parks and recreation program. Basically, there are rules and practices about participation that may exclude people. Perhaps it something the staff has done for a number of years not realizing it actually excludes some children. This is something you never find in a specialized setting, of course, but definitely something to be mindful of in an inclusive program. There may be activities within the program that may not be a good fit for children with certain types of disabilities. I take that as a sign that the staff may lack experience in facilitating

an inclusive program. If that is the case then other questions come to mind. Do they know how to make adaptations to the program? Do they know about adaptive equipment?

**For those parents of children with intellectual disabilities who have participated in both inclusive and specialized recreation programs, how do they compare their various experiences? What are the barriers that inhibit participation in inclusive recreation programs?** Participant McCoy explained:

Jessica makes a valid point. I've observed this time and time again in several inclusive programs. I will say that when I discuss this with the leadership within the program it is generally remedied quickly. It may be, as Jessica said, a lack of experience among certain staff members. Nevertheless, this is a barrier that we should not be addressing in this day and age. We need to hire educated and well-trained staff in these programming positions. My wife and I were speaking with our local director of parks and recreation a few months ago about significant barriers for people with disabilities. That is, what barriers are we seeing most prevalent within our communities. We talked about transportation and lack of money to participate. There are several people with disabilities that do not drive and in rural areas they may not have access to public transportation. Also, there are many people that simply do not have the money required for program fees or admission to special events. The lack of disability supports such as accommodations or even a Certified Therapeutic Recreation Specialist may also prevent people from participating if they require help with doing specific activities being offered through the recreation program.

**For those parents of children with intellectual disabilities who have participated in both inclusive and specialized recreation programs, how do they compare their various experiences? What are the barriers that inhibit participation in inclusive recreation programs?** Participant Parker explained:

After I was invited to participate in this study, I mentioned it to a few friends I have known for several years. These are a few parents I know primarily from participating in Special Olympics. We were all discussing barriers to inclusive recreation in general and many relate to lack of training of staff and volunteers on inclusive practices. As Jessica mentioned, there are rules and regulations that some programs need to revisit and change in order to truly be inclusive.

Otherwise, parents will not allow their children to participate. It just isn't welcoming. One of my friends no longer participates in inclusive programs because he and his wife had numerous negative experiences with their local community agency. Also, there can be a lack of leadership within programs to better promote inclusion, and a lack of outreach to those people who may be excluded. Funding for supports that can assist with the overall inclusion process is also huge issue.

**For those parents of children with intellectual disabilities who have participated in both inclusive and specialized recreation programs, how do they compare their various experiences? What are the barriers that inhibit participation in inclusive recreation programs?** Participant Rand explained:

I realize what a struggle it can be to secure funding for inclusive programs, but I am often in awe how many architectural and structural barriers I still encounter. If

my son and I visit a facility and it lacks ramps, automatic door openers, elevators, and similar accommodations then that projects a clear message that anyone with a disability simply isn't welcome.

**For those parents of children with intellectual disabilities who have participated in both inclusive and specialized recreation programs, how do they compare their various experiences? What are the barriers that inhibit participation in inclusive recreation programs?** Participant Walters explained:

That's horrible, Dan. I was in a facility just as you described with my cousin and his children last summer. I never went back. It makes one realize the importance of the recreation facility itself. I was thinking why would a parks and recreation department be housed in a building like this? An understanding of the barriers children with disabilities face is critical to inclusive programs and yet communities are housing their recreation service agencies in building's that should be torn down. I guess it all goes back to funding. Still, our government and community leaders should do something to help improve this situation. As mentioned before, inclusion is a value and a way of thinking. People may believe that children with disabilities require separate recreation programs or activities. This is a failure to understand inclusion and what it means in terms of belonging and acceptance. These barriers can often be the most difficult to address.

### **Summary of Findings**

This study intended to understand whether participation in specialized recreation programs, which are designed for individuals with disabilities, increases opportunities of participation in inclusive programs, which are designed for both individuals with and



without disabilities. More research in the field is needed to determine if participation in specialized recreation programs increases opportunities for participation in inclusive recreation programs, or if specialized recreation unintentionally enables barriers to inclusion. The findings of this study show that the participants, all of whom are parents of children with intellectual disabilities, highly value specialized recreation programs such as Special Olympics, yet strongly desire to be included in community recreation programs of an inclusive nature.

The International Classification of Functioning, Disability and Health for Children and Youth (ICF-CY), a classification of the health components of functioning and disability, provided the conceptual framework for the study and facilitated the interpretation of the findings. Research has not identified whether participation in specialized programs may increase opportunities for participation in inclusive recreation or if they enable barriers. I hope this research has the potential to lend valuable insight into the phenomenology of participation in specialized and inclusive recreation programs.

## CHAPTER V

### DISCUSSION & CONCLUSIONS

#### **Introduction**

It has been over a year since that Sunday afternoon in the park when I first read the journal article by Tremblay (2013), which compared two instructional models for students with learning disabilities with regard to their effect on academic achievement and class attendance. Although the results of the study revealed no considerable difference between the two models in terms of target population and objectives, significant differences were observed in the effects of student outcomes in reading, writing and attendance, with the inclusion model being more effective when compared to the specialized education setting (Tremblay, 2013, p. 256). Essentially, Tremblay's article is an example of the importance of inclusive education for individuals with and without intellectual disabilities. After reading the article, it was on that same June afternoon that I explained to my two inquisitive children what an intellectual disability was and why the playground in the park includes a play area containing adaptive equipment for children with special needs.

It was at that very moment that I was reminded how inclusive recreation could be anything an individual with a disability likes to do, activities that occur in the natural environments at school, in the community, or in recreation service agency settings, alongside people with disabilities. As I continued to observe and educate my children on the subject of inclusion, it was apparent to me that inclusive recreation was as important to quality of life as inclusive education. That day I realized that I had indeed found the subject of my dissertation. Everyone should have the option to participate fully in leisure

without discrimination. Inclusive recreation breaks down the barriers that separate individuals with disabilities from those without disabilities or at least, it should if it is planned and delivered correctly.

Research in this chapter is presented in the following manner: (a) Introduction; (b) Managing the Physical, Emotional and Financial Demands Related to the Disability; (c) Managing Overall Family Dynamics; (d) Managing Social Interaction Participation in Recreation Programs; (e) Unresponsiveness and Lack of Intellectual Disability Awareness in the Community; (f) The Barriers to Inclusive Recreation; (g) Implications and Conclusions and, (h) A New Model of Inclusion. This study intended to understand whether participation in specialized recreation programs, which are designed for individuals with disabilities, increases opportunities of participation in inclusive programs, which are designed for both individuals with and without disabilities. The eight research participants, all parents of children with intellectual disabilities, identified numerous factors that enhanced or limited their participation in inclusive recreation programs. They are mainly related to source of stress and anxiety, significant barriers in their everyday life, and parents' attempts to engage their children in recreational programming (Malone et al., 2012; Verschuren et al., 2012). The study revealed that the overall family dynamic was affected in a variety of different ways by the child's intellectual disability and subsequent disorders such as a lack of adequate communication skills, as well as by a series of other factors related to social, educational, and professional organizations (Rimmer, 2006; Malone et al., 2012; Verschuren et al., 2012).

As a qualitative researcher, I am interested in studying numerous viewpoints of a human being's understanding of reality, thereby approximating the truth behind the story.

This type of study is manifested through observations, interviews and focus groups. Furthermore, I chose to utilize a phenomenological approach within my qualitative study. As defined by Creswell (2007), phenomenology is a form of study that focuses on the commonality of a lived experience within a particular group. In recreation programming, phenomenology can enable the identification of the underlying dimensions on various perspectives of specialized and inclusive experience.

During the interviews and focus group, four themes emerged in relation to constraints parents faced during inclusive recreation program participation emerged: (a) managing the physical, emotional and financial demands related to the disability; (b) managing overall family dynamics; (c) managing social interaction participation in recreation programs; and (d) the unresponsiveness and lack of intellectual disability awareness in the community. To support my research questions (refer to Chapter I) as well as my review of the literature (refer to Chapter II), I present the discussion below using qualitative content analysis in order to gain deeper insight and a more general view of the meaning of the research.

### **Managing the Physical, Emotional and Financial Demands Related to the Disability**

Reflective of all group participants, there is a tremendous amount of stress placed on the parents of children with intellectual disabilities (Malone et al., 2012; Verschuren et al., 2012). Parents of children with intellectual disabilities may have several conflicting tasks to perform while managing the varied and often tiresome physical, emotional and financial demands of their child's disability (Rimmer, 2006; Malone et al., 2012; Verschuren et al., 2012). In addition, participants felt they may, have to parent their other children or care for their own aging parents and respond to their demanding roles in the

workforce to financially support their families (Malone et al., 2012; Verschuren et al., 2012). Participants discussed that an important factor in defining recreation is that recreation has always been viewed as restoration from the labor of work (DeGrazia, 1962; Godbey, 2008; Kelly, 1990; Kelly & Godbey, 1992; Rossman & Schlatter, 2011; Russell, 2013). Parents acknowledged and understood that research has primarily examined barriers from two viewpoints: barriers individuals with disabilities could face while participating in inclusive recreational programming, as well as barriers that agencies could confront in providing inclusive recreational programming (Devine & Lashua, 2002; Devine, 2004; Malone, Barfield, & Brasher, 2012; Schleien, Miller, Walton, & Pruett, 2014).

### **Managing Overall Family Dynamics**

Reflective of all group participants, the demands directly related to a child's intellectual disability and balancing the needs of all family members also has an impact on choices made for participation in recreational programs (Mactavish & Schleien, 2004; Zabriskie, Lundegren, & Groff, 2005). All eight participants frequently discussed conflicts they encounter when trying to meet the collective and individual needs of the family (Mactavish & Schleien, 2004; Rimmer, 2006; Schleien et al., 2014). It was evident that the disability often overshadows the desires and preferences of the other family members when choosing activities that included everyone (Duvdevany, 2002; Fisher & Meyer, 2002; Malone et al., 2012; Verschuren et al., 2012). Participants discussed the overall meaning of inclusion as it relates to the family dynamic as inclusion in recreation and leisure is the philosophy that individuals with and without disabilities have the opportunity to participate together (Devine & Lashua, 2002; Godbey, 2008;

Mayer & Anderson, 2014; Rossman & Schlatter, 2011; Smith, 2002). Participants acknowledged and understood that research has shown the concept of inclusion, where individuals with and without disabilities participate in recreation programming together has become the widespread dynamic in recreation programming (Anderson & Kress, 2003; Devine, 2004; Friend & Bursuck, 2011; Godbey, 2008; Mayer & Anderson, 2014).

### **Managing Social Interaction Participation in Recreation Programs**

Reflective of all group participants, the belief that a family's social inclusion is very crucial for parents themselves, as well as for the child (Schleien et al., 1997 & 2009; Taylor, 2004). Participants discussed how they advised new parents that they come into contact with to maintain their social life and to have frequent contact with neighbors, friends, relatives, and social networks (Causton-Theoharis & Theoharis, 2008; Devine and Lashua, 2002). Participants feel because parents of children with intellectual disabilities sometimes experience anxiety and depression about their child's future welfare, as well as embarrassment about their child's behavior in various social situations, they are more likely to isolate themselves and to avoid regular social contact outside their homes and immediate families (Olkin & Howson, 1994; Rimmer, 2006). Participants find that inclusive program settings provide diverse opportunities for developing friendships and increasing self-esteem (Dattilo, 2002; Dattilo, 2013; Skulski, 2007; Shank & Coyle, 2002; Taylor, 2004). Participants acknowledged and understood that the research has proven that recreation provides benefits such as physical and mental health, stress management, and increases self-esteem (Anderson & Kress, 2003; Russell, 2013), while leisure is important for people with disabilities, not only for physical and

mental benefits, but research shows the most important benefit may be the social aspects of recreation participation (Godbey, 2008; Kleiber, Walker, & Mannell, 2011).

### **Unresponsiveness and Lack of Cognitive Disability Awareness in the Community**

Reflective of all group participants, parents who have children with intellectual disabilities spend a great deal of time advocating for their educational and medical needs (Renzagli et al., 2003). Thus, they often lack the additional energy required to also advocate for community recreation opportunities to support their family's needs (p. 144). Participants believed that community recreation agencies need to expand qualified staff and resources to enhance disability awareness and inclusive programming to assist family members in participation in recreation experiences that include all family members regardless of ability (Anderson & Heyne, 2000; Brault, 2012; Devine & Kotowski, 1999; Drum et al., 2009; Lieberman & Stuart, 2002; Rossman & Schlatter, 2011; Scholl et al., 2005). Participants discussed while including individuals with disabilities in inclusive recreation programming, several types of barriers have been established in the literature (Bendini, 2000; Devine, 2004; Schleien, Germ, & McAvoy, 1996; Schleien, Miller, Walton, & Pruett, 2014; Scholl, Glanz, & Davison, 2006; Stumbo, Wang, & Pegg, 2011). Although, the participants believe inclusive services in the U.S. need to be enhanced overall, they acknowledge that many recreation agencies have made impressive strides over the last decade to remove barriers and implement greater access for people with disabilities (Austin & Youngkhill, 2013; Datillo, 2002; Devine & McGovern, 2001; Heyne & Schleien, 1997; Schleiem, Miller, Walton, & Pruett, 2014). Participants acknowledged and understood that, in school systems, research has consistently shown the academic and social benefits of placing students with and without disabilities together

in the classroom setting (Fischer, Pumpian, & Sax, 2000; McDonnell, Thorson, Disher, & Mathot- Buckner, 2001).

### **The Barriers to Inclusive Recreation**

The study participants collectively agreed that Special Olympics provided support that helped to overcome some of the constraints and challenges, and often, relieved parents of stress involved in participating in recreational programming. Reflective of all group participants, and as explained by Widaman and Siperstein (2005), Special Olympics assisted their families in, (a) increasing opportunities for physical fitness, experiencing joy, and sharing skills and friendship with community, increasing satisfaction with family relationships, and (c) providing an increased sense of acceptance among other participating families.

Participants explained how Special Olympics is a program that excels in meeting the necessary support needs of its target audience, and that, generally speaking, other specialized recreation programs aspire to if not achieve the same results (Siperstein et al., 2006). When discussing their experiences in specialized recreation programs, the participant reactions were largely positive, while information shared in terms of inclusive programs was a combination of both positive and negative comments (Siperstein et. al, 2007, p. 445). Participants discussed how, historically, individuals with disabilities have been limited in recreation participation by means of specialized activities where people participate in programs based on disability, not specific interest (Datillo, 2013; Olkin & Howson, 1994; Scholl, Dieser, & Davison, 2005; Watcher & McGowan, 2002).

It became evident during the interviews and focus group discussions that participants valued recreation participation as an important aspect of their children's



quality of life, but sometimes found overall access to inclusive community programs limited. Participants were fatigued by the tremendous responsibility they felt the need to assume in support of their children's participation when access was finally gained, and were experiencing a vast amount of isolation in doing so (Thompson & Emira, 2011). The decision to be directly involved in activities with their child was the result of what they perceived to be inadequate support needs within the inclusive program setting (Mullick, 2013; Stumbo, Wang, & Pegg, 2011).

Furthermore, participants had strong desires for their children's full inclusion, but struggled with internal conflict between active participation and social interaction and the need to keep their children safe from harm (Schleien, Miller, Walton & Pruet, 2014, p. 67). It was interesting that despite their strong desires for full inclusion in recreation, participants also supported specialized programs. Thompson and Emira (2011) observed this contradiction among parents of children with autism, concluding "how one squares the circle between the principle of full inclusion and meeting the practical needs of families is uncertain" (p. 75). The dilemma between advocating for inclusive recreation programs versus specialized recreation programs will continue to grow until community agencies become more willing to expand their services to serve individuals of varying abilities (Schleien, Miller, Walton, & Pruet, 2014).

The findings of this qualitative study found that there were a number of personal and environmental barriers related to access and participation reported by the participants in both interviews and the focus group session. These barriers were discussed in greater detail during the focus group session, and were remarkably similar to those identified by

Rimmer, Riley, Wang, Rauworth, & Jurkowski (2004), which were grouped into ten major categories (see Table 4).

**Table 4**

**Major Categories of Barriers and Facilitators and Their Definitions**

Category	Definition
Built and Natural Environment	Barriers related to aspects of built or natural environment.
Codes, Regulations and Laws	Barriers related to the use and interpretation of laws and regulations concerning accessibility.
Emotional and Psychological	Barriers related to emotional or psychological issues.
Equipment	Barriers related to accessibility of recreation equipment and supplies needed for inclusive programs and activities.
Funding/Economic	Barriers related to funding recreational programs or costs associated with making facilities accessible.
Information Availability	Barriers related to access of information, including signs, brochures, and advertisements.
Perceptions and Attitudes	Barriers related to perceptions and attitudes of professionals and individuals without disabilities.
Policies and Procedures	Barriers related the implementation of agency or community imposed policies and regulations.
Qualified Staff and Training	Barriers related to education, qualification and training of professionals for inclusive programs and activities.
Resource Availability	Barriers related to obtaining needed resources for inclusive programs and activities, including transportation and adaptive equipment.

Source: ADA, American with Disabilities Act, 2004.

In terms of barriers, the interviews and focus group session findings were very similar to a qualitative national study funded by the Centers for Disease Control and

Prevention (CDC) to examine barriers and facilitators to physical activity associated with participation in fitness and recreation programs and facilities among individuals with disabilities (Rimmer, Riley, Wang, Rauworth, & Jurkowski, 2004, p. 420). The study organized focus groups in ten regions across the nation, and included four sets of participants: (1) people with disabilities, (2) architects, (3) fitness and recreation professionals, and (4) city planners and park district managers (p. 422). The results of this qualitative national study, discovered a number of personal and environmental barriers related to recreational access and participation reported by both individuals with disabilities and professionals associated or employed in the broad field of health sciences.

By limiting my study to eight parents of children with intellectual disabilities, and conducting both interviews and a focus group session, I was able to identify both positive and negative factors in terms of participation in specialized and inclusive recreation programs. During the focus group session, the parent participants discussed their attempts to engage their children in inclusive programs, thus identifying the main barriers that limited their participation in inclusion. At the end of the focus group session, I asked each of the eight participants if they planned to both continue participation in specialized recreation programs and participate further in inclusive recreation programs. Although all participants planned to continue participating in Special Olympics, Dr. McCoy made the decision not to participate in inclusive recreation program at present, while Mr. Rand opted to affirm undecided at present (see Table 5).

**Table 5**

**Participant Decision of Future Participation in Specialized and Inclusive Recreation Programs**

Participant who is a parent of a child with an intellectual disability	Plan to continue participation in Specialized Recreation Programs	Plan to continue participation in Inclusive Recreation Programs
Mrs. Walker	Yes	Yes
Mr. Lang	Yes	Yes
Mrs. Jones	Yes	Yes
Ms. Drew	Yes	Yes
Dr. McCoy	Yes	No
Mr. Parker	Yes	Yes
Mr. Rand	Yes	Undecided
Ms. Walters	Yes	Yes

The International Classification of Functioning, Disability and Health for Children and Youth (ICF-CY) is a framework for organizing and documenting information on functioning and disability (WHO, 2007). The ICF-CY conceptualizes functioning as a dynamic interaction between a child's health condition, environmental factors and personal factors (see Figure 2). Functioning and disability are understood as umbrella terms denoting the positive and negative aspects of functioning from a biological, individual and social perspective (WHO, 2007, p. 11). Definitions and categories in the ICF-CY are worded in neutral language, wherever possible, so that the classification can be used to record both the positive and negative aspects of functioning (p. 11). Although quantitative and qualitative data can be organized with the ICF-CY, it was my hope that the ICF-CY would provide a concise framework for functioning and disability in terms of organizing qualitative responses.

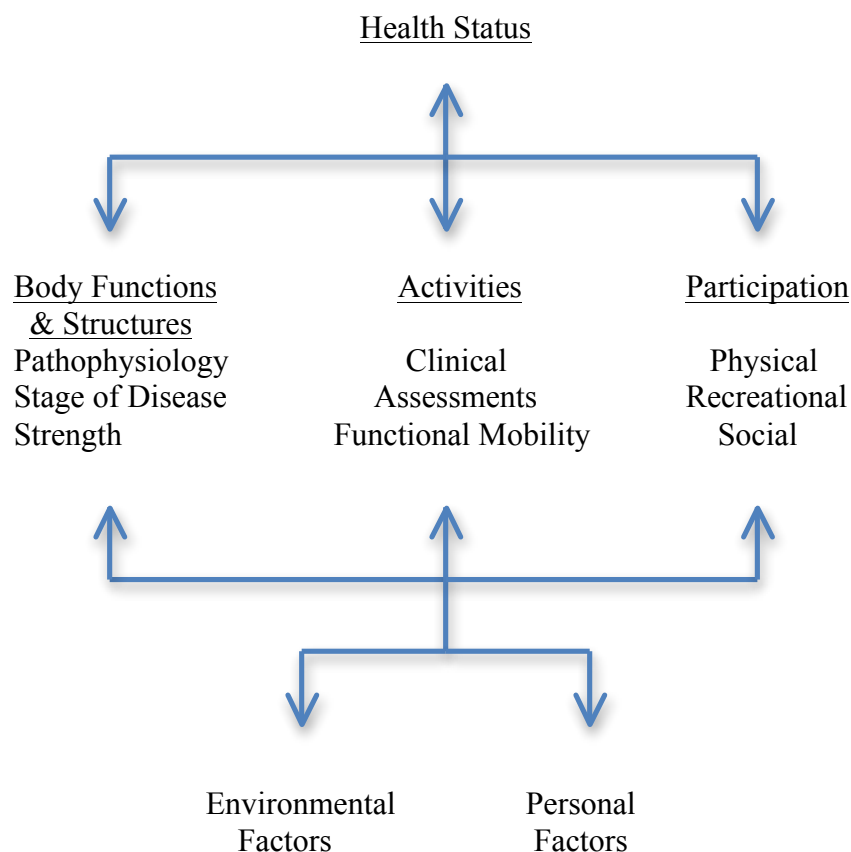


Figure 2. Interactions Between the Components of ICF-CY.  
Source: World Health Organization (2013, p. 17).

Although the points of view from the children are missing from this study, the parents provided detailed accounts of varied personal experiences and barriers their children have experienced in inclusive recreational settings. As reflective of the study participants, parents who care for children with intellectual disabilities need opportunities from recreation service providers to express their opinions and take part of professional planning and development during the inclusive recreation program processes (Drum et al., 2009). In this study, the ICF-CY framework of participation provided a well-focused lens through which to understand the barriers to inclusive participation faced by parents of children with intellectual disabilities. In addition, and reflective of most participants in the study, the data helps to better understand that participation in specialized recreation

programs does increase opportunities for participation in inclusive programs, as parents strongly desire to be more involved in their communities, and more importantly, involve their children.

The findings indicate uncovered subjective variations in perceived problems with barriers regarding activities and participation in inclusive recreation programs. For example, if the participant reported that he or she observed their child having communication problems with staff or peers in an inclusive recreation setting, I asked the participant to elaborate on the situation and describe if and how the issue was resolved. Furthermore this study shows that overall, positive and negative recreation experiences, although subjective, were very similar among the eight participants while participating in an inclusive program setting. Hammel, Magasi, Heinemann, Whiteneck, Bogner, and

Rodriguez (2008) found that individuals with disabilities experience participation as a complex and dynamic phenomenon, which is dependent upon personal choices and environmental influences. I focused on the Activities and Participation component within the ICF-CY, which has significant relevance to the barriers encountered in leisure settings, along with objectives relating to inclusion (see Figure 3). Barriers or restrictions to participation experienced by individuals with disabilities may include any and all situations that interfere with participating in life events such as inclusive recreational programming (WHO, 2007).

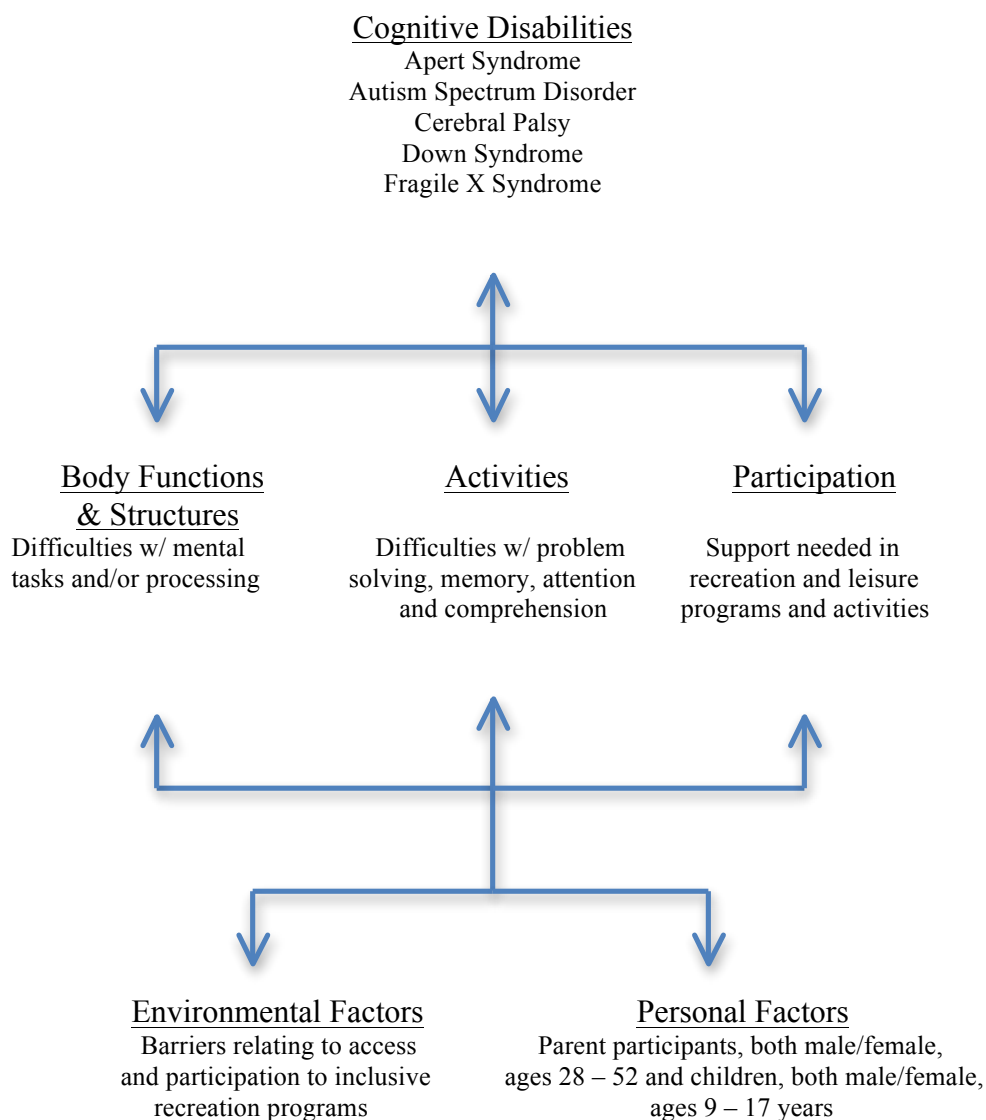


Figure 3. Interactions Between the Components of ICF-CY with Study Participants.  
Source: World Health Organization (2013).

In the IFC-CY, the Activities and Participation component comprise nine chapters (as indicated in Table 6) with the two qualifiers for the Activities and Participation component being the performance qualifier and the capacity qualifier (WHO, 2007, p. 17). The performance qualifier describes what an individual does in his or her current environment, as this qualifier can also be understood as “involvement in a life situation” or “the lived experience” of people in the actual context in which they live and engage in recreation (p. 19). The capacity qualifier describes an individual’s ability to execute a

task or action as this qualifier identifies the highest probable level of functioning that an individual may reach in a given domain at a given moment and represents the severity of the problem (p. 19). Moreover, the participants identified many problems while engaging in inclusive recreation programs, which I linked back to ICF-CY Codes and Categories (see Table 6 and Table 7). Based on the data obtained during the interviews and focus group session, the following are the most relevant categories or codes for the Activities and Participation component concerning the cognitive disabilities of the children aged nine to seventeen years. The numeric value representing the degree of relevance for each code is interpreted as follows: values closer to 3.00 indicate lower relevance, and values nearer to 1.00 indicate higher relevance. For example, participants generally agreed that “d350 Conversation” (average relevance value 1.20) is more likely to be a category where a greater barrier or set of barriers will be present during engagement in recreation programs than “d660 Assisting other” (average relevance 2.60).

**Table 6**

**Number of Problems (n=94) in the ICF-CY Activities and Participation Categories Reported by Participants (n=8)**

ICF-CY Code	Category Title	Number of Problems & Relevant Degree
Chapter 1: Learning and applying knowledge		Total Problems: 5 Total Relevance: 2.70
d155	Acquiring skills	Problems: 5 Relevance: 2.70



**Table 6 (Continued)**

ICF-CY Code	Category Title	Number of Problems & Relevant Degree
Chapter 2: General tasks and demands		Total Problems: 10 Total Relevance: 4.30
d210	Undertaking a single task	Problems: 6 Relevance: 2.20
d240	Handling stress	Problems: 4 Relevance: 2.10
Chapter 3: Communication		Total Problems: 12 Total Relevance: 3.60
d350	Conversation	Problems: 5 Relevance: 1.70
d399	Communication	Problems: 7 Relevance: 1.90
Chapter 4: Mobility		Total Problems: 14 Total Relevance: 4.00
d450-460	Walking and moving around	Problems: 7 Relevance: 2.10
d465	Moving around using equipment	Problems: 7 Relevance: 1.90
Chapter 5: Self-care		Total Problems: 6 Total Relevance: 2.70
d570	Looking after one's health	Problems: 6 Relevance: 2.70
Chapter 6: Domestic life		Total Problems: 5 Total Relevance: 2.40
d 660	Assisting others	Problems: 5 Relevance: 2.40
Chapter 7: Interpersonal interactions and relationships		Total Problems: 20 Total Relevance: 11.40
d710	Basic interpersonal interactions	Problems: 5 Relevance: 3.10

**Table 6 (Continued)**

ICF-CY Code	Category Title	Number of Problems & Relevant Degree
d720	Complex interpersonal interactions	Problems: 7 Relevance: 2.20
d750	Informal social relationships	Problems: 5 Relevance: 2.90
d760	Family relationships	Problems: 3 Relevance: 3.20
Chapter 8: Major life areas		Total Problems: 13 Total Relevance: 4.70
d820	School education	Problems: 6 Relevance: 3.20
d880	Engagement in play	Problems: 7 Relevance: 1.50
Chapter 9: Community, social and civic life		Total Problems: 9 Total Relevance: 1.40
d 920	Recreation and leisure	Problems: 9 Relevance: 1.40
		Total Problems: 94 Total Relevance: 19.70

Based on the data obtained during the interviews and focus group session, the following are the most relevant categories or codes for the Environmental Factors component concerning the cognitive disabilities of the children aged nine to seventeen years. The numeric value representing the degree of relevance for each code is interpreted as follows: values closer to 3.00 indicate lower relevance, and values closer to 1.00 indicate higher relevance. For example, participants generally agreed that “e410 Individual attitudes of immediate family members” (average relevance value 1.30) tends to have a greater effect on facilitating or hindering participation in inclusive recreation programs than “e460 Societal attitudes.”

**Table 7****Number of Problems (n=119) in the ICF-CY Environmental Factors Categories****Reported by Participants (n=8)**

ICF-CY Code	Category Title	Number of Problems & Relevant Degree
Chapter 1: Products and Technology		Total Problems: 24 Total Relevance: 10.40
e115	Products and technology for personal use in daily living	Problems: 4 Relevance: 2.00
e120	Products and technology for personal indoor and outdoor mobility and transportation	Problems: 4 Relevance: 1.90
e125	Products and technology for communication	Problems: 2 Relevance: 2.00
e130	Products and technology for education	Problems: 3 Relevance: 1.60
e140	Products and technology for culture, recreation and sport	Problems: 6 1.50
e150	Design, construction and building products and technology of buildings for public use	Problems: 5 Relevance: 1.40
Chapter 2: Natural Environment and Human-Made Changes to Environment		Total Problems: 8 Total Relevance: 8.90
e240	Light (natural or artificial)	Problems: 2 Relevance: 3.10
e250	Sound	Problems: 3 Relevance: 2.90
e260	Air quality	Problems: 3 Relevance: 2.90
Chapter 3: Support and Relationships		Total Problems: 14 Total Relevance: 11.70
e310	Immediate family	Problems: 3 Relevance: 2.50
e315	Extended family	Problems: 4 Relevance: 3.10

**Table 7 (Continued)**

ICF-CY Code	Category Title	Number of Problems & Relevant Degree
e320	Friends	Problems: 4 Relevance: 2.90
e325	Acquaintances, peers, colleagues, neighbors and community members	Problems: 3 Relevance: 3.20
e340	Personal care providers and personal assistants	Problems: 6 Relevance: 1.60
Chapter 4: Attitudes		Total Problems: 28 Total Relevance: 13.90
e410	Individual attitudes of immediate family members	Problems: 4 Relevance: 1.30
e415	Individual attitudes of extended family members	Problems: 4 Relevance: 2.80
e420	Individual attitudes of friends	Problems: 3 Relevance: 2.90
e425	Individual attitudes of acquaintances, peers, colleagues, neighbors and community members	Problems: 3 Relevance: 2.90
e440	Individual attitudes of personal care providers and personal assistants	Problems: 4 Relevance: 1.50
e460	Societal attitudes	Problems: 6 Relevance: 1.20
e465	Social norms, practices and ideologies	Problems: 4 Relevance: 1.30
Chapter 5: Services, Systems and Policies		Total Problems: 39 Total Relevance: 12.00
e510	Architecture and construction services, systems and policies	Problems: 7 Relevance: 1.10
e520	Open space planning services, systems and policies (public lands, parks, etc.)	Problems: 7 Relevance: 1.20
e540	Transportation services, systems and policies	Problems: 4 Relevance: 1.40
e550	Legal services, systems and policies	Problems: 4 Relevance: 1.20

**Table 7 (Continued)**

ICF-CY Code	Category Title	Number of Problems & Relevant Degree
e555	Associations and organizational services, systems and policies	Problems: 4 Relevance: 1.20
e575	General social support services, systems and policies	Problems: 3 Relevance: 2.30
e580	Health services, systems and policies	Problems: 5 Relevance: 1.90
e585	Education and training services, systems and policies	Problems: 5 Relevance: 1.70
		Total Problems: 119 Total Relevance: 56.90

The ICF-CY does not actually classify children but rather defines factors of importance for children's health (WHO, 2007). Simeonsson, Sauer-Lee, Granlund, & Bjorck-Akesson (2010) explain that these factors within the ICF-CY include the environment, which is not always common in assessment measures, indicating a shift from diagnoses of disability to function. Therefore, children with disabilities are not classified as a diagnosis but rather described as children with functional problems in specific situations (Simeonsson, et al., 2010, p. 44). From this point of view, the use of the ICF-CY may change the way recreation programmers develop inclusive programs.

The participants, with the best interests of their children in mind, make choices about recreation not merely based on preference, but on other variables about program structure, supports, and accommodations. A constant perception related to participation in recreation throughout the research, including this study is freedom of choice in selecting programs (Bedini & Thomas, 2012; Kelly, 1990; Kleiber, Walker & Mannell, 2011; Schleien & Green, 1992). Various findings arose from the interviews and focus group

session that explored how parents chose among options that include specialized and inclusive programs. One of the major findings was that some parents chose specialized rather than inclusive recreation because of components like competition levels and the skill-building component within specialized programs such as Special Olympics. This finding is consistent with other recreational programming research (Mayer & Anderson, 2014; Schleien et al., 1997; Siperstein et al., 2006).

### **Implications and Conclusions**

A key finding of this study was the perceived benefits that parents and children gained benefits from both specialized and inclusive recreation programs. However, reflective of all participants in this study, is an expectation of adequate facilities, staffing and instruction for an inclusive program environment. For example, specialized programs typically offer accommodations and supports in overall program planning, particularly in types of equipment and in activity instruction (McDonnell, Mathot-Buckner, Thorson, & Disher, 2001; Siperstein, et al., 2007). However, although specialized programs offer good accommodations and supports in overall programming, most participants in this study, noted barriers to participation between both family and friends, especially in terms of social interaction (Skulski, 2007; Vershuren, et al., 2012). Inclusive programs offer opportunities for parents and children with or without disabilities to socialize and learn from one another. Bueno (1994) has noted that inclusive programs do not offer some of the accommodations and supports that tend to attract people to specialized programs. In addition, the participants discussed how they choose to participate in specialized recreation programs in order for their children to obtain physical exercise as well as increase their self-confidence. However, physical exercise and increased self-confidence

could be consistently obtained from inclusive programs if the appropriate accommodations and supports are made available for individuals with disabilities. Schleien, Miller, & Shea, (2009) and Schleien, Miller Walton, and Pruett (2014) identified that participants and their families continue to experience a lack of these accommodations and supports in many inclusive programs.

A second key finding in this study was the important role of supports in inclusive programs. In this study, parents have participated in Special Olympics among other specialized programs because often such programs were encouraged by their support system (Siperstein et al., 2006). According to the participants, the role of supports is also true in terms of participation in inclusive recreation settings. Thus, the influence that support systems have on participation is important for recreation programmers and service providers to recognize, as educational outreach and marketing can be targeted to parents, as key decision makers and stakeholders for individuals with disabilities (Zabriski et al., 2005; Siperstein, et al., 2006). Anderson & Heyne (2012) observed that recreation service providers must use an ecological perspective in their service provision, not only addressing the needs of individuals with disabilities, but their support systems as well.

A third key finding in this study was the identification of elements of both specialized and inclusive recreation programs that parents and children considered to be negative. For example, parents recognized that specialized programs have an exclusive nature and a lack of social norms (Wachter & McGowan, 2002; Stumbo, Wang, & Pegg, 2011). Children sometimes desire to recreate with their parents and other family members or friends who may not have a disability, which is not possible in all specialized

programs due to the methods of their structure (Mactavish & Schleien, 2004; Thompson & Emira, 2011). As Mactavish and Schleien (2004) observed, the family dynamic is frequently where the majority children's recreation occurs. Parents who have children with disabilities perceive recreation as a tool to enhance the quality of family life and prove development of skills and interests (Mactavish & Schleien, 2004). In addition, research suggests that individuals with disabilities enjoy participating in recreation with family members (Zabriskie, Lundegren and Groff, 2005 & Schleien, Miller, Walton, & Pruett, 2014), as parents have several ideas and suggestions about their children's participation in community recreation.

However, reflective of all group participants, parents and other family members do not always desire to be an active part of the program activities. Participants recognized that while caring for a child with an intellectual disability, mental and physical exhaustion takes a toll on their health (Schleien, et al., 2014). It was discussed in the interviews and focus group session that many inclusive programs expect a high level of involvement from the parents of children who wish to participate in activities. Participants felt that this is an unfair expectation of the recreation service provider and could be remedied by the addition of more qualified and well-trained staff to manage and assist in inclusive recreation programs (Schleien, et al., 2014; Scholl, Dieser, & Davison, 2005). Participants indicated that they spend vast amounts of time advocating for their child's educational and medical needs, therefore, they often lack the additional physical and mental energy to also advocate for inclusive community recreation opportunities or be made to actively manage or supervise their child during an inclusive program (Schleien, et al., 2014; Scholl, Glanz, & Davison, 2006; Thompson & Emira, 2011).



Lastly, a key finding in this study was that there are service providers operating facilities that are in need of upgrades or full renovations in order to attract parents and their children with disabilities to inclusive program settings (Anderson & Heyne, 2011; Anderson, et al., 1997; Datillo, 2002; Drum, et al., 2009; Malone, et al., 2012; Mullick, et al., 2013). In addition, many service providers lack the necessary adaptive equipment and staff to successfully facilitate inclusive recreation programs (Datillo, 2002; Mullick, et al., 2013; Schleien et al., 2014; Skulski, 2007). In defense of community parks and recreation agencies and non-profit service providers, and discussed among the participants, it is most often parks and recreation programs that are the first to receive budget cutbacks in tough economic times, particularly those municipal agencies located in rural areas (Schaumleffel & Payne, 2010). In contrast, wealthier urban cities and communities may experience greater support for parks and recreation funding to meet resident demands, increases property values, and promotes development (p. 34). Furthermore, though some state grants often target low-income cities; they fail to equalize gaps in public or municipal funding and application processes often require detailed proposals and matching funds, which places low-income communities at a disadvantage (p. 34). As Lieberman and Stuart (2002) explained, many individuals, including those with disabilities, desire inclusion and access to community recreation programs, yet the barriers faced by individuals with disabilities are often multilayered as opposed to singular.

As indicated in NRPA's 2015 Field Report (NRPA, 2015), although parks and recreation department responsibilities have expanded well beyond traditional park-related functions in recent years, agencies have not seen corresponding increases in budget. The

survey results of both operating and capital budgets have remained largely static across the past four years (p. 21). Total operating expenditures for agencies surveyed stayed flat in 2014 as they have since 2011, regardless of agency size and, more importantly, agency budgets across the board have not returned to 2010 levels (p. 21). Yet, as the laws of supply and demand would have it, recreation departments across the nation have seen no corresponding decrease in the demand for their services, particularly in reference to recreational programming (Anderson & Kress, 2003; Schaumleffel & Payne, 2010; Scholl, Glanz, & Davison, 2006; Shields, Synnot, & Barr, 2012).

The purpose of this study was to understand if participation in specialized recreation programs, which are designed for individuals with disabilities, increases opportunities of participation in inclusive programs, which are designed for both individuals with and without disabilities. As Mayer and Anderson (2014) have examined, specialized programs are segregated and do not consistently lead to inclusion within recreational settings. As more research in the field is needed to determine if participation in specialized recreation programs increases opportunities for participation in inclusive recreation programs, or if specialized recreation unintentionally enables barriers to inclusion, I hope this study adds to that literature and helps recreational programmers and educators better provide inclusive services. This study does help to better understand why individuals with disabilities and their families choose to participate or not participate in inclusive recreation programs.

If the study were replicated in the future, it may be helpful to include the perspective of children and to develop the screening tool by identifying content for each code set. Results in the present phenomenological study has prepared for the tool by

identifying various examples of everyday life situations and problems as a basis for barrier-specific code sets for inclusive recreation participation. It may also be helpful to replicate the study by classifying the children to a specific intellectual disability or age range. If this study were replicated in the future, it may be helpful to include the perspective of children and to develop the screening tool by identifying content for each code set. Results in the present phenomenological study has prepared for the tool by identifying various examples of everyday life situations and problems as a basis for barrier-specific code sets for inclusive recreation participation. It may also be helpful to replicate the study by classifying the children to a specific cognitive disability or age range. Furthermore, a larger sample of parent participants and children would provide better clarity on both specialized and inclusive recreation programming, but also a deeper understanding of how parents, family members and children with cognitive disabilities make the choices in recreation they do. Another recommendation for future implications could be to select research participants that focus on one or more variables pertaining to the parents' social and economic background, which may include gender, age, marital status, occupation, education, income, and geographic or residential location. It is clear that much of the research on the topic of barriers to participation in inclusive recreation programs has been conducted with individuals with disabilities, parents and/or caretakers, and service providers. However, there is also a need for qualitative research to study inclusive recreation programs by focusing on the attitudes and experiences of community members themselves, not just individuals with disabilities, parents, and service providers.

The findings of this study demonstrate that parents of children with intellectual disabilities value specialized programs settings that help individuals with disabilities

build specific skills and engage in fair competition with peers. However, the participants understand the vital importance of inclusion and desire to participate in inclusive programs so that no individual is deprived of the ability to grow and to flourish through participation in leisure. In 1999, the National Recreation and Park Association adopted a Position Statement on Inclusion (NRPA, 1999), the purpose of which was to “encourage all providers of park, recreation, and leisure services to provide opportunities in settings where people of all abilities can recreate and interact together” (p 94). Major federal disability rights legislation has been in effect for several decades now, yet “people with disabilities are still experiencing significant physical and programmatic barriers at recreation facilities and parks, as well as being denied the equal opportunity to participate and benefit comparably to people without disabilities” (Skulski, 2007, p. 1). The findings in this study coincide with research observations during the past two decades, which is that numerous service agencies designed to facilitate inclusive recreation services have been developed. However, despite extensive dissemination of these inclusive practices, they are not commonly practiced in a majority of community recreation agencies, and inclusive recreation services are grossly inadequate (Anderson & Heyne, 2000; Devine & Kotowski, 1999; Devine & McGovern, 2001; Skulski, 2007; Wachter & McGowan, 2002). If the parks and recreation profession is to live up to the standards championed by NRPA (1999), then we must begin to understand what makes inclusion for individuals with disabilities possible and successful.

### **A New Model of Inclusion**

The various findings presented within this phenomenological, qualitative study indicate that eight parents of children with intellectual disabilities who regularly

participate in specialized programs strongly desire to be included in community-based inclusive recreation programs. During the focus group session, which concluded my research directly with the participants, I learned that one of the eight participants has foregone participation in inclusive programs due to negative experiences. Another participant, decided to opt out of inclusive programs for the time being due to personal family matters. This participant noted that he and his child will continue to participate in Special Olympics, however. The challenge lies before us. It is time for agency administrators, community leaders, and all stakeholders to get more involved in the initiative, design, implementation, and evaluation of inclusive recreation programs through which children with disabilities are no longer on the outside looking in, but always included. Expanding Special Olympics into a more inclusive model can help individuals with disabilities and their families participate actively in an inclusive recreational environment.

Former Senior Vice President with Special Olympics and current Senior Advisor to the National Inclusion Project, Stephen B. Corbin (2015) said, “While progress has been made, there is still a long way to go before people with disabilities have equitable access to opportunities for productive lives, vocationally, socially, and culturally. Laws can be passed, but changing minds and hearts is a slower and more gradual process” (p. 45).

Reflective of all participants in this study, there are still too many barriers in inclusive recreation programs, however, each participant still greatly advocates for inclusion. Therefore, what would a new model of inclusive recreation be today? In considering the necessity of inclusion, one can surmise what will happen as Special

Olympics continues to adopt inclusion into their recreational programming. Special Olympics aims to build a society of acceptance and inclusion for individuals with intellectual disabilities, therefore, it appears inclusive programs is indeed a new focus in programming (Special Olympics, 2015). In fact, Special Olympics continue to build successful programs that focus on inclusion. For example, Project Unify is an education-based program that uses the sports and education initiatives of Special Olympics to activate youth to promote school communities where all young people are agents of change, fostering respect, dignity, and advocacy for people with intellectual disabilities (para. 9). The program, created by Special Olympics in partnership with the U.S. Government, is engaging over 1,700,000 youth from more than 3,000 schools in 45 states (para. 11). Project Unify offers participants fully inclusive programs as youth with and without intellectual disabilities play together in programs such as Unified Sports, Unified Sports Competitive, Unified Sports Player Development, and Unified Sports Recreation (para. 14).

Furthermore, a press release in May 2015 announced that Special Olympics, would be convening the first Special Olympics Social Impact Summit focused on creating a truly unified generation, where youth participated together to fight inactivity, intolerance and injustice (Lee, 2015). Special Olympics (2015) explained, “The GenUIn Social Impact Summit is designed to generate critical change around the pressing issues facing people with intellectual disabilities” (para. 2). This six-day summit was held from July 2015 during the Special Olympics World Games in Los Angeles, California and included 120 young leaders aged 16-25 years old, with and without intellectual disabilities, from various parts of the world, who challenged each other to foster inclusion

in their respective communities (Lee, 2015, para. 7). The convening of this summit followed the historic announcement that Special Olympics made in July 2014 when President Barack Obama hosted a dinner for Special Olympics at the White House (Special Olympics, 2015, para. 13). The announcement at the event described the creation of the first-ever Generation Unified and the work that Special Olympics has been doing “to activate young people to fight inactivity, intolerance and injustice in their schools and communities” (Special Olympics, 2015, para 13).

Another example of Special Olympics offering inclusive recreational programs while still maintaining their traditional specialized programs is their commitment to the National Intramural Recreational Sports Association (NIRSA), their partner in aligning efforts to increase inclusive sports opportunities for individuals of all abilities (Special Olympics, 2015, para 11). Beginning in 2016, NIRSA and Special Olympics will work to expand Special Olympics Unified Sports inclusive programs at participating NIRSA member colleges and universities throughout the U.S. as both organizations share missions, visions and cultures dedicated to the enhancement of inclusion, community, and health for all through participation (para. 13). Unified Sports is an inclusive program within Special Olympics that brings individuals with and without intellectual disabilities, of all ages, together as teammates, building friendships and understanding (para. 12). As stated in a press release by Special Olympics,

Through this alignment, Special Olympics and NIRSA aim to bring Unified Sports to more U.S. college campuses; to offer students and participants a platform to learn the values of inclusion through experiential sports; to provide meaningful student-learning opportunities for college students and encourage

them to become leaders within Special Olympics; and to provide Special Olympics athletes a forum to experience the physical and social benefits gained through ongoing interaction with peers (Special Olympics, 2015, para. 4).

Special Olympics appear to be making great strides in adopting a more concise model of inclusion into their traditionally segregated programming. I imagine this new model of inclusion will be the topic of much future research, including doctoral dissertations. In closure, it is my hope that the findings from this study will optimistically provide recreation programmers and educators with understandings that could have a direct impact on the phenomenon of participation in specialized and inclusive recreation programming. Finally, I hope this study can help those with intellectual disabilities and their families inspire, contribute, and enrich the lives of the people in their communities through of inclusion.



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