# LEISURE PARTICIPATION AND PERCEIVED CONSTRAINTS OF PARENTS AND CAREGIVERS OF CHILDREN WITH DISABILITIES

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# ABSTRACT

The purpose of this study is to help gain a better understanding of the perceived leisure constraints of parents/caregivers of a child with disabilities and when given the opportunity for respite from parenting roles, how they use their leisure time. A total of 39 parents/caregivers completed the electronic questionnaire with the majority of respondents being female parents. Five main themes were identified in result of the common response patterns embedded throughout the parents/caregivers questionnaire responses, which were: (a) leisure activities, (b) time, (c) extra planning, adaptations, and modifications, (d) resources, and (e) attitude. Findings identified the perceived barriers to leisure of parents/caregivers of a child with disabilities and types of negotiation strategies used in order to participate in chosen leisure activities. During a time of respite, the majority of the parents/caregivers took advantage of more passive leisure activities such as relaxing, recharging their batteries, reflecting, and reconnecting with significant other and friends. This study supports the need for more respite opportunities for parents/caregivers and families of a child with disabilities as well as provides practical implications to expand the field of therapeutic recreation.

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# CHAPTER I
# INTRODUCTION

Leisure is a multidimensional, dynamic concept that, in the simplest terms, is defined as free time (Gunter & Gunter, 1980; Lee, Dattilo, & Howard, 1994; Russell, 2009). Leisure is experienced differently for everyone and is heavily dependent on the people, place, and time (Russell, 2009). Leisure is described in terms of passing time, exercising choice, escaping pressure, and achieving fulfillment (Watkins & Bond, 2007). This optimal, unique experience is best characterized by the components of perceived freedom, self-expression, intrinsic motivation, free time, and forms of positive affect including enjoyment, fun, and relaxation (Schulz & Watkins, 2007). According to leisure scholars Kernan and Domzal (2000), our modern "day-to-day lives have been reduced to sedentary, boring routines, largely devoid of excitement, challenge, and personal growth" (p.79). The neglect of leisurely pursuits is largely related to perceived constraints we experience daily.

A leisure constraint is an obstacle to leisure participation (Jackson, Crawford, & Godbey, 1993), which is also referred to as a barrier. Researchers Crawford and Godbey (1987) developed a constraints model in order to better understand and conceptualize the construct of constraints in the leisure preference-participation relationship. This model is divided into three distinct categories: intrapersonal, interpersonal, and structural. Instead of constraints completely seizing and putting an end to leisure participation, Crawford, Jackson, and Godbey (1991) purposed that people negotiate through perceived constraints in order to maintain or modify leisure participation. Crawford et al. (1991) expanded and combined the original constraints model into a single sequential, hierarchical model in which people actively respond to constraints

by negotiation. The different types of constraints are closely and highly interrelated, but can be successfully negotiated through rather than the outcome of constraints being nonparticipation.

The obligation of being a parent adds to the perceived constraints an individual may encounter regarding leisure participation. In a dual-earner family, in which both the father and mother work, both parents must negotiate and divide the responsibilities of working the "second shift" (Bakker & Karsten, 2013; Hochschild, 1989) when coming home from work. Time available for personal leisure opportunities may seem nonexistent or will change since a parent's schedule and time completely revolve around his/her children and family (Wayne & Krishnagiri, 2005). Being a parent is a job within itself, but being a parent of a child with disabilities introduces a variety of new, different challenges and certain adaptations that revolve around his/her child with disabilities. There is even more organizing, coordinating, and planning schedules required to meet the demands of a child with disabilities (Mactavish & Schleien, 2004; Wayne & Krishnagiri, 2005), which include finding the appropriate doctors and if needed, a trustworthy, skilled caregiver.

Parents are not the only ones whose leisure time suffers, but the situation is extremely similar for caregivers of children with disabilities. Stress, strain, and negative responses to caregiving are well recognized as issues, which can alter a caregiver's lifestyle (as cited in Dunn & Strain, 2001). There are many factors and reasons involved in a parent/caregiver changing, reducing, negotiating, or giving up leisure activities and interests such as not enough time or other obligations. In order to accommodate, cope, and demonstrate adequate adjustment to daily stressors and the various challenges in parents/caregivers lives, there are a variety of coping strategies that may be used (Leyser, Heinze, & Kapperman, 1996; Wayne & Krishnagiri, 2005).

One of the coping strategies that may be used is to take time off. In other words, seek a respite opportunity (Leyser et al., 1996). One respite opportunity that is offered to parents/caregivers of children with disabilities in East Tennessee is an outdoor education program called Camp Koinonia ("About the camp koinonia", n.d.). Not only do the parents/caregivers achieve respite, but their children with disabilities also benefit from the program.

There is a broad scope of existing research done on family recreation, benefits of leisure for children with disabilities, balancing work and raising a child with disabilities, and contributions of family leisure to family functioning. However, there is limited research regarding the leisure time of parents and caregivers of children with disabilities.

## Purpose

The purpose of this study is to help gain a better understanding of the perceived leisure constraints of parents/caregivers of a child with disabilities and when given the opportunity for respite from parenting roles, how they use their leisure time. Through the lens of the constraints model framework (Crawford & Godbey 1987; Crawford et al., 1991), the perceptions of barriers to leisure of parents/caregivers of a child with disabilities will be examined in connection with leisure participation during a time of respite. This study will identify parents/caregivers perceived constraints (intrapersonal, interpersonal, and structural). Also, parent/caregiver leisure participation will be compared when they are responsible for providing care to their child versus their time during a respite opportunity.

## Problem Statement

Research has addressed family recreation (Mactavish & Schleien, 2004), benefits of leisure for children with disabilities, balancing work and raising a child with disabilities

(Brandon, 2007), and contributions of family leisure to family functioning (Dodd, Zabriskie, & Widmer, 2009), but there is limited research regarding the leisure time of parents/caregivers of children with disabilities and the constraints parents/caregivers perceive to leisure participation. It is assumed that once having to care for children, parents' and caregivers' personal time and leisure activities are often forfeited and/or reduced in order to care for their children and family (Brandon, 2007). Leisure time may not be completely nonexistent, but may be modified in a way that fits already existing family and spouse schedules.

## Significance of study

This study is significant due to the limited amount of research specifically examining leisure participation of parents/caregivers of a child with disabilities when given a respite opportunity. To begin with, the results from this study will identify the perceived leisure constraints experienced by parents/caregivers. With the described results, parents/caregivers can recognize their perceived constraints and start to formulate solutions to decrease or negotiate through their perceived constraints in order to participate in their leisure interests.

From a programming standpoint, organizations, such as community recreation programs, schools, therapeutic fields, and practitioner offices may gain awareness for the need to develop and create more respite opportunities for parents/caregivers to help decrease parents/caregivers perceived leisure constraints. Since respite is considered a type of coping strategy, organizations can provide families with educational opportunities and resources about different positive, adaptable coping strategies that best fit the family's needs. Including the family unit, creating the awareness of developing inclusive programs based on the needs and interests of the whole family would also be beneficial and appealing for a respite opportunity, as well as, creating

chances to strength and enhance high family functioning. In sum, this study will reveal the perceived constraints of parents/caregivers and bring awareness to the need of intervention programs aimed at reducing and alleviating the perceived constraints.

Another significance of this study is the composed and formed body of literature that has been compiled from multiple research studies. Not only does this study grasp concepts, themes, models, and theories from other researchers, it combines and ties all relevant information into one body of work that all highly relates to each other.

## Limitations

Although every effort was made to be thorough, there were certain limitations to the current study. To begin with, the questionnaire was distributed electronically. Parents/caregivers may have disregarded the questionnaire due to thinking it is junk mail, which could have yielded a low response rate. Adding to this, once the questionnaire was distributed through email, there was no way of knowing that the participants actually received the email. Another limitation was the broad population of the parents/caregivers. Results may have been scattered due to the wide range of children with a multitude of various disabilities rather than focusing on one specific disability population.

## Delimitations

The study focused on the perceived leisure constraints of parents/caregivers of a child with disabilities. The sample population was delimited specifically to parents/caregivers of children with disabilities who attended Camp Koinonia 2014 in East Tennessee. All parents who have an active email address provided were invited to participate in the study.

## DEFINITIONS

**Barrier:** any factor that intervenes between the preference for an activity and one's participation (Crawford & Godbey, 1987)

**Caregiver:** a family member or a paid helped who regularly looks after child or a sick, elderly, or disabled person ("Caregiver", n.d.)

**Constraint:** something that limits or restricts someone's actions or behavior ("Constraint", n.d.)

**Disability:** a physical or mental condition that limits a person's movement, sense, or activities (examples such as autism, cerebral palsy, intellectual disabilities) ("Disability", n.d.)

**Leisure:** free time; free from obligations; recreational activities that are non-work experiences (Russell, 2009)

**Leisure Constraint:** an obstacle to leisure participation (Jackson et al., 1993)

**Respite:** a short period of reset or relief from something difficult or unpleasant; a break ("Respite", n.d.)

**Second-shift:** working a job during the day then coming home to do domestic household work and chores which include taking care of the children, cleaning the house, preparing and cooking meals, etc. (Hochschild, 1989)

# CHAPTER II
# LITERATURE REVIEW

## Leisure

The term "leisure" is a complex concept that consists of multidimensional and different meanings depending on the people, place, and time (Gunter & Gunter, 1980; Russell, 2009). In Russell's (2009) textbook of compiled works, she further identified contemporary themes in leisure's meanings that include and combine leisure as free time in which people are free from obligations, recreational activities that are non-work experiences, and attitude as a self-actualized perspective. Free time involving leisure consists of two concepts: freedom "from" and freedom "to". Freedom "from" involves escaping from the necessities of life. In other words, leisure is a natural escape from every day obligations. Freedom "to" means leisure provides freedom to make the most of possibilities and have the freedom to choose to participate in leisure pastimes. Leisure as a recreational activity is an experience or participation in an activity that is personally rewarding or of great benefit to someone. Lastly, attitude is a main factor when understanding leisure. A person's leisure experience is something unique and different for each person. This results in having a special attitude and state of mind, which fosters a rewarding, optimistic leisure experience as well as producing meaningfulness in life, self-expression, and self-actualization. (Russell, 2009)

There are a combination of approaches and definitions to demonstrate the concept of leisure. Two of the earliest leisure researchers, Donald and Havighurst (1959), defined the meaning of leisure as the satisfaction individuals gain from their favorite leisure activities. The meanings of leisure derived from their research include pleasure, change from work, new experience, contact with friends, achieving something, and passing time (Donald & Havighurst,

1959; Schulz & Watkins, 2007). Similarly, Watkins and Bond (2007) researched leisure experiences which resulted in four qualitatively different leisure experiences labeled as passing time, exercising choice, escaping pressure, and achieving fulfillment. Expanding on these, passing time regarding leisure was related to time that was leftover from other important life aspects (such as work, school, sports), occurred in short blocks of time in between higher priorities, is not planned, is sedentary, non-strenuous, non-serious, and/or an activity done to avoid boredom. Exercising choice is focused on personal choice, doing what one wants to do, expressing control and autonomy, pursuits that are passive and active, and activities that are often highly social. Leisure as escaping pressure is described as getting away, relaxing, and rejuvenating oneself. It is focused on restoring well-being, passive and solitary activities, and experienced through mental relaxation and feeling pleasure. Lastly, leisure as achieving fulfillment involves feeling happy and content with oneself. It also involves affirming one's personal identity, something that is pleasurable, mentally and spiritually relaxing, provides choice, satisfaction, mastery, and self-worth.

Continuing to add to the understandings of leisure, researcher Iso-Ahola (1979) discovered key determinants in the definition of leisure, which include perceived freedom, intrinsic motivation, and low work orientation. Shaw (1984) identified dimensions of freedom of choice, intrinsic motivation, enjoyment, relaxation, and lack of self or other evaluation that are all strongly associated with the experience of leisure. One of the major theories related to the study of leisure is flow theory, developed by Csikzentmihalyi (2000) and his colleagues (Csikszentmihalyi, Abuhamdeh, & Nakamura, 2005). The use of the word flow is used to describe a state of being in which you become so involved in some activity or experience that

nothing else seems to matter. Csikzentmihalyi (2000) discovered that flow is an optimal experience and subjective state people experience and feel during an intense engagement in an activity. This optimal flow experience is characterized by loss of self-consciousness, a merging of action and awareness, a sense of being in control, and an altered sense of time. Adding to the characteristics of flow, there are also specific conditions that are important to enable this sense of flow, such as, having a clear set of goals, autotelic (intrinsically motivating), and achieving a balance between perceived challenges and perceived skills. When reaching this state of flow, one is participating in leisure at an optimal level. Other phrases used to describe the flow theory consist of "being in the zone" or reaching your absolute peak experience. (Csikszentmihalyi, 2000; Csikszentmihalyi et al., 2005)

Among the collective results and extensive knowledge regarding leisure, it can be concluded that leisure is characterized by components such as perceived freedom, self-expression, intrinsic motivation, free time, and forms of positive affect including enjoyment, fun, and relaxation (Schulz & Watkins, 2007).

## Constraints Models

In order to experience leisure, one must actually participate in his/her chosen leisure pastime. Leisure participation has a direct relationship with leisure constraints and barriers that can affect one's level of leisure participation (Crawford & Godbey, 1987; Kay & Jackson, 1991). A constraint is something that limits or restricts someone's actions or behavior ("Constraint", n.d.). More specifically, a leisure constraint is considered as an obstacle to leisure participation (Jackson et al., 1993), which is also referred to as a barrier. Crawford and Godbey (1987) define a "barrier" as any factor that intervenes between the preference for an activity and one's

participation. Lewin (1951) further defines the term "leisure barrier" as a social-psychological matter to denote internal (intrapersonal) psychological states, attributes, and characteristics, and external (interpersonal and situational) circumstances which are experienced as individual behavioral restraining forces (as cited in Crawford & Godbey, 1987). Of the scholarly research done on leisure, a conceptual framework and model was created in order to better understand the construct of barriers in the leisure preference-participation relationship. Crawford and Godbey's (1987) constraints model is divided into three distinct categories: intrapersonal, interpersonal, and structural.

Intrapersonal barriers involve individual psychological states and attributes, which interact with leisure preferences rather than intervening between preferences and participation (Crawford & Godbey, 1987). They tend to be relatively unstable, changeable, and modified over time (Crawford & Godbey, 1987). These barriers are highly related to an individual's attitude, mood, feelings, and motivations. Interpersonal barriers are the result of interaction of the relationship between individuals' characteristics (Crawford & Godbey, 1987), in other words, relationships with others. Barriers in this category are related to the parent-child relationships within the family system, the spousal relationship, and relationships outside of the family system, such as, friendships. Structural barriers represent constraints as intervening factors between leisure preference and participation. Examples of structural barriers include the family life-cycle stage, family financial resources, season, climate, the scheduling of work time, and the availability of opportunity and knowledge of such availability. (Crawford & Godey,1987). Regardless of how barriers are categorized, barriers are influences upon, not determinants, of

leisure behavior. It is the relative strength of barriers along with the leisure preference which will most likely predict leisure behavior (Crawford & Godbey, 1987).

Crawford, Jackson, and Godbey (1991) proposed that instead of reacting passively to constraints on leisure by not participating, people negotiate through them, thus succeeding in initiating or continuing leisure participation (Jackson et al., 1993). Crawford et al. (1991) believed the three distinct categories of constraints (intrapersonal, interpersonal, and structural) are all interrelated and connected which led to the creation of a single model of constraints that interact within a sequential hierarchy. In this model, the three types of constraints are arranged in a hierarchy of importance in which people move through the sequence of constraints to achieve participation (Crawford et al., 1991; Jackson et al., 1993). The hierarchy begins with intrapersonal constraints, then interpersonal, and lastly, structural. Depending on the individual and the leisure activity, one may need to negotiate through the hierarchy of constraints in order to achieve participation. Instead of constraints preventing leisure participation, the developed proposition is that participation is dependent not on the absence of constraints, but on the negotiation through them. This negotiation may modify rather than foreclose participation (Jackson et al., 1993).

As previously mentioned, the new assumption regarding leisure constraints is that people are actively responding to constraints by negotiation rather than passively responding by nonparticipation. Researchers have identified strategies and resources used by people to negotiate constraints. For instance, Scott (1991) identified that individuals adapt or alleviate constraints by altering schedules due to time commitments. Kay and Jackson (1991) researched the variations of constraints experienced and reported by their participants. The two most

frequently mentioned leisure-related problems were financial and time constraints. When dealing with or negotiating through the financial constraints, participants reported that they reduced their participation, saved money in order to participate, tried to find the cheapest opportunity, made other economies, or did not participate at all (Jackson et al., 1993; Kay & Jackson, 1991). With regard to time constraints, participants reported that they cut down on their leisure in various ways, reduced the time they spent on household tasks, or reduced their work time (Jackson et al., 1993; Kay & Jackson, 1991). Findings from these two studies resulted in the emergence of three key points in the negotiation proposition. First, people do in fact negotiate constraints in a variety of ways. Depending partly on the problem encountered, strategies include efforts to enhance the awareness of opportunities, acquisition of skills, alterations in the timing or frequency of leisure participation (including delayed or reduced participation), or modification to other aspects of life to accommodate leisure needs. Secondly, the effect of constraints is not necessarily nonparticipation. Lastly, participation from negotiation is likely to be different from participation that might have occurred in the absence of constraints, such as the scheduling of engagement may be altered, the level of specialization may change, and participation may occur less frequently. (Jackson et al., 1993)

Again, reflecting on Kay and Jackson's (1991) research, three groups/categories of people emerged in relation to the three negotiation propositions that have been developed. The first group is categorized as a reactive response, which consists of people who do not participate in their desired activity. The second group is categorized as a successful proactive response in which people, despite experiencing a constraint, do not reduce or otherwise change their

participation at all. The third group is categorized as a partly successful proactive response due to people participating, but in an altered manner. (Jackson et al., 1993)

The ability to adapt, alleviate or eradicate constraints deals with the knowledge and potential to adopt various forms of negotiation strategies (Jackson et al., 1993). Rather than nonparticipation, the negotiable nature of leisure constraints will result in modified participation instead of completely ending and ceasing participation. The different types of constraints are highly interrelated, but can be negotiated through rather than resulting in nonparticipation, depending on a person's motivation regarding choice of action.

Since the early foundational findings of constraints negotiation research, more recent research has made advances in theory and method by placing negotiation in a broader context of leisure behavior and by exploring relations between constraints and other concepts (White, 2008). There is evidence that the motivation to participate may be an important element of the leisure constraint negotiation process (Hubbard & Mannell, 2001). Motivation theory attempts to provide answers as to why people participate in leisure activities by identifying the various motives and satisfactions that compel them to seek out specific leisure activities and experiences (Hubbard & Mannell, 2001). Reflecting back on the foundational leisure constraints framework, (Crawford et al., 1991; Jackson et al., 1993), a balance proposition was introduced in which notions the outcome of a response to leisure constraints may be viewed as a function of the interaction, or balance between constraints and motivations. The balance proposition directly states: "Both the initiation and outcome of the negotiation process are dependent on the relative strength of, and interactions between, constraints on participating in an activity and motivations for such participation" (Jackson et al., 1993, p.9). In other words, a factor of motivation is

brought into the negotiation process of the leisure constraints framework reiterating that leisure participation is the product of a balance between constraints and motivations (Jackson et al., 1993).

Hubbard and Mannell's (2001) research described and examined four competing models and their interrelationships among constraint, negotiation, and motivation in relation to participation in a recreation setting. The four models included the independence model, the negotiation buffer model, the constraint-effects-mitigation model, and the perceived-constraint-reduction model. Of the four models, the constraint-effects-mitigation model illustrated the strongest connection among constraints, negotiation, and motivation. Results concluded that encountering constraints appeared to directly trigger negotiation efforts that can mitigate the negative effects of constraints, with motivation being an important factor in such that "people who are highly motivated to participate expend greater effort of negotiating and are more successful at starting, maintaining, or increasing their level of participation" (Hubbard & Mannell, 2001, p.158-159). With regards to their study, motivation to participate had its greatest effect on the level of participation indirectly by encouraging greater use of negotiation resources and strategies (Hubbard & Mannell, 2001). In sum, one's motivation effect on participation is mediated by their ability to negotiate through constraints (Hubbard & Mannell, 2001; White, 2008).

Loucks-Atkinson and Mannell (2007) further extended this research by drawing on social cognitive theory and incorporating a negotiation-efficacy construct. In their study, the concept of negotiation-efficacy, "defined as a people's confidence in their ability to successfully use negotitation strategies to overcome constraints," was measured and examined (Loucks-Atkinson

& Mannell, 2007, p. 20). Hubbard and Mannell's (2001) constraint-effects mitigation model was modified to include the negotiation-efficacy construct in order to test competing models of the leisure constraints neogitation process by examining the relations among constraints, motivation, negotiation, negotiation-efficacy, and participation (Loucks-Atkinson & Manell, 2007). Their findings were consistent with the concept that constraints decreased participation, but also triggered the use of negotiation strategies that in turn increased participation. Ultimately, a constraints negotiation theory proposition was proposed in relation to negotiation-efficacy: "The greater people's confidence in the successful use of negotiation resources to cope with constraints, the greater the motivation and effort to negotiate and the higher level of participation" (Loucks-Atkinson & Manell, 2007, p. 19).

Son, Mowen, and Kerstetter (2008) extended Hubbard and Mannell's (2001) modeling of the constraint negotiation process by creating the motivation-balance model. Again, their findings support the notion that motivation plays a vital role in the development and use of strategies to overcome constraints to participation. Adding to this, motivation positively influences negotiation strategies, which in turn, positively influences participation.

White (2008) further evolves and contributes to the leisure constraints negotiation research by examining the interaction of motivation, constraints, negotiation, negotiation-efficacy, and their effects on outdoor recreation participation. The results were consistent with previous research on the expanding and evolving conceptual model by further suggesting that the constraints negotiation process is a dynamic interaction of influences promoting outdoor recreation participation.

## Obligation of being a Parent

Adding to the knowledge of the leisure constraints models, the obligation of being a parent adds to the perceived constraints an individual may encounter regarding leisure participation. Being a parent of children is a job within itself. Reflecting on traditional gender roles, working mothers will work during the day then come home to work the "second shift" (Hochschild, 1989). Hochschild's term "second shift" consists of doing domestic household work and chores which include taking care of the children, cleaning the house, preparing and cooking meals etc. Due to an increase of women in the work force, society has begun placing fathers in this second shift category. Society is moving away from the traditional, nuclear family, in which the father works full-time and is the primary wage earner to a dual-earner family, in which both the father and mother work (Bakker & Karsten, 2013). Working fathers and mothers sometimes find it difficult to achieve the balance of work and family responsibilities (Bakker & Karsten, 2013; Brandon, 2007). Once a person enters into the world of parenthood, his/her child's needs come first before addressing his/her own. A parent's schedule and time completely revolve around his/her children and family. Balancing care, work, and leisure becomes a constant, ongoing obligation due to trying to keep everyone's schedules and commitments organized, interconnected, and overlapping (Bakker & Karsten, 2013). During the parenting years, an adult's leisure participation may reflect more passive choices, such as reading, walking, watching TV or movies, spending time with the children, and listening to music since these activities fit more easily into the daily lives and routines of parents (Wayne & Krishnagiri, 2005). The passive leisure activities do not require additional expenditures of energy, can be engaged in for short periods of time, do not require much planning, and can be

interrupted without impacting others (Wayne & Krishnagiri, 2005). For parents, leisure opportunities may not completely come to an end, but the time available for leisure opportunities will change (Wayne & Krishnagiri, 2005).

## Obligation of being a Parent of a Child with Disabilities

Raising a child has its challenges, but raising a child with disabilities introduces a variety of new, different challenges, and adaptable changes. A child with disabilities has different needs and requires attention compared to a child without disabilities (Brandon, 2007). Parents, especially working parents, spend a vast amount of their time organizing, coordinating, and planning their schedules to meet the demands of their child with disabilities (Mactavish & Schleien, 2004; Wayne & Krishnagiri, 2005) such as doctor and/or therapy appointments, and providing direct care for their child (Brandon, 2007; Wayne & Krishnagiri, 2005). Working parents of a child with disabilities have difficulty finding an appropriate caregiver they truly trust and someone who has adequate skills and training necessary to provide for and tend to their child (Brandon, 2007; Wayne & Krishnagiri, 2005). Adding to this, pay for special services is usually a higher demand that must be met. Raising a child, more specifically, a child with disabilities restricts and limits a parent's leisure time and engagement in personal leisure activities. Wayne & Krishnagiri (2005) research identified factors that affect the leisure occupations of parents raising a child with Down syndrome. Their research indicated that raising a child with disabilities impacted leisure in ways similar to raising a typically developing child such as less time for leisure, changes in types of leisure, increased planning and scheduling required, and changes in social relationships. Even though the factors are similar, the degree of impact was much greater due to raising a child with disabilities (Wayne & Krishnagiri, 2005). For example,

work, exhaustion, lack of energy, and commitments to work were the most commonly reported leisure barriers. Additionally, limitations in the types and duration of leisure choices are highly affected. In conclusion, raising a child with disabilities has more challenges and the impact of leisure barriers is greater than raising a typically developing child.

## Family Structure

Considering the structure of a family with a child with a disability, the parents are not the only ones affected and impacted in regards to leisure. According to the family systems theory perspective, a family unit is defined by three elements: family structure, family interactions, and family functions (Turnbull & Turnbull, 2001). Family structure refers to the number of individuals in and the nature of the family unit. For example, the family can be a two-parent or single-parent household. Family interaction denotes the complex and dynamic social exchanges and relationships between various family subsystems (marital, parental, sibling, and extended family). Lastly, family function characterizes the tasks or activities that families undertake to meet and/or support the individual and collective needs of their members (Mactavish & Schleien, 2004; Turnbull & Turnbull, 2001).

Along the same lines of family structure, the Core and Balance Model of Family Leisure Functioning was developed to further describe family leisure patterns and family functioning. The Core and Balance Model indicates that there are two basic categories of patterns of family leisure, core and balance, in which families utilize to meet needs for both stability and chance, and ultimately facilitate outcomes of family cohesion and adaptability which are primary components of family functioning (Dodd, Zabriskie, Widmer, Eggett, 2009; Zabriskie & McCormick, 2001; Zabriskie & McCormick, 2003).

Core family leisure patterns include "common, everyday, low-cost, relatively accessible, often home-based activities that many families do frequently" (Zabriskie & McCormick, 2003, p.168). Core activities often require little planning are resources and are quite spontaneous and informal (Zabriskie & McCormick, 2001). Examples of core activities are "watching television and videos together, playing board games, playing together in the yard, shooting baskets together in the driveway, gardening, or playing in the leaves once the pile has been raked together" (Zabriskie & McCormick, 2001, p. 283). These activities are usually considered to be play and "just for fun" but have an effect to which family members feel consoled, rewarded, refreshed, and rejuvenated (Zabriskie & McCormick, 2001).

Balance family leisure patterns are depicted through activities that are generally less common and less frequent than core activities, thus, providing novel experiences (Zabriskie & McCormick, 2001; Zabriskie & McCormick, 2003). These activities usually require greater investment of resources, such as time, effort and money, and are usually not home-based (Zabriskie & McCormick, 2001). Examples of balance activities are "family vacations; most outdoor recreation (camping, fishing, boating); special events; trips to a theme park, a sporting event, or the bowling alley" (Zabriskie & McCormick, 2001, p.284).

The Core and Balance Model suggests that core family leisure patterns address a family's need for familiarity and stability by regularly providing predictable family leisure experiences that foster personal relatedness and feelings of family closeness or cohesion (Zabriskie & McCormick, 2003). On the other hand, balance family leisure patterns address a family's need for novelty and change by providing new experiences that require families to negotiate and adapt to new input, to be challenged, and to develop as a working unit in a leisure context (Zabriskie &

McCormick, 2003). Families who regularly participate in both core and balance types of family leisure activities report higher levels of family functioning (Dodd et al., 2009).

Diving into the research of family structure, leisure patterns, and family functioning, Mactavish and colleagues (Mactavish & Schleien, 2004; Mactavish, Schleien, & Tabourne, 1997) focused their research on patterns of family recreation in families that include children with disabilities as well as parent perspectives on recreation. Overall, the findings demonstrate that family recreation was a positive means for promoting overall quality of family life and for helping children develop life-long skills. Family recreation was most commonly conducted in a subunit pattern, which predominately involved mothers interacting with their children with a disability and/or all of their children. In order to make family recreation happen, parents must balance work and play, find common ground amongst everyone in the family about what activity to do, and compensate for limited opportunities. Parents did admit that they tended to spend more recreational time with their child with disabilities due to his/her lack of opportunity compared to his/her siblings that were able to recreate individually on their own, with other friends, or at school. Looking at the constraints of family recreation as a whole with a child with disabilities, the leading constraints were limitations imposed by work responsibilities, lack of time, family commitments and juggling schedules, accommodating differences in age and ability, planning demands, and limitations of information. Even though there is constraints presented in regards to family recreation and may be an additive to family stress, family recreation serves a complex role in family functioning and may also be viewed as a coping strategy for the whole family.

As mentioned, the high physical and emotional demands on families of children with disabilities may limit parental time for other children and have a significant emotional and social impact on such siblings as well (Dodd et al., 2009). Having a child with a disability in the family requires the whole family to develop adaptive skills necessary for healthy family functioning such as learning skills that will help them accept and negotiate through the constraints and challenges they encounter (Dodd et al., 2009). Even though considerable modifications may need to be made for family recreation to happen in order to include everyone, the benefits of recreation for the family as a whole seem to overpower the negative aspects (Mactavish & Schleien, 2004). The benefits are specific to the adults in relation to marriage satisfaction, the children in relation to learning recreation and life skills, and the entire family by making everyone closer, doing something fun together, and improving overall family life and functioning (Mactavish & Schleien, 2004). In addition, Wayne and Krishnagiri (2005) found that the other siblings in a family with a child with disabilities were especially sensitive, compassionate, and able to interact well with other children with special needs. Having a family with a child with disabilities seems to contribute to the other siblings' personal growth by exposing them to appreciative challenges and learning experiences (Wayne & Krishnagiri, 2005). In sum, according to the family systems theory, family cohesion and family adaptability are primary components of family functioning (Dodd et al., 2009), which can be enhanced with family recreation, utilizing core and balance family leisure patterns.

## Caregivers

As mentioned, parents of a child with disabilities have difficulty finding an appropriate, trustworthy caregiver, as well as, paying for personal, higher demand services for their child. A

caregiver is simply defined as "a family member or paid helper who regularly looks after a child or a sick, elderly, or disabled person" ("Caregiver", n.d.). Similar to parents, caregivers adjust, change, organize, and adapt their schedules based on their role as a caregiver. Stress, strain, and negative responses to caregiving are well recognized as issues, which can alter a caregiver's lifestyle (as cited in Dunn & Strain, 2001). Dunn and Strain (2001) identified several reasons to why caregivers reduced or give up leisure activities; these reasons include: lack of equipment and/or supplies, lack of information, lack of financial resources, lack of others with whom to participate, weather restrictions, physical health, being too tired, lack of time due to caregiving, lack of time due to work outside the home, family commitments, too much stress, lack of interest, and lack of freedom. The obligation of being a caregiver is also affected by leisure constraints, which may result in reducing activities, adjusting their schedules, or giving up activities and interests.

## Coping Strategies

Once having to care for children, parents' and caregivers' personal time and leisure activities are often forfeited and/or reduced in order to care for their children and family (Brandon, 2007). Parents, as well as caregivers, need leisure time to do something for themselves. In other words, they need a break from daily obligations, time to recharge their batteries, do something that is personally enjoyable and rewarding, and/or an opportunity to maintain their personal identities (Wayne & Krishnagiri, 2005). In order for parents and caregivers to achieve their leisure desires, they must plan and schedule it into their already busy schedules (Wayne & Krishnagiri, 2005). Living in a productive society, parents tend to neglect

the utilization of leisure by ignoring the value of relaxation, as well as, the concept of recharging out batteries.

Reflecting on the constraints theory in relation to having barriers and neglecting the utilization of leisure, there are many types of coping strategies used to accommodate, cope, and demonstrate adequate adjustment to daily stressors and various challenges in people's lives (Leyser et al., 1996; Wayne & Krishnagiri, 2005). Coping is defined as "constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person" (Lazarus & Folkman, 1984, p. 141). Coping is a way people manage stressful conditions and can describe the process individuals employ to participate in leisure despite constraints (Schneider & Wilhelm Stanis, 2007), similar to the concept of constraint negotiation.

Folkman, Schaffer, and Lazarus (1979) outlined five broad categories of coping resources: health/energy/morale; problem-solving skills; social networks; utilization resources; and general and specific beliefs (as cited in Leyser et al., 1996). Leyser et al. (1996) research further investigated and examined the stressors, needs, and coping strategies of families of children with visual impairments. The findings from this study suggest many families experience major stressors and concerns such as future uncertainties, financial strains, personal doubts about being able to meet the child's needs, concerns about the availability of adequate services, having little time for spouses, the possible disruptive impact of the child on siblings, and worries about the social isolation of the special members. From the data reported in this study, these experiences were not necessarily overwhelming due the families' coping strategies and trying to live as normally as possible. The coping strategies of the families and parents

include: families actively seeking informal support (emotional support and assistance from family members, relatives, and friends) and formal support (professionals such as classroom teachers, physicians, psychologists, and social workers); networks and resources; utilization of active problem-solving approach; supporting their child in being successful in both school and non-school related areas; becoming involved in some leisure and recreational activities; taking some type off (respite) from their daily pressures and hardships; and finding support in their religious beliefs and practices (praying and meditating).

## Camp Koinonia

Of the mentioned coping strategies founded by Leyser et al. (1996) and findings of Dunn and Strain (2001), leisure is identified as a type of coping resource. With leisure being a very dynamic concept, there are many components that make up leisure including relaxation, recharging our batteries, rest, and respite, which are some of the more passive rather than active components. One of the options for a parent of a child with disabilities to achieve the respite component of leisure is to have his/her child with disabilities attend an outdoor education program, such as Camp Koinonia. Camp Koinonia, meaning fellowship and caring community, is an outdoor education program for children ages 7-21 who have multiple disabilities ("About the camp koinonia", n.d.). The program was first developed in 1977 at Virginia Tech as part of university class. One of the primary purposes was to provide a meaningful, experiential learning opportunity for university students while involving children and young adults with disabilities in outdoor activities that they would not be able to do otherwise ("About the camp koinonia", n.d.). The goals of Camp Koinonia are:

1. to provide each camper with an education and fun oriented experience in an outdoor environment;
2. to provide an educational experience for each university student involved in the program;
3. to provide an enriching and rewarding experience that will foster the emotional, social, and physical well-being of each camper;
4. to emphasize appropriate socialization in terms of playing and working together;
5. to emphasize what the camper can do rather than what he/she cannot do;
6. and to provide programs that are within the range of abilities of each camper. ("About the camp koinonia", n.d.)

Not only will parents achieve their week of respite, but their child will also benefit from attending an outdoor education program, such as Camp Koinonia.

# CHAPTER III
# MATERIALS AND METHODS

The current study is composed of a qualitative design utilizing a constant comparative method as the process to breakdown, examine, compare, conceptualize, and categorize the data (Strauss & Corbin, 1990). An electronic questionnaire was created then distributed by email to the selected sample. The sample included parents/caregivers of the children with multiple disabilities who attended Camp Koinonia 2014. The sample was recruited by using the parents/caregivers given email address on the child's application for Camp Koinonia 2014.

## Instrumentation

The instrument that was used in this research was a questionnaire that was distributed electronically to the parents/caregivers email following Camp Koinonia (see Appendix A). The questionnaire was available through the Qualtrics software. The questionnaire contained a total of twelve questions regarding leisure participation and perceived constraints before Camp Koinonia and during the week their child with disabilities was at Camp Koinonia (see Appendix A). The first seven questions were multiple choice and short-answer questions pertaining to the family and child demographics. The last five questions were open-ended questions pertaining to leisure time, barriers, coping strategies, and time while child with disabilities was at camp.

## Data Collection Procedures

After receiving approval from the Institutional Review Board (IRB, see Appendix B), data collected for this study was obtained electronically by the use of a questionnaire to the parents/caregivers via email. Due to issues of confidentiality, emails were sent by someone outside of the research team. Parents/caregivers received an email containing a brief description

of the study as well as the questionnaire link. There was a three-week period in which the electronic questionnaire was open for completion. Within the three weeks, a follow-up email was sent out once a week reminding those who have not participated to please do and thanking those who have responded. After the three weeks, the active questionnaire link was closed. After the parents/caregivers completed the questionnaire, the responses were automatically recorded within the online questionnaire database and downloaded into the qualitative analysis software. Those who do not complete the questionnaire or the questionnaires that were incomplete were not included in the sample.

## Data Analysis Procedures

The questionnaire responses were examined for common themes related to leisure participation and perceived constraints of leisure. To begin with, the two researchers created predetermined codes based on assumptions of what they expected to find when analyzing the data. Once the predetermined codebook was created, the researchers independently used the QDA Miner qualitative analysis software to code the data. After independently coding within QDA, the two researches came together to discuss, collaborate, and compare findings from coding. After sharing results, the researchers added new codes to the existing codebook to further analyze the data one more time. After recoding the data a second time, common themes from the data emerged, which were described in further detail as well as related and compared to already existing research. Once the two researchers were completely done coding the data independently, the two project copies were merged. The combined projects revealed a 96% agreement between the two researchers and a good inter-rater reliability was reported (Krippendorff's Alpha = 0.839).

# CHAPTER IV
# LEISURE PARTICIPATION AND PERCEIVED CONSTRAINTS OF PARENTS AND CAREGIVERS OF CHILDREN WITH DISABILITIES


## Abstract

The purpose of this study is to help gain a better understanding of the perceived leisure constraints of parents/caregivers of a child with disabilities and when given the opportunity for respite from parenting roles, how they use their leisure time. A total of 39 parents/caregivers completed the electronic questionnaire with the majority of respondents being female parents. Five main themes were identified in result of the common response patterns embedded throughout the parents/caregivers questionnaire responses, which were: (a) leisure activities, (b) time, (c) extra planning, adaptations, and modifications, (d) resources, and (e) attitude. Findings identified the perceived barriers to leisure of parents/caregivers of a child with disabilities and types of negotiation strategies used in order to participate in chosen leisure activities. During a time of respite, the majority of the parents/caregivers took advantage of more passive leisure activities such as relaxing, recharging their batteries, reflecting, and reconnecting with significant other and friends. This study supports the need for more respite opportunities for parents/caregivers and families of a child with disabilities as well as provides practical implications to expand the field of therapeutic recreation.


## Introduction

Leisure is a multidimensional, dynamic concept that is experienced differently depending on the people, the place, and time (Russell, 2013). With leisure being such a complex concept, there is a multitude of meanings used to describe leisure. To put it simply, leisure is defined as freely chose activity for its qualities of satisfaction (Kelly, 2012). In other words, the definition

of leisure as free time entails people being free from obligations, recreational activities that are non-work experiences, and attitude as a self-actualized perspective (Russell, 2009). Among the collective results and extensive knowledge regarding leisure, it can be concluded that leisure is characterized by components such as perceived freedom, self-expression, intrinsic motivation, free time, an optimal experience, and forms of positive affect including enjoyment, fun, and relaxation (Csikzentmihalyi, 2000; Schulz & Watkins, 2007; Shaw, 1985).

In order to experience leisure, one must actually participate in his/her chosen leisure pastime. Leisure participation has a direct relationship with leisure constraints and barriers that can affect one's level of leisure participation (Crawford & Godbey, 1987; Kay & Jackson, 1991). Crawford and Godbey (1987) created a constraints model in order to better understand the construct of barriers in the leisure preference-participation relationship. Their original constraints model is divided into three distinct categories: intrapersonal, interpersonal, and structural. Intrapersonal barriers involve individual psychological states and attributes, which interact with leisure preferences rather than intervening between preferences and participation (Crawford & Godbey, 1987). They tend to be relatively unstable, changeable, and modified over time (Crawford & Godbey, 1987). These barriers are highly related to an individual's attitude, mood, feelings, and motivations. Interpersonal barriers are the result of interaction of the relationship between individuals' characteristics (Crawford & Godbey, 1987), in other words, relationships with others. Barriers in this category are related to the parent-child relationships within the family system, the spousal relationship, and relationships outside of the family system, such as, friendships. Structural barriers represent constraints as intervening factors between leisure preference and participation. Examples of structural barriers include the family life-cycle

stage, family financial resources, season, climate, the scheduling of work time, and the availability of opportunity and knowledge of such availability (Crawford & Godey, 1987). The ability to adapt, alleviate or eradicate constraints deals with the knowledge and potential to adopt various forms of negotiation strategies (Jackson et al., 1993). The different types of constraints are highly interrelated, but can be negotiated through rather than resulting in nonparticipation, depending on a person's motivation regarding choice of action.

Researchers Crawford & Godbey (1987) and Jackson et al. (1993) have created a foundation for other researchers to propose and test models based on their original constraints framework as well as create an evolution of thinking and research in regards to perceived barriers and constraints, leisure, and participation. Hubbard and Mannell's (2001) research described and examined four competing models and their interrelationships among constraint, negotiation, and motivation in relation to participation in a recreation setting. Loucks-Atkinson and Mannell (2007) further extended this research by drawing on social cognitive theory and incorporating a negotiation-efficacy construct. Shores, Scott, and Flyod (2007) utilized a multiple hierarchical stratification to investigate how combinations of statuses (gender, age, socio-economic status, race/ethnicity) affected individuals perceived constraints to outdoor recreation. Son, Mowen, and Kerstetter (2008) extended Hubbard and Mannell's (2001) modeling of the constraint negotiation process by creating the motivation-balance model. White (2008) further evolves and contributes to the leisure constraints negotiation research by examining the interaction of motivation, constraints, negotiation, negotiation-efficacy, and their effects on outdoor recreation participation. The research is consistent on the expansion and

evolution of the conceptual model by suggesting that the constraints negotiation process is a dynamic interaction of influences promoting leisure participation.

The obligation of being a parent adds to the perceived constraints an individual may encounter regarding leisure participation. Once a person enters into the world of parenthood, his/her child's needs come first before addressing his/her own. Balancing care, work, and leisure becomes a constant, ongoing obligation due to trying to keep everyone's schedules and commitments organized, interconnected, and overlapping (Bakker & Karsten, 2013). Being a parent is a job within itself, but being a parent of a child with disabilities introduces a variety of new, different challenges and certain adaptations that revolve around his/her child with disabilities. A child with disabilities has different needs and requires extra attention compared to a child without disabilities (Brandon, 2007). There is even more organizing, coordinating, and planning of schedules required to meet the demands of a child with disabilities (Mactavish & Schleien, 2004; Wayne & Krishnagiri, 2005), which include finding the appropriate doctors, balancing normal parental tasks with treatment programs (Paster, Brandwien, & Walsh, 2009), and if needed, a trustworthy, skilled caregiver.

Parents are not the only ones whose leisure time suffers; the situation is extremely similar for caregivers of children with disabilities. Stress, strain, and negative responses to caregiving are well recognized as issues, which can alter a caregiver's lifestyle (as cited in Dunn & Strain, 2001). Since the obligation of being a caregiver is also affected by leisure constraints, they too may be more required to reduce activities, adjust their schedules, or give up activities and interests.

In order to accommodate, cope, and demonstrate adequate adjustment to daily stressors and the various challenges in parents/caregivers lives, there are a variety of coping strategies that may be used (Kuhaneck, Burroughs, Wright, Lemanczyk, & Darragh, 2010; Leyser, Heinze, & Kapperman, 1996; Rizk, Pizur-Barnekow, & Darragh, 2011; Wayne & Krishnagiri, 2005). Types of coping strategies parents/caregivers of children with disabilities may utilize include: families actively seeking informal support (emotional support and assistance from family members, relatives, and friends) and formal support (professionals such as classroom teachers, physicians, psychologists, and social workers); networks and resources; utilization of active problem-solving approach; supporting their child in being successful in both school and non-school related areas; becoming involved in some leisure and recreational activities; taking some type off (respite) from their daily pressures and hardships; and finding support in their religious beliefs and practices (praying and meditating) (Leyser et al., 1996).

Of the variety of coping strategies mentioned, leisure is an identified coping resource (Caldwell, 2005; Dunn & Strain, 2001; Leyser et al., 1996; Rizk et al., 2011). With leisure being a very dynamic concept, there are several components that define leisure as a coping source which include relaxation, recharging our batteries, rest, and respite, all of which are more passive rather than active components. One of the options for a parent/caregiver of a child with disabilities to achieve the respite component of leisure is to have his/her child with disabilities attend an outdoor education program, such as Camp Koinonia. Camp Koinonia, meaning fellowship and caring community, is an outdoor education program for children ages 7-21 who have multiple disabilities ("About the camp koinonia", n.d.). One of the primary purposes of Camp Koinonia was to provide a meaningful, experiential learning opportunity for university

students while involving children and young adults with disabilities in outdoor activities that they would not be able to do otherwise ("About the camp koinonia", n.d.). Not only will parents achieve their week of respite, but their child will also benefit from attending an outdoor education program, such as Camp Koinonia.

The purpose of this study is to help gain a better understanding of the perceived leisure constraints of parents/caregivers of a child with disabilities and when given the opportunity for respite from parenting roles, how they use their leisure time. Through the lens of the original constraints model framework (Crawford & Godbey 1987; Crawford et al., 1991), the perceptions of barriers to leisure of parents/caregivers of a child with disabilities are examined in connection with leisure participation during a time of respite. This study identifies parents/caregivers perceived constraints (intrapersonal, interpersonal, and structural). Also, parent/caregiver leisure participation is compared to when they are responsible for providing care to their child versus their time during a respite opportunity.

## Methods

The current study employs a qualitative design utilizing a constant comparative method as the process to breakdown, examine, compare, conceptualize, and categorize the data (Strauss & Corbin, 1990). An electronic questionnaire was created then distributed by email to the selected sample. The sample included parents/caregivers of the children with multiple disabilities who attended Camp Koinonia 2014. The sample was recruited by using the parents/caregivers given email address on the child's application for Camp Koinonia 2014.

## Instrumentation

The instrument that was used in this research was a questionnaire that was distributed electronically to the parents/caregivers email following Camp Koinonia (see Appendix A). The questionnaire was available through the Qualtrics software. The questionnaire contained a total of twelve questions regarding leisure participation and perceived constraints before Camp Koinonia and during the week their child with disabilities was at Camp Koinonia (see Appendix A). The first seven questions were multiple choice and short-answer questions pertaining to the family and child demographics. The last five questions were open-ended questions pertaining to leisure time, barriers, coping strategies, and time while child with disabilities was at camp.

## Data Collection Procedures

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### Data Analysis Procedures

The questionnaire responses were examined for common themes related to leisure participation and perceived constraints of leisure. To begin with, the two researchers created predetermined codes based on assumptions of what they expected to find when analyzing the data. Once the predetermined codebook was created, the researchers independently used the QDA Miner qualitative analysis software to code the data. After independently coding within QDA, the two researches came together to discuss, collaborate, and compare findings from coding. After sharing results, the researchers added new codes to the existing codebook to further analyze the data one more time. After recoding the data a second time, common themes from the data emerged, which were described in further detail as well as related and compared to already existing research. Once the two researchers were completely done coding the data independently, the two project copies were merged. The combined projects revealed a 96% agreement between the two researchers and a good inter-rater reliability was reported (Krippendorff's Alpha = 0.839).

## Results

### Demographics of the Sample

A total of 123 email addresses were obtained from the Camp Koinonia campers' applications. Of the 123 email addresses that were emailed the questionnaire, a total of 39 respondents fully completed the questionnaire, approximately a 35% response rate, which is a comparable response rate to other studies that have examined families of a child with disabilities (Kuhaneck et al., 2010; Mactavish et al., 1997; Resch, Mireles, Benz, Grenwelge, Peterson, & Zhang, 2010; Rizk et al., 2011; Wayne & Kristnagiri, 2005). Of the addresses provided, 12 of

the emails were undeliverable. Thirty-eight respondents were female and 1 was male. When answering whether the respondent was a parent or caregiver of a child with disabilities, 38 indicated "parent" while 1 indicated "caregiver". When stating their job occupation, the majority (36%) responded to being a stay-at-home mom or homemaker. Other common responses relating to occupation included: management, administrator, and office-like positions (26%); educator (10%); registered nurse (10%); retired (5%); volunteer (5%); other (8%). In response to family structure makeup, 67% indicated their family structure was comprised of two parents living in the same home, 28% were single parents, 3% were two adult caregivers, and 3% consisted of one parent and one stepparent. The majority of respondents had 1-2 children living in the home, with at least one child having disabilities for which the respondent was responsible for providing care. In order for the child with disabilities to attend Camp Koinonia, the child must have more than one disability. Some of the types of disabilities mentioned included cerebral palsy, Down syndrome, autism, intellectual disability, visual impairments, speech and language disorders, motor difficulties, and attention hyper deficit disorder. More details on the disabilities can be found in Table 1.2 (Appendix C).

**Themes**

When reviewing and analyzing the data from the five open-ended questions from the questionnaire, five main themes were identified in result of the common response patterns embedded throughout the parents/caregivers responses. The five main themes identified were: (a) leisure activities, (b) time, (c) extra planning, adaptations, and modifications, (d) resources, and (e) attitude. The review of data is broken down by each main theme followed by supportive descriptions and quotes.

**Leisure Activities.** Leisure activities is the first theme that became apparent from the identified common patterns throughout the parents/caregivers responses. Of the parents/caregivers who responded, the types of passive leisure activities mentioned were reading, watching television and movies, relaxing, sleeping, being still, and being on the computer. Other parents/caregivers mentioned enjoying creative arts and crafts activities, such as, scrapbooking, photo journaling, beading, quilting, crocheting, playing the piano, and cooking. These activities are considered passive activities due to participation not requiring exerting immense amounts of energy while engaging in these activities, activities that can be done alone, in small bursts of free time, and inside the home.

Unlike passive leisure, active leisure requires more energy and is usually done outside of the home. Of the parents/caregivers who responded, the types of active leisure activities mentioned were running, walking, swimming, biking, and exercising. Other parents/caregivers commented on enjoying activities they are able to do outdoors such as gardening, fishing, camping, and hiking. Since active leisure is typically done outside of the home, additional scheduling and planning may be required in order to fully participate in one of the chosen activities. For example, needing to find someone to watch the children while you leave the home for a given amount of time as well as the possible extra costs needed to participate in a given activity. Other examples of active leisure activities mentioned by the parents/caregivers are shopping, traveling, socializing with friends and family, and volunteering.

**Time.** Time is the second theme that became apparent from the identified common patterns throughout the parents/caregivers responses. In regards to leisure, lack of time to participate in leisure was consistently mentioned throughout the parents/caregivers responses.

90% of the parents/caregivers responded that having a child with disabilities has impacted their leisure time. Due to the more challenging responsibilities of caring for a child with disabilities, leisure time is not always an available option for some parents/caregivers. Respondent 23 commented:

> [Having a child with disabilities has impacted leisure time] completely. Until recently, I couldn't even go to the store with him. I now can take him into Costco and Bi-Lo, but not women's stores or the hair salon, etc. Even working out, which he needs, and so do I, is difficult for us.

Respondent 28 wrote, "For me, having a child with disabilities is a huge challenge when it involves personal leisure time. Everything I do involves my son. I do not take time off for personal leisure activities." Further supporting both of these comments, respondent 24 expressed, "I believe having any child impacts your leisure time. Your child comes first and then if there is any time left, that becomes your leisure time."

Even when parents/caregivers happen to get an opportunity for personal leisure time, they never seem to fully unwind and relax. Respondent 11 supports this statement with his/her response:

> Yes! As a parent, I am always worried about how much time he demands. You never relax as a parent of a child with disabilities. Whether they are home or not, no matter if you are "enjoying" date night, there is a constant buzz in your mind about the wellbeing of your child. Having a child that cannot communicate verbally what is happening in his life makes this exponentially worse.

Common patterns identified in regards to the child with disabilities impacting leisure time include no rest time, zero time for leisure, and not being able to have leisure time alone or without children. Respondent 4 concludes in his/her comment, "There is little leisure time when I am taking care of my son. I am always 'on.' It's just the way it is."

In addition to providing care for a child with disabilities, limitations on time can be due to other parental duties, obligations, and commitments. In response to what things stop participation in leisure activities, respondent 36 commented, "Trying to give time to the other child and work a 'full time' job with demanding client base. Keeping my home in order and picked up, grocery shopping, cooking, laundry, dishwasher, you name it!" According to the parents/caregivers, time as a perceived barrier to leisure results from work responsibilities outside of the home, household chores, and caring for other family members.

*Finding time for leisure.* When caring for a child with disabilities, one of the common coping strategies the parents/caregivers used to help cope with daily challenges of having a child with disabilities was finding time and interests separate from the disability, in other words, finding time for leisure. Respondent 11 stated:

> I regularly do exercise DVD workouts 4-6 days a week. I tend to my garden every day during growing/harvest season. My ex-husband keeps him [child with disabilities] every other weekend so my current husband and I get date night (2 nights) of 'rest'. I also play guitar.

Respondent 22 wrote, "I exercise for an hour while he's at school. This helps me mentally and physically. I enjoy walking and talking with my friends for leisure." Along the lines of leisure, respondents consistently commented on finding, creating, and taking advantage of "me time".

For example, respondent 30 stated, "I try to schedule 30 minutes at night when she is in bed so that I can read, de-stress, and mentally prepare for the upcoming days." Taking advantage of any kind of personal time, whether it is in the mornings when everyone else is asleep (like respondent 14 mentioned) or finding time to take a quick walk, finding time for personal leisure helps the parents/caregivers cope with the daily challenges of having a child with disabilities.

*Time while child with disabilities was at camp*. When parents/caregivers were asked to describe how the things they like to do in their leisure time differed while their child was at camp compared to when their child is at home, responses revolved around having more time to do things, having alone time, less structure and planning, and freedom from the everyday, constant routine. Of all the questions on the questionnaire, the parents/caregivers expressively responded the most on this topic. Respondent 4 commented:

> I was able to freely have leisure when my child was at camp. I didn't have to wait until he fell asleep at night to read a book or watch a movie. In fact, I was able to be out after dark.

Respondent 31 wrote:

> Simply the freedom to get up and go to work without the struggle of getting him on the bus every morning was a blessing. What I loved most though was being able to change plans at the last minute without having to contact two or three different people to cover plans, and that there were no childcare costs during that time. Also, just some quiet time to be alone and decompress was wonderful.

During this week of respite, the parents/caregivers were "free from the normal routine of bathing, feeding, dressing, etc. and could do the things [they] enjoy and not feel rushed or guilty"

(respondent 35). The parents/caregivers had more flexible, free time during a respite opportunity rather than sticking to a constant, routine structure. Adding to this notion of freedom of time, several parents/caregivers took advantage of this free time by relaxing and recharging their batteries. Respondent 13 expressed, "I can't say my leisure time was different; the structure of my entire day was different. It allowed more time for relaxation in the evening rather than the routine of dinner, shower, and bedtime." Respondent 24 commented:

> While we love being with our daughter all the time, the reality is, she will live with us forever and her time at camp allows us one time a year to recharge our batteries. Camp is so refreshing and renews our strength!

The freedom of time allows the parents/caregivers to freely go about their day doing what they enjoy, provide them with free time to relax and unwind, and have a break from the constant demands of being a parent/caregiver of a child with disabilities.

Along similar lines to the freedom of time, several parents/caregivers took advantage of their leisure time by spending time with their significant other and reconnecting with one another. Respondent 5 wrote:

> For the very first time since our child was born, my husband and I had time to ourselves. Camp allowed us the time to reconnect and enjoy being together. Camp wasn't just an amazing experience for our child it was wonderful for us as well.

While some parents/caregivers mentioned spending quiet, relaxing time with their significant other during this time of respite, others mentioned going on more dinner dates and outings. For example, respondent 30 stated, "We were able to go different places, not prepare days in advance

and had much more time to be husband and wife as we had more time in each day." Respondent 11 wrote:

> We tend to go out each night to enjoy our time. We visit restaurants we'd not go to with my son because we know he will not enjoy it. We drag out our massage table at home and treat each other to rejuvenate and reconnect. We aren't rushed to be anywhere at all and truthfully that feels wonderful. I don't have to fiddle with cooking dinner or making sure I am cooking something my child likes. Life is just kind of peaceful kind of like when you don't have a schedule as there's no rush for nighttime routine, etc.

Similar to spending time with significant others during a time of respite, the parents/caregivers indicated being able to catch-up on work related tasks. Whether the parents/caregivers stayed at work longer or left for work earlier, there was flexibility surrounding their work schedule, which granted them more time to accomplish work-related tasks. Respondent 13 commented, "I was able to get to work earlier than usual and leave earlier. This left more time in the afternoon and evening with my husband." Likewise, respondent 34 stated:

> I work part time and it is difficult getting my hours in with my child's schedule. I generally work while he is in school. I did spend more time at work that week to help catch up, and my husband and I spent more time together, including several dinners out.

Overall, the parents/caregivers expressed having the free time to catch-up or work that has not been accomplished including household projects and jobs around the house.

Even though the majority of the parents/caregivers responses commented on having more free time to enjoy personal leisure and being able to have a break of the constant, structured daily routine, 21% of the parents/caregivers stated that their leisure time did not significantly differ.

Although one child was away at camp, select parents/caregivers still had to care for the other children in the family and maintain the usual daily structure of the rest of the family. Respondent 15 commented:

> Not much [was] different [while our child with disabilities was at camp]. It just is like a week to regain energy for the parents and because it's during a regular school time, we as a family really don't change our schedules. If it was during a school break, we may do more camping, hiking, and water playing.

Respondent 23 stated, "I really did not do anything differently while my child was at camp. Well, maybe worked longer. I felt lost without her, but I knew she was having a great time." Even though leisure time did not drastically change while the child with disabilities was at camp, the parents/caregivers and other family members did receive a break from their usual structured routine.

**Extra planning, adaptations, and modifications.** The third theme that became apparent from the parents/caregivers responses relates to the modifications and adaptations needed for a child with disabilities, as well as, the additional planning and scheduling required in order to participate in leisure activities. To begin with, the physical abilities of a child with disabilities and the level of constant care provided for a child with disabilities were both identified as perceived barriers to leisure among the parents/caregivers responses. Depending on the severity of the disabilities, there is usually constant 24/7 care needed for a child with disabilities. This continued care makes participation in leisure difficult to achieve due to the "child with disabilities never being able to be left alone or unattended" (respondent 9). Respondent 30 stated:

> There is not much time for leisure. Our son requires lots of monitoring to try to ensure appropriate behaviors are taught and reinforced. There is little downtime with a child with Autism. When he participates in sports or scouts it requires a parent to be there to monitor and teach him. Our son cannot be involved in anything (other than school) without our participation.

Respondent 31 commented:

> [Our daughter] requires special care and attention due to safety issues and medication issues 24 hours a day. We always have to have a plan and backup due to her disabling conditions and always need to be reached in case of emergency.

Reflecting on the physical abilities of the child with disabilities, the more active leisure activities are, the more physically demanding it is for a child with disabilities, usually resulting in nonparticipation in a given activity for parents/caregivers unless the proper adaptations and modifications are made. Respondent 25 stated:

> We try to find activities that she can participate in with us. Four-wheeling and water sports are her favorite and we have worked hard to pay for equipment that will help her be safe in these environments. Modifications often must be made for her. Some activities we are unable to do with her.

Respondent 19 commented:

> Our daughter's pace for walking, hiking, and the utter disdain for biking creates challenges for group activities with the family. Team sports seem to work better, but you have to have individuals who are supportive of inclusion of a person with special needs.

At times, parents/caregivers have to rely on others' support to participate and engage in a chosen leisure activity with their child with disabilities. Similar to respondent 19's comment, respondent 18 stated:

> Participating with typically developing youth is too competitive and the population of special needs youth who are interested and whose parents choose to support participation in extracurricular activities is limited, so a very diverse spectrum of special needs is usually pulled together for team sports which requires special adaptation and the ability to modify the sport for the individual with special needs.

Other than equipment modifications and team adaptations, other considerations mentioned for adapting leisure activities include "taking extra rest breaks, having water available at all times, going at a slower pace."

*Extra planning*. Directly related to the required adaptations and modifications needed to include a child with disabilities in parents/caregivers leisure participation, extra planning and scheduling is also required. Extra planning can encompass scheduling and organizing with and around other people's schedules. For example, respondent 13 wrote, "Her father and I work out time in order for me to engage in activities that cannot include my daughter." Other responses revolved around trying to find appropriate, qualified childcare in order to participate in leisure activities without their child with disabilities, which is rather difficult (discussed further in the next theme). Extra planning also encompasses preplanning before a desired leisure activity. In other words, parents/caregivers cannot simply leave the house without having a set plan. This could be due to "medication schedules, limitations, stamina, etc." (respondent 30). Whether there is extra scheduling and planning around others' schedules to fit in leisure time or additional

adaptations and modifications for the child with disabilities, both instances are identified as perceived barriers and impact leisure time. For parents/caregivers of a child with disabilities, participation in leisure activities do seem to be occurring; however, it is apparent that there are certain adaptations and modifications needed as well as extra planning when the child with disabilities is involved. A final summation commented by respondent 17, "We have to plan a bit more, prepare her a bit more, go a bit more slowly, otherwise, we have continued to try to do the same things we have always enjoyed."

**Resources.** The fourth theme created from the parents/caregivers responses is related to the resources the parents/caregivers utilize when having a child with disabilities. When caring for a child with disabilities, different types of coping strategies are often used to help cope with daily challenges. The vast majority of the parents/caregivers responded on how they utilize different types of support groups. Numerous respondents commented on how they "talk with other parents and friends", "talk to others who understand", "talk to friends with children with disabilities", "engaging other parents", "ask for help from friends and family", etc. Socializing and talking with others was a common, reoccurring answer among all the responses. Another type or source of support the parents/caregivers mentioned is the utilization of networks and professional organizations. Respondent 17 commented, "[I] constantly network with organizations and individuals who share relevant source information." Along the lines of support provided by created programs, respondent 18 commented on coping through active participation in community events:

> We have participated in most events offered by our therapeutic recreation program locally. We treat her as we did our typically developing children, but awareness in the

> community of opportunities to include our daughter is a challenge. By that, I mean people in our area do not routinely embrace providing an outlet for young adults with special needs. I think it has been the job of the therapeutic recreation program director and parents who have to advocate for this population of individuals.

The respondent commented on how she "digressed from the original question", but I think the respondent made an excellent point on how he/she takes advantage of community opportunities provided by the therapeutic recreation program in order to spread awareness about people with disabilities. Programs in relation to coping may become more available or created if others are more aware of the need to have such a type of program resource for parents/caregivers of children with disabilities.

*Lack of resources*. Certain resources are not always readily available or at the parents/caregivers convenience such as childcare and financial resources. Lack of childcare was a perceived barrier to leisure identified by the parents/caregivers. The parents/caregivers are the primary ones providing constant care for their child with disabilities. When wanting time for leisure, finding childcare is a difficult obstacle to overcome. When identifying the things that stop parents/caregivers from participating in leisure activities, responses included "lack of responsible caregivers, "arranging care for a child with disability", and "lack of appropriate childcare." When parents/caregivers choose to participate in leisure alone without their child with disabilities, qualified childcare is difficult to find that will meet the high demands of a child with disabilities. Respondent 18 stated, "It's nearly impossible to find someone who can manage the level of care required for our daughter." Respondent 12 commented:

> It is not an easy task to care for someone with a disability much more one with multiple disabilities like my daughter. I love her very much; therefore, I always want the best care for her. I have to make sure that she is healthy, clean, comfortable, and enjoys her environment. Since, she cannot tell us what she likes and don't like, also since she cannot see what or who is around her, I am always going to be her mouth and her eyes to choose what's best for her.

Further supporting this notion regarding lack of childcare, respondent 21 expressed, "It has impacted it [leisure participation] very much in the fact that finding childcare for one child is not easy, but for three is nearly impossible." Of the given responses, it is apparent that there is a lack of responsible, qualified childcare available for children with disabilities, which negatively impacts leisure participation.

Directly related to the lack of childcare is the limited financial resources to pay a caregiver. When parents/caregivers want to participate in a leisure activity, the cost of a caregiver to watch their child with disabilities is usually too high. Responses simply stated "lack of money" in response to perceived barriers to leisure regarding childcare. Respondent 24 specifically stated, "Often the cost of paying a caregiver exceeds our budget." As mentioned earlier, finding suitable childcare is a challenge for parents/caregivers; however, even when an appropriate provider is found, the cost of care is not budget friendly.

**Attitude.** The fifth and final theme involves the parents/caregivers attitude. When asked about what things stop the parents/caregivers from participating in leisure activities, there was mention of personally feeling guilty, being too tired or lacking energy. Respondent 36 stated, "I feel guilty leaving to be honest. I worry about what happens when I am gone, usually because

something bad does." Other responses specifically expressed "being too tired to participate in leisure activities" (respondent 4) and having "no energy" (respondent 5). When parents/caregivers have an opportunity to participate in leisure activities, they tend to feel guilty when leaving their child with disabilities. On the contrary, parents/caregivers may not even participate in leisure activities because they are too tired or do not have enough energy due to taking care of their child with disabilities.

*Attitude as a coping strategy*. From the responses related to coping strategies, the parents/caregivers seem to utilize and benefit from having a positive attitude to help cope with the daily challenges of having a child with disabilities. Having a good attitude can encompass "having a 'just do it attitude" (respondent 5); "retaining a good sense of humor, working together as a team and knowing that every day holds the possibility of a miracle!" (respondent 17); and "basically just suck it up!" (respondent 29). Making the best of a challenging situation seems to help the parents/caregivers cope with certain challenges they encounter. Other than the parents/caregivers attitude, several parents/caregivers empower and encourage their child with disabilities by assigning him/her small household tasks and keeping their child with disabilities involved with activities outside of the home. For example, respondent 32 commented:

> We are teaching her small household chores, which occupy her energy and attention for periods of time. We teach her things to do on her own, like collecting trash from the wastebaskets, loading/unloading the dishwasher, sweeping, cleaning tubs, scrubbing toilets, etc. She enjoys these tasks and they give her a sense of accomplishment.

Adding to this, respondent 28 wrote, "We try to get her involved as much as possible. Encourage self-care (it takes a lot of encouragement)." In relation to doing things outside of the house, respondent 28 stated:

> We are lucky to have a child who loves the outdoors as we do. I think we have tried to find ways to modify most of our activities that she can be included, which helps. We play a lot and that keeps us from sitting around wishing we could do things. Sure there are things we like to do that we often cannot do, but we find things we can do all together as much as we can.

Not only do the parents/caregivers focus on having and maintaining a positive attitude, they pass it along to their child with disabilities.

## Discussion

The purpose of this study was to help gain a better understanding of the perceived leisure constraints of parents/caregivers of a child with disabilities and how, when given the opportunity for respite from parenting roles, they use their leisure time. This study contributes to the leisure constraints research by utilizing the original constraints model (Crawford & Godbey, 1987) and providing insight on the perceived constraints of parents/caregivers of a child with disabilities. The three types of barriers (intrapersonal, interpersonal, and structural) were all identified among the parents/caregivers responses. The most commonly perceived intrapersonal barrier to leisure was the parents/caregivers attitude. The parents/caregivers expressed not participating in leisure due to feeling guilty, being too tired, or lacking energy. The most commonly perceived interpersonal barrier to leisure was the child with disabilities. The child with disabilities unintentionally affected leisure decisions of the parents/caregivers by physically not being able

to participate in certain leisure activities, usually resulting in nonparticipation from the parents/caregivers. If the parents/caregivers wanted to participate in leisure without their child with disabilities, proper planning and scheduling around other people's schedules for personal leisure time was required. Leading into the third type of perceived barrier, the most commonly perceived structural barrier was time. As mentioned within the parents/caregivers responses, the parents/caregivers expressed having zero time for leisure due to caring for their child with disabilities as well as maintaining other parental responsibilities and obligations. Another structural barrier identified was lack of resources, specifically childcare and the limited financial resources to pay appropriate childcare.

All three types of identified perceived constraints of the parents/caregivers are highly interrelated and connected to one another. Instead of leisure immediately resulting in nonparticipation, types of negotiation strategies were identified among the parents/caregivers. In order to participate in personal leisure, some of the parents/caregivers looked for appropriate childcare, even though rare to find and usually exceeding the family's financial budget. Another example of negotiation is including their child with disabilities in their leisure by making the required adaptations and modifications such as using adaptive equipment, modifying an activity, taking extra rest breaks, or going at a slower pace. The findings support the early literature in regards to identifying perceived constraints and the types of constraints encountered (Crawford & Godbey 1987; Kay & Jackson, 1991). Even though the sample was not directly asked questions in regards to negotiation strategies and their motivation to participate in leisure, the parents/caregivers did utilize types of negotiation strategies to participate in leisure (Crawford et al., 1991; Jackson et al., 1993). The assumption was made that they were motivated to do so in

relation to the following proposition: the greater the motivation to participate in leisure activities, the greater people's efforts to negotiate (Hubbard & Mannell, 2001; Loucks-Atkinson & Mannell, 2007;).

Consistent with the current study findings and previous research (Caldwell, 2005; Dunn & Strain, 2001; Leyser et al., 1996; Rizk et al., 2011), leisure is identified as a type of coping source. The parents/caregivers commented on how they find time and interests separate from the disability, in other words, finding time for leisure to help cope with the daily challenges of having a child with disabilities. When the parents/caregivers were granted a week of respite when their child with disabilities went to Camp Koinonia, the parents/caregivers were able to have more personal free time and were free from the daily structured, routine schedule of caring for their child with disabilities. With more available free time, the parents/caregivers were able to participate in activities they enjoy doing, spend time with their significant other, and had the simple pleasure of relaxing. Instead of participating in high active leisure activities, the majority of the parents/caregivers took advantage of more passive activities such as relaxing, recharging their batteries, reflecting, and reconnecting with significant other and friends. The freedom of time allowed them to have a mental release and break from daily challenges. Findings from the study support the multidimensional meaning of leisure in such that leisure does not always mean actively participating in activities (Schultz & Watkins, 2007; Watkins & Bond, 2007).

Similar to previous findings related to the obligation of being a parent (Bakker & Karsten, 2013; Wayne & Krishnagiri, 2005), some of the parents/caregivers were not able to take full advantage of their respite time due to their ongoing obligation of being a parent for a family structure of more than one child. For example, even though the child with disabilities went to

camp for a week, the weekly school schedule and daily routine still continued for the rest of the family. Even though the daily family routine did not change as much, the family did have more rest time while the child with disabilities was away at camp. Another finding in regards to the obligation of being a parent was that the identified themes in relation to leisure and perceived barriers are probably extremely similar for parents of typically functioning children. For example, lack of time, lack of money, finding childcare, and scheduling personal leisure time in coordination with others' schedules are all different aspects any parent will encounter (Bakker & Karsten, 2013; Wayne & Krishnagiri, 2005). Even though there are similarities between parents of typically functioning children and parents/caregivers of children with disabilities, there are significant differences. One difference is the extra challenges added to the everyday routine. For example, depending on the severity of the disability, a child with a disability or multiple disabilities is much more dependent on a parent/caregiver for completing activities of daily living than a typically functioning child. A parent/caregiver of a child with disabilities whole day is much more structured and has added demands than a parent of a typically functioning child. Another difference between the two types of parents is highly related to the added demands and level of care for a child with disabilities. Unlike parents of typically functioning children, a child with disabilities will most likely depend on the parent/caregiver's care for the rest of his/her life. In reality, typically functioning children will eventually reach an age and maturity level to move out of their parent's house and live on their own; a child with disabilities will always depend on the care and support of a parent/caregiver.

Other than leisure, the parents/caregivers mentioned additional coping strategies and sources they utilized to cope with daily challenges of having a child with disabilities. Our

findings are consistent with previous research about coping strategies and resources (Leyser et al., 1996; Kuhaneck et al., 2010; Tehee, Honan, & Hevey, 2009; Wayne & Krishnagiri, 2005) with specific examples pertaining to "me time", informal and formal support, networks and resources, supporting their child, being involved in leisure and recreational activities, religious support, and relaxation. Since families utilize different types of coping mechanisms to cope with every day challenges, programs and organizations should become aware of the different ways they can provide support for family members of a child disabilities.

*Limitations*. Although every effort was made to be thorough, there were certain limitations to the current study. To begin with, the questionnaire was distributed electronically. Parents/caregivers may have disregarded the questionnaire due to thinking it is junk mail, which could have yielded a low response rate. Adding to this, once the questionnaire was distributed through email, there was no way of knowing that the participants actually received the email. Another limitation was the broad population of the parents/caregivers. Results may have been scattered due to the wide range of children with a multitude of various disabilities rather than focusing on one specific disability population; however, the study generated a general idea and insight of what these families of children with multiple disabilities are doing in regards to leisure and coping. Lastly, the questionnaire did not take into consideration how many years the child has been attending Camp Koinonia. Responses may have been scattered depending if Camp Koinonia was the parent/caregiver's first respite opportunity versus if it was a repeated respite opportunity.

Relating the findings to the field of therapeutic recreation, there are practical implications presented that not only will benefit parents/caregivers of children with disabilities, but growth in

the field of therapeutic recreation as well. To begin with, the study identified perceived leisure constraints of parents/caregivers of a child with disabilities as well types of negotiation strategies used in order to overcome the constraints to participate in leisure. By doing this, the study provides an improved understanding and insight of this population that will help benefit leisure service providers and recreation professionals in developing strategies and/or programs to limit constraints, encourage negotiation, and maximize opportunities for leisure. It is important for therapeutic recreation professionals to provide consultation for this population as a way of negotiating leisure constraints. Consultation services can involve leisure education, coping strategies, more respite opportunities, education and knowledge of community resources, and creating opportunities for families, parents, caregivers, and children with disabilities. Collaboration with other professional service providers is necessary in order to help the whole family find the right ways to cope and adapt to different needs. Adding to this, continuing to be a strong advocate for children with disabilities and their families will further promote their needs within the community and among other professionals.

In regards to leisure, further promoting the therapeutic benefits of leisure should be a constant in practice. Service agencies and providers are now more aware of the needs of the parents/caregivers of a child with disabilities to hopefully start developing and creating programs that may better serve this population. Programs can be aimed at educating more people of the demanding care needs of a child with disabilities in order to have more qualified, affordable childcare available. Along the lines of childcare, more respite opportunities need to be made available for these families. From a programming standpoint, addressing and identifying the parents/caregivers direct needs will be crucial in developing successful programs. Programs can

also be created to address the needs of the child with disabilities. For example, creating leisure programs that can be done together or separately, but at the same facility. By doing this, the parent/caregiver and the child with disabilities will both be able to participate in leisure. Expanding focus from just the child with disabilities to looking at the whole family as a holistic unit is the suggested approach to therapeutic treatment.

The current study yields important findings for future research in the field of therapeutic recreation. Information could be gathered regarding what parents/caregivers would personally like to see in relation to programming and opportunities provided for their child with disabilities and the family as a whole. For example, what parents/caregivers want to see more of with programs or what could be done differently to benefit both the child with disabilities and the family. Also, gathering information about what more could others do to help families of a child with disabilities. Receiving answers directly from these families is the best way towards developing stronger programs to meet their needs. Future research directly comparing families of typically functioning children and families of children with disabilities would be beneficial to further identify significant similarities and differences. By identifying specific differences, more services and opportunities can be created and provided addressing certain needs in order to be equally available for both types of families. The majority of current research in regards to coping strategies focuses on families of a child with one disability such as autism. Expanding the research to include families of children with multiple disabilities would provide a wider approach in understanding different coping strategies utilized by families of children with disabilities. With these future research implications, the field of therapeutic recreation can

continue to grow and expand, promote and advocate services, educate others, and benefit families as a whole in regards to a child with disabilities.

## Conclusion

This study supports the literature regarding the lack of leisure time available for parents/caregivers of a child with disabilities due to additional challenges and demanding needs. In order to cope with the daily challenges of having a child with disabilities, the parents/caregivers utilized certain coping strategies, such as, different types of social support, making required adaptations and modifications, and trying to find time for personal interests, such as leisure activities. From the concluded responses, there is an apparent need for more respite opportunities for parents/caregivers and families of a child with disabilities. The field of therapeutic recreation needs to work to holistically improve an individual's quality of life as well as the family's quality of life due to the family unit being an integral part in an individual's life. The population of people with disabilities is often overlooked, even more so the parents/caregivers caring for those individuals. It is important to have their voice heard and their needs identified in order to provide them with opportunities others are able to take advantage of. These parents/caregivers should have more opportunities of respite and leisure in order to regain their strength to provide optimal quality of care for their child and family and to regain their sense of self and identity through their leisure pursuits

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# APPENDIX

# APPENDIX A

Email:

You are being invited to participate in this questionnaire concerning your leisure participation and perceived constraints to leisure. Your responses should be based on your typical leisure patterns and your participation of leisure while your child is at Camp Koinonia. The completion of this questionnaire indicates your informed consent to participate in this study.

Submitted answers will remain anonymous and will not be linked back to you in any way.

There is no penalty for choosing not to complete the questionnaire.

You can access the questionnaire here… [LINK]

You are being invited to participate in this questionnaire regarding your leisure participation while your child attended Camp Koinonia 2014. For the purpose of this questionnaire, leisure is defined as free time, free from obligations, and recreational activities that are non-work experiences.

This questionnaire is a University of Tennessee Knoxville graduate student project and will provide insight into ways in which Camp Koinonia does/does not provide parents/caregivers with leisure time during an opportunity of respite.

This questionnaire will take approximately 10 minutes of your time.

The completion and submission of this questionnaire indicates your informed consent to participate in this study.

Submitted answers will remain anonymous and will not be linked back to you in any way.

There is no penalty for choosing not to complete the questionnaire.

1. Are you male or female?
2. What is your occupation?
3. Are you a parent of a child with a disability or are you a caregiver?
4. Number of children living in the home
5. Number of children with a disability living in the home for whom you are responsible for providing care
6. What is your child's disability (name all) (If more than one child, indicate child 1, child 2, etc.):
7. Which option best describes your family structure?
    a. 2 parents living in the same home
    b. Single parent
    c. 2 adult caregivers
    d. Single caregiver
    e. Other
8. What do you enjoy doing in you leisure time?
9. What things, if any, stop you from participating in leisure activities?
10. How has having a child with a disability impacted your leisure time, if at all?
11. What types of things do you do to help you cope with the challenges of having a child with a disability?
12. Briefly describe how the things you like to do in your leisure time differed while your child was at camp compared to when your child is at home.

# APPENDIX B

## FORM A

### Certification for Exemption from IRB Review for Research Involving Human Subjects

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**A. PRINCIPAL INVESTIGATOR(s) and/or CO-PI(s)** (For student projects, list both the student and the advisor.)**:**
Kayla Kiernozek
Dr. Angela Wozencroft - Advisor

**B. DEPARTMENT:**
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**D. TITLE OF PROJECT:**
Leisure Participation and Perceived Constraints of Parents/Caregivers of Children with Disabilities

**E. EXTERNAL FUNDING AGENCY AND ID NUMBER** (if applicable)**:**
N/A

**F. GRANT SUBMISSION DEADLINE** (if applicable)**:**
N/A

**G. STARTING DATE** (NO RESEARCH MAY BE INITIATED UNTIL CERTIFICATION IS GRANTED.)**:**
Upon IRB Approval

**H. ESTIMATED COMPLETION DATE** (Include all aspects of research and final write-up.)**:**
Spring 2015

**I. RESEARCH PROJECT**

1. **Objective(s) of Project** (Use additional page, if needed.)**:**
   The objective of this project is to examine parents/caregivers' leisure participation and perceived constraints in their daily lives and during the week their children are at Camp

Koinonia 2014.

2. **Subjects** (Use additional page, if needed.)**:**
   Participants will be the parents/caregivers of children who attend Camp Koinonia 2014. Participants must have an active email address that has been provided on their child's camp application.

3. **Methods or Procedures** (Use additional page, if needed.)**:**
   Data will be collected by distributing an electronic questionnaire (see attached) to the parents/caregivers' email addresses after the completion of Camp Koinonia 2014. The questions asked on the questionnaire will regard the parents/caregivers' leisure participation and perceived constraints in their daily lives and while their children attended Camp. Email addresses will be obtained from each child's camp application. The participants will be informed that all data collected will be kept confidential. A member of the Camp Koinonia staff, who is not part of the research team, will send an email containing a hyperlink to the questionnaire to the parents/caregivers. To assure confidentiality, no member of the research team will have access to the email addresses and the Qualitrics survey tool that will be used to collect data which will protect the identities of those who participate. The completion of the questionnaire will constitute the respondents' consent to participate in the study. The participants will be instructed that there will be no penalty for choosing not to participate in the study.

4. **CATEGORY(s) FOR EXEMPT RESEARCH PER 45 CFR 46** (See instructions for categories.)**:**
   Category 2: Research involving the use of educational tests (cognitive, diagnostic, aptitude, achievement), survey procedures, interview procedures or observation of public behavior.

**J. CERTIFICATION:** The research described herein is in compliance with 45 CFR 46.101(b) and presents subjects with no more than minimal risk as defined by applicable regulations.

**Principal Investigator**:

_____ _____ _____
_____

Signature Name Date

**Student Advisor:**

_____ _____
_____

Signature Name Date

**Department Review Committee Chair:** _____
_____ _____

Name Signature
Date

**APPROVED:**
**Department Head:**

_____ _____ _
_____
Name
Signature Date

**COPY OF THIS COMPLETED FORM MUST BE SENT TO COMPLIANCE OFFICE IMMEDIATELY UPON COMPLETION.**

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Rev. 01/2005

# APPENDIX C

TABLE 1.1

| DEMOGRAPHICS | |
|---|---|
| Male | 1 |
| Female | 38 |
| | |
| Parent | 38 |
| Caregiver | 1 |
| | |
| **Family Structure** | |
| 2 parents | 67% |
| Single parent | 28% |
| 2 adult caregivers | 3% |
| 1 parent, 1 stepparent | 3% |
| | |
| **Occupation** | |
| Homemaker | 36% |
| Office positions | 26% |
| Educator | 10% |
| Registered nurse | 10% |
| Retired | 5% |
| Volunteer | 5% |
| Other | 8% |

TABLE 1.2

| **Disabilities** | **N** |
|---|---|
| Cerebral palsy | 13 |
| Down syndrome | 10 |
| Autism/autistic tendencies | 8 |
| Intellectual disability | 8 |
| Visual impairments | 8 |
| Speech and language disorders | 9 |
| Motor difficulties | 7 |
| Attention hyper deficit disorder | 3 |
| Seizure disorder | 5 |
| Developmental delays | 3 |
| Dandy-walker syndrome | 3 |

# VITA

Kayla Kiernozek was born in Cleveland, Ohio to the parents of Kelly and Stan Kiernozek. She is the first of 3 daughters: Leah and Kelsey. Her family moved to Memphis, Tennessee where Kayla attended St. Ann middle school and St. Benedict High School. After graduation, she headed east to Maryville, Tennessee to attend Maryville College to play collegiate soccer. She obtained a Bachelor of Arts degree from Maryville College in May 2013 in Child Development as well as a minor in Spanish. She was accepted into graduate school at the University of Tennessee Knoxville for Therapeutic Recreation. Kayla completed a therapeutic recreation internship at Cincinnati Children's Hospital Medical Center in Cincinnati, Ohio. Kayla will graduate in May 2015 with a Master of Science degree in Therapeutic Recreation with plans to pursue earning her doctoral degree in the near future. Kayla has plans to earn dual certification as a certified therapeutic recreation specialist and a certified child life specialist.