Mothers of children with developmental disabilities: A study of the meaning of leisure occupations

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MOTHERS OF CHILDREN WITH DEVELOPMENTAL DISABILITIES: A STUDY OF THE MEANING OF LEISURE OCCUPATIONS

BY

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THESIS

Submitted to the University of New Hampshire
In Partial Fulfillment of
the Requirements for the Degree of

Master of Science

in

Occupational Therapy

December 2006
This thesis has been examined and approved.

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DEDICATION

For my husband, Tom,
whose patience, support, and sense of humor
 gave me the strength and motivation to complete this manuscript.
ACKNOWLEDGEMENTS

My most sincere appreciation is extended to my colleagues who have given me their support and encouragement throughout this research endeavor.

To my mother Glenda who gives me gentle encouragement, love and immeasurable support.

To Shelley Mulligan for her steady encouragement, invaluable insight, careful editing and helping me to remain on course with this study.

And to the mothers who allowed me the opportunity to hear their sincere thoughts and provide a voice to their feelings of mothering and occupational balance.
TABLE OF CONTENTS

DEDICATION .................................................................................... iii
ACKNOWLEDGEMENTS .................................................................... iv
LIST OF TABLES ............................................................................. vii
ABSTRACT ..................................................................................... viii

CHAPTER PAGE

INTRODUCTION .............................................................................. 1
I. LITERATURE REVIEW ................................................................ 4
II. RESEARCH METHODS ............................................................ 38
    Purpose of Study and Research Methods .................................. 38
    Stance of Researcher ................................................................ 40
    Data Collection and Data Analysis ........................................... 42
    Participants ........................................................................... 44
III. RESULTS .................................................................................. 51
IV. DISCUSSION AND IMPLICATIONS FOR PRACTICE ................. 77
LIST OF REFERENCES ................................................................. 88
APPENDICES ............................................................................... 93
APPENDIX A SAMPLE INTERVIEW QUESTIONS ............................ 94
APPENDIX B INFORMED CONSENT AGREEMENT ......................... 95
APPENDIX C CONSENT TO CONTACT .......................................... 97

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LIST OF TABLES

Table 1. Demographics of Children and Their Mothers...................45
ABSTRACT

MOTHERS OF CHILDREN WITH DEVELOPMENTAL DISABILITIES:
A STUDY OF THE MEANING OF LEISURE OCCUPATIONS

by

Jennifer L. Bellen

University of New Hampshire, December 2006

The purpose of this study was to further our understanding of how the leisure occupations of mothers are influenced by having a child with significant developmental disabilities. Qualitative research methods specifically, a phenomenological approach was used to develop an understanding of how the mothers of children with developmental disabilities engage in leisure activities and the feelings and meanings they attach to leisure participation. Data were collected through in-depth interviews with mothers who shared their experiences regarding their leisure activities. In this study I explored time constraints, daily routines, engagement in leisure activities and the meanings attributed to them. Analysis of the data revealed common themes related to: a) evolving definitions of leisure; b) engagement in leisure; c) having and finding time to engage in leisure; and d) satisfaction with leisure engagement. The implications for pediatric occupational therapists for supporting mothers
of children with developmental disabilities to manage their time and find ways to pursue meaningful leisure activities are discussed.
INTRODUCTION

How do mothers of children with developmental disabilities orchestrate daily occupations, use their time and engage in leisure activities? As an occupational therapist in family-centered early supports and services, I work with children with various disabilities and developmental delays. Through my work, I have become increasingly sensitive to the needs of mothers and the juggling they do on a daily basis to manage the medical needs of their children, in addition to the many other roles required of them. Despite work, housework and caregiving, mothers continue to express the desire to engage in leisure activities like anybody else. As occupational therapists, it is important that we evaluate a person's occupational performance in the areas of work, self-care and play. As I began my career as an occupational therapist, I realized that the importance related to certain occupations differed for persons in various situations. My work as an occupational therapist has focused specifically on the pediatric, birth to 3-year old population and providing services to children and their parents/caregivers within the home environment. Through the relationships I have built with many of the mothers with whom I have worked, I have developed an understanding of their caregiving activities, time management strategies and their use of coping mechanisms. I have also come to understand their need to take
a break from childcare activities, to take time for themselves and to engage in fulfilling and meaningful leisure activities. These relationships have allowed me to gain some insights into the impact of having a child with a disability on a mother’s engagement in leisure occupations, and this has sparked my curiosity to explore this more systematically.

The purpose of this study was to further our understanding of how the leisure occupations of mothers are influenced by having a child with significant developmental disabilities. Through an in-depth look at the lives of four mothers with children with significant disabilities, this study provides insights to assist mothers with children with disabilities to experience enjoyable and meaningful leisure time.

Understanding the ‘time use’ of specific populations and how people orchestrate their daily routines has largely been studied using qualitative methods. Qualitative methods were felt to be particularly well suited to examine the differences and similarities in mothering a child with developmental disabilities, their occupations, and in understanding specifically their leisure engagement. A phenomenological approach allowed me to develop an understanding of how and why mothers of children with disabilities engage in leisure activities.

The purpose of the study was to describe how mothers with children with significant disabilities engage in, perceive and value leisure. The following research questions were addressed:
1. What kinds of challenges do mothers of children with significant developmental disabilities face related to engagement in leisure activities?

2. How does having a child with significant developmental disabilities influence a mother's engagement in leisure activities?

3. For mothers of children with developmental disabilities, in what ways does engaging in leisure activities promote their overall sense of well-being?

4. How do mothers orchestrate their own leisure occupations with the demands of daily living?

5. What meanings and values do mothers of children with significant developmental disabilities place on their leisure occupations?
CHAPTER I

LITERATURE REVIEW

Relevant literature includes a review of mothering, occupations, time use, and leisure pursuits of mothers, and in particular those who care for children with developmental disabilities. Previous research that has examined the differences and similarities of how mothers of developmentally disabled and typically developing children orchestrate their daily occupations, manage their time and engage in leisure activities is reviewed. The early intervention literature was examined to explore how health care providers such as occupational therapists have assisted mothers struggling to engage in desired leisure activities within their busy and sometimes unpredictable daily schedules.

Since many mothers work (71.7%, U.S. Labor Statistics, 2006) outside of the home, careful planning is often necessary to maintain daily routines and to allow mothers to participate in occupations that are beneficial to all family members. Maintaining employment places an extra burden on all mothers, but the time demands placed on caring for a child with a disability makes working even more of a challenge (Warfield, 2001). Mothers of children with disabilities face many challenges in creating and
managing daily routines, and their daily routines may have different meanings in comparison to the meanings attached to the daily routines of mothers of typically developing children. Everyday, mothers and children participate in some predictable, familiar routines (Kellegrew, 2000). It is these routines that provide children with opportunities to engage in activities that promote overall development and skill acquisition. For mothers of children with disabilities, these routines are rooted in time. Smith (1986) found that the presence of a physically disabled child in the household places constraints upon the time use of mothers.

**Occupation**

The American Occupational Therapy Association (1995b) recognized the importance of understanding the nature of the typical daily occupations in which people engage; that is, what people do, how they do, and why they do it. Law, Steinwender and Leclair (1998) defined occupation as “groups of activities and tasks of everyday life, named, organized and given value and meaning by individuals and a culture” (p.83). Occupations always have some degree of personal meaning, having contextual, temporal, psychological, social, symbolic, cultural, ethnic, and/or spiritual dimensions (AOTA, 1997). Occupations are generally viewed as activities that have unique meaning and purpose in a person’s life. Occupations are central to a person’s identity and
competence, and they influence how one spends time and makes decisions (AOTA, 2002).

Engagement in the occupation of leisure activities has different meanings for people depending on desire and need, lifestyle, family constraints and change in life circumstances. Leisure as an occupation varies from one individual to another. An individual’s definition and prioritizing of leisure can be seen through the activities in which they engage, how often they engage in certain leisure activities and the reported meanings and benefits that may result. Leisure activities should be fun, relaxing and have health benefits. It is these benefits that have the potential to facilitate feelings of well-being, fulfill a psychological need and promote a balance between obligatory and non-obligatory tasks.

Motherhood and Mothering

For the purpose of this study, research has focused on motherhood and mothering within the United States. Historically, motherhood has been defined and viewed in many ways. Francis-Connolly (2000) discussed how motherhood, until 20 years ago was considered unworthy of study; rather it was a phenomenon taken for granted due to its commonness. Larson’s (2000a) review of the history of mothering explored the political and societal influences on mothering from the 1950s to the 21st century. These influences included: 1) the idea that mothering is viewed by society
as a cultural bedrock instilling social values in the new generation, 2) political policies that support mothering (i.e. Family and Medical Leave Act, 1993), and 3) the study of the historical roots of the mother’s role in the family.

DeVault (1991) described the complexity of a mother’s planning and managing mealtimes. Hochschild (1989) described mothers who worked a first shift at paid employment, and then a second shift at home. This work provides further insights into the challenges of mothering, and the social and political influences that affect mothers, in and out of the paid work force.

Studies of motherhood and mothering suggest that motherhood is an enfolding activity that involves multiple tasks requiring attention simultaneously (Segal, 2000). Segal reported mothers used three adaptive strategies: 1) enfolding occupations to perform more than one occupation at a time; 2) temporal unfolding occupations occurs when mothers reconstructed their own occupations so they can focus on enabling their children’s occupational performance; and 3) unfolding by inclusion happened when mothers delegated chunks of activities or their own occupations to other persons so they can enhance their ability to meet their child’s needs. These strategies enabled mothers to care for their children with disabilities; however, using enfolding or temporal
unfolding meant that mothers have less time for their own occupations (Segal, 2000).

Francis-Connolly (2000) reported that mothers become immersed in motherhood and that mothers use daily occupations and routines to foster overall growth and development of their children. Francis-Connolly described this phenomenon in terms of two themes: *motherhood immersion* and *mothering as an enfolded activity*. Motherhood immersion occurred when mothers of preschool children were completely immersed in motherhood and were extremely busy meeting the ongoing demands of their young children outside of their own occupations and interests. Mothering young children is an intense occupation, and the mothers from Francis-Connolly's study reported that motherhood was extremely demanding of their time. The mothers reported that the endless demands of their young children were unexpected and they felt overwhelmed and unprepared for the intensity of mothering. Mothering as an enfolding activity, required mothers to engage in a variety of caregiving activities while paying attention to their children simultaneously (i.e. playing peek-a-boo with their child while changing a diaper). Nurturing tasks were meshed within daily routines, such as changing diapers and feeding their children. These tasks were viewed as the entire work of mothering and not as separate entities. Francis-Connolly also reported that mothers continued to demonstrate *motherhood immersion* and *mothering as an*
enfolded activity as their children grew and matured. Mothers continued to "mother" across the lifespan; nurturing and teaching their children and remaining invested and active participants in their children's lives, providing them with advice and emotional support.

The occupations and routines of mothers are complex, ongoing and require flexibility to accommodate the internal and external demands of home, work and society (Larson, 2000b). Mothers engage in a variety of daily activities and occupations to enhance the growth and development of their children. Whether working at home or outside of it, mothers have a unique ability to nurture, support and manage everyday occupations while responding to the constraints of time.

Mothering includes activities involved in nurturing and caring for children in which women engage to ensure the growth of their children (Francis-Connolly, 1998). Francis-Connolly (1998) also studied the occupation of mothering and how it changes and evolves throughout a mother's life-course. Emergent themes from Francis-Connolly's research included: 1) mothering as a lifetime occupation; 2) the influence of the "perfect mother" image on the occupation of mothering; and 3) how they mothered changed over time, with the role of being a mother never ending.

Olson and Esdaile (2000) examined mothering in challenging environments. They reported that the environment is a constant
influence, shaping the participants' occupations of mothering. Crowe,
VanLeit, Berghmans and Mann (1997) described mothers of children with
disabilities as having more roles and role demands than mothers of
typically developing children. Crowe et al. (1997) also found that all of
the mothers they studied, placed some value on their occupational roles
suggesting that the mothers engaged in roles that they believed are
important, and that were beneficial to themselves and their children.
Research was based on the perceptions of the mothers themselves, and
their views on their “mothering” or maternal work.

*Occupation and time use of mothers with typically developing children*

When a newborn arrives home, a flurry of activity occurs relating to
schedules, routines, planning and organizing. As children develop and
learn new skills, mothers learn to change and adapt routines to meet their
child’s ever-changing needs. Through the construction of daily routines
and occupations, mothers provide their children with endless
opportunities to practice and develop skills necessary to participate
successfully in society (Kellegrew, 2000). Time is an example of a
fundamental resource to family well-being that families can only partially
generate and control themselves. Time is a valuable resource, when it is
available, when it can be negotiated, and used (Brotherson & Goldstein,
1992). Time management refers to time use, allocation of time, and the
human resource of time. Gillis (1996) defined time as “something we live by, something we use to think about the world and to act on it” (p.6).

Sanik (1990) compared the time use of parents with infants in 1967 with the time use of parents with infants in 1986. Sanik (1990) found that mothers spent on average 2.9 hours/day doing childcare activities in 1967 compared to 3.9 hours/day in 1986. Sanik reported this as a significant increase in time spent in childcare, explaining this change as a result of a corresponding decrease in time spent in household tasks in 1986. Sanik suggested that this decrease in time spent doing household tasks as being the result of mothers increased interest in providing quality childcare, and increased efficiency in getting housework done or a decreased interest in doing household tasks. In 1986, mothers were spending more time doing obligatory activities specifically childcare while employed mothers reported more time in childcare and paid work than nonemployed mothers. Sanik (1990) reported the differences in time use of parents with an infant in 1967 and in 1986. Mothers' time spent parenting increased from 2.9 hours per day in 1967 to 3.7 hours per day in 1986.

Bryant and Zick (1996) studied parents of two children and the hours spent raising them to age 18. Bryant and Zick analyzed data from three studies: 1) 1975-1981 Time Use Longitudinal Panel Study, 2) the 1977-'78 Eleven State Time Use Survey, and 3) the 1985 American Use of Time Data. Bryant and Zick found that mothers who did not work during child-rearing

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years, together with their spouses, spent 7.7 hours per day on caregiving activities. Mothers who worked outside the home spent 7.3 hours per day on caregiving activities. Parents of two children spent 7.5 hours/day, seven days/week in child rearing activities. The three studies used by Bryant and Zick defined time spent by parents in caregiving included help with homework, taking them to or participating with their hobbies, eating, driving, cooking and a variety of other activities performed to enhance academic, social, emotional, and physical growth and development of their children (Bryant & Zick, 1996).

Dyck (1992) examined the dynamics of how the environment influences time use of mothers and how it shapes mothering activities. She presented the results in the form of time-space maps of the women (married and unmarried) involved in the study. Time-space maps allow a greater understanding of how mothers organize child-rearing activities throughout the day and provided a means of comparing mothers who do and do not work outside the home. Mothers working full-time do most child-rearing activities at the beginning and end of the day. Mothers who remained at home presented with busier time-space maps with periods of child-rearing activities throughout the day. Their child-rearing activities were spread out during the day allowing them more opportunities to spend with their children.
As mothers spend more time in the workforce, children’s activities change. The types of activities in which children engage are likely to be shaped by their current family context, including maternal employment, education and family structure (Hofferth and Sandberg, 2001). Hofferth and Sandberg (2001) described how children under the age of 13 spend their time. The authors used national data collected in 1997 to understand what factors are associated with children’s time use. Factors associated with the differences in time use included: child’s age, mother’s time spent in the workforce, parents’ education, family structure (single, married) and cultural differences. The authors found that children of mothers who worked spent more time in daycare and as a result, they spent less time in school-related activities, structured play, and family activities including sleeping, eating and learning time.

Hofferth and Sandberg (2001) found that mothers needed to schedule and account for changes in routines, as a child got older. These routine changes involved children’s sleep and eating habits and assistance needed with homework. Mothers in general expressed concern with how their children were using their time, maintaining schedules and the need for guidance on the appropriate developmental activities for their children. Mothers also expressed the desire to balance out-of-home and home-based activities for their children as well as themselves (Hofferth & Sandberg, 2001).
Daly (2001) explored the relationship between parents’ expectations and experiences with family time. Families consisted of both single and married, dual and single-earner households. Both mothers and fathers were interviewed separately and then again, when applicable, as a couple. Most of the children were under the age of five and attended childcare settings or were cared for at home by babysitters. Three themes emerged from the research: 1) yearning for family time; the pursuit of ideals, 2) the practice of family time, and 3) understanding the differences between expectation and experience. In the theme Daly labeled “yearning for family time; the pursuit of ideals,” parents were seeking to provide their children with family time that would create positive memories that involved togetherness. Parents sought to experience family time as remembered from their past and the desire to carry on traditions. “Practicing family time” found parents struggling with the management of time use and identifying barriers (i.e. demands of housework and paid work) that often prevented them from experiencing their family time ideals. Families expressed certain “expectations of family time,” often affirming their beliefs about family togetherness and positive interactions. However, the busy schedules often prevented them from achieving family time goals. Families felt disillusioned with their schedules and reported difficulty maintaining schedules and finding family time.
Parents reported feeling guilty over what they could not do with their children (Daly, 2001).

While most of this research is time-dated, it still appears relevant to families raising their children at the current time and suggests that there is a need to study how mothers currently use and manage their time.

In summary, the literature on mothers of typically developing children developed over the past 10-15 years indicates that mothers devote considerable amount of time to the many activities and tasks involved in raising their children and they view being a mother as an important role. Mothers engage in and value activities that promote family time and family togetherness (Daly, 2001).

**Occupation and Mothers' Time Use: Impact of a child's disability**

This next section addresses mothers of children with developmental disabilities and their use of leisure time and their construction of daily occupations. Mothers of children with developmental disabilities have a great desire to engage in leisure, however they continue to report a lack of time. Similar to mothers of typically developing children, mothers of children with developmentally disabilities see their roles and the engagement in occupations as supporting the growth and development of their children.

The literature reviewed (primarily from the United States) indicates that studies have been done investigating: a) how mothers of children
with disabilities use their time, how their time is impacted by having a child with a disability and how they construct their daily occupations; b) the similarities and differences in the orchestration of occupations and time use of mothers with a child with disabilities and mothers of typically developing children; c) how routines, roles and their daily occupations are affected by mothering a child with disabilities; and d) mothers’ coping strategies.

The orchestration of occupations by all mothers is a complex and dynamic process that changes as external demands change. This orchestration impacts a mother’s feelings of well-being and perception of being a good mother. Larson (2000b) found that mothers of children with disabilities linked their successes in parenting to their feelings of subjective well-being. The mothers consistently linked their feelings of well-being with their child’s progress and their ability to meet the daily challenges of taking care their child with disabilities. Mothers reported feeling like they had more control over their lives, feeling better physically and an increase in family health when their child with a disability was making good progress towards their goals.

Larson (2000b) found that through the desire to provide their child with positive learning and nurturing experiences, mothers’ orchestration of occupations were guided by eight thought processes that afforded them opportunities for optimistic thinking, a sense of life control, daily task
completion and use of time. Mothers used these thought processes to compose maternal and child-sensitive occupations. These thought process were: 1) planning an occupation; 2) organizing an occupation; 3) balancing an occupation; 4) anticipating an occupation; 5) interpreting an occupation; 6) forecasting an occupation; 7) placing a perspective on occupation; and 8) meaning making in occupation. Larson also stated that these processes were constrained and afforded by the mothers' personal and cultural values and were influenced by demands of family and resources (Larson 2000b). Mothers who engaged in this thought process were able to design their present occupations and plan for their future daily occupational rounds for themselves and their family members. In the context of using this thought process while engaging in an occupation with their child, the mothers Larson interviewed reported their child-parent interactions were positive and fulfilling and were linked to their values of being a good mother. Feelings of well-being and success at managing child and family occupations were linked to a greater desire to seek out and engage in preferred leisure activities or "down time." Breslau (1983) found that a child with a disability increased the amount of time a mother spent completing household work. Breslau also suggested that the extra time needed to meet the needs of a child with a disability decreases the amount of free time the mother would have to engage in leisure activities.
McGuire, Crowe, Law & VanLeit (2004) identified a lack of occupational balance in the lives of mothers of children with disabilities. Many of the mothers McGuire et al., questioned, reported feeling that they were the primary person responsible for the well-being of their child with a disability resulting in feelings of frustration and disorganization. They reported having less time for occupations they considered important such as sleep, their own leisure pursuits, and quality family time. As a result, the women struggled with burn out, questioned their self-identity, and experienced a loss of self-esteem.

Studies by Kellegrew (2000), Larson (2000b), Segal & Frank (1998), and Segal (2000) focused on the need to develop a clearer picture of how mothers structure daily routines and orchestrate their occupations. These studies examined the influence of a child’s disability on a mother’s occupations, including the completion of caregiving tasks, medical management, household tasks, and meeting the overall needs of their children and families. Kellegrew (2000) found the routines that mothers constructed were complex and the orchestration of these daily routines, specifically the child’s self-care routines, resulted from accommodation to everyday events, and the mothers’ anticipation of the child’s future needs.

Larson (2000b) explored the relationship of mothers’ orchestration of daily occupations when parenting a child with a disability and the
mothers' feelings of well-being. Larson found mothers felt successful when they were able to meet the demands of mothering, the family was in good health and there was progress towards desired goals. Successful mothering resulted in an increase in emotional and physical health.

*Mothers’ Occupations and Time use: Comparison of mothers with and without a child with disabilities:*

The literature reviewed is time dated and suggests that there is a need to study how mothers of children with developmental disabilities use their time, orchestrate their daily occupations and engage in leisure.

Breslau’s (1983) study on the care of children with disabilities and women’s time use suggested that parents of children with disabilities spend a significant amount of time in childcare tasks and scheduling of activities to meet the needs of their children. Mothers of children with disabilities spent significantly more time doing housework than mothers of typically developing children. Breslau also found that married mothers of children with disabilities spent more time in housework, than single mothers, and mothers of typically developing children.

Families with a child with a disability have many demands that may influence their ability to use time effectively (Brotheson & Goldstein, 1992). Careful planning of medical appointments, therapies, social groups and other avenues of play and development are often required of parents with children with disabilities. Parents are responsible for maintaining the
daily routines of their children. Busy lifestyles and constant care and nurturance of a child with disabilities, places time constraints on other aspects of daily life (work tasks, housework, leisure time). Parents of a typically developing child often face the same challenges of scheduling, time use and occupational engagement. However, mothers of typically developing children do not have to attend as many medical and therapy appointments, moreover they do not have to manage adaptive equipment, complex daily self-care and medical management tasks.

Studies by Cantwell and Sanik (1993) and Smith (1986), documented the impact that a child with and without disabilities can have on a marriage as well as on leisure occupations. These studies provided information regarding the time use of each parent in the care and nurturing of the child. Cantwell and Sanik (1993) explored leisure time of mothers and fathers during the 3rd trimester of pregnancy and the first 3 months after the birth of the first child. Leisure was defined as “the sum of time reported in non-work activities of organization participation, social and recreational activities, personal care (including rest and sleeping) and eating” (p.143). Their data showed that the wife’s leisure time decreased by 3.86 hours per day for stay at home moms. If employed, leisure was decreased by 2.31 hours per day. Mothers are spending more time in childcare activities and less time in housework. Smith (1986) studied the Saturday time use of parents with a child with disabilities. This
study found that parents of a child with disabilities used over 40 minutes more per Saturday for all childcare activities than parents in the nationwide sample. Interestingly, Smith (1986) found that parents of children with disabilities considered Saturday the “busiest day of the week.” Parents would often “borrow” time from other Saturday activities (i.e. housework, lawn care, chores, errands) and reduce their time commitments across the other time categories (i.e. cooking, home chores, laundry, gardening and errands) to engage in leisure time and pursuits. Although Smith’s study did not show reductions in total leisure time of parents of children with disabilities, he provided the readers a better understanding of parents’ time use one day a week, and demonstrated the impact a child with a disability may have on parents’ use of time.

Crowe (1993) compared the time use of 45 mothers of typically developing children with that of 45 mothers of children with multiple disabilities, and 45 mothers of children with Down syndrome. Mothers in the study had children distributed across three age ranges: 15 children from six to 12 months of age, 15 children from one to three years and 15 children from three to five years. Crowe used both inferential statistics and descriptive data to test the hypothesis that daily activities including childcare, recreation and socialization/participation would vary between the groups of mothers. She documented differences and similarities in
seven categories (homemaking, childcare, recreation, employment, personal care, education, and socialization/participation). Mothers in all three groups spent the most time on childcare and homemaking activities. Mothers of children with multiple disabilities spent more time performing childcare activities than mothers of children with Down syndrome, and mothers of typically developing children. Crowe found no major differences between mothers of children with multiple disabilities and mothers of children with Down syndrome in numbers of hours spent per week in recreational activities. Mothers of children with multiple disabilities spent 13.01% of waking hours per week in recreational activities while mothers of children with Down syndrome spent 13.16% of their waking hours per week in recreational activities. Crowe found that maternal age affected the amount of time mothers spent on recreation with older mothers tending to engage in slightly more recreational activities, and that mothers in all groups spent most of their leisure time in sedentary recreation (i.e. art, listening to music, reading, watching television or praying) rather than active recreation activities. Mothers of typically developing children reported more time per week spent (17.66%) in recreational activities. Finally, mothers of typically developing children were found to be involved in more socialization activities than those of children with multiple disabilities or the mothers of children with Down syndrome.
Recently Crowe and Florez (2006) compared the time use of mothers of children with and without disabilities. They found significant differences between the two groups of women when comparing mean hours spent per week by mothers in occupations involving childcare activities and recreational activities. Mothers of children with disabilities spent significantly more time in childcare activities and significantly less time in recreational activities (5.7 fewer hours) as compared to mothers of children without disabilities. Mothers of children with disabilities also reported fewer typical days and rated the quality of these days as poorer. The authors thought that this could be because of the disruption in daily routines and schedule due to the unpredictability of their child’s health. Crowe and Florez (2006) also found that as children with disabilities got older (5 years of age and older), mothers spent less time in childcare activities and more time in recreational activities. However, mothers of children with disabilities continued to spend more time in childcare activities in comparison to mothers of typically developing children regardless of the child’s age.

Roles, routines and changes

Although mothers of children with disabilities may assume different roles from mothers of children who are typically developing such as advocate, educator, liaison and developmental interventionist, Crowe et al. (1997) found that mothers of disabled children reported fewer roles
than mothers of typically developing children. Mothers of children with disabilities gave up roles because they had to spend more time taking care of their children's self-care and medical needs. All three groups of mothers lost roles since motherhood. Mothers of children with Down syndrome reported a loss of more roles than the other two groups. These roles were identified as: hobbyist, friend, volunteer, worker and student. There were notable differences between the number of roles fulfilled by both the mothers of children with Down syndrome and mothers of children with multiple disabilities. Raising a child with a disability is enormously challenging, requiring an increased amount of energy and time (Crowe et al., 1997). Therefore, Crowe surmised it may be necessary for mothers of children with disabilities to eliminate roles, adjust daily routines and give up certain occupations to devote the necessary time to childcare activities.

Taanila, Jarvelin & Kokkonen (1999) studied how a child's physical or intellectual disability and/or diabetes affected family cohesion, the parents' social life, work and leisure time activities. The parents of 89 children aged 12-17 were studied and results indicated that the majority of the families (75%) valued friends as an important or very important form of social support and mothers reported the importance of connecting with other families with a child with the same disability. When asked about the importance of work and leisure-time activities, 16% of the
mothers of children with an intellectual or physical disability thought the importance of their work and career had decreased. Almost one-half of the mothers of a child with a physical disability and a third of those with an intellectual disability reported that the importance of leisure-time activities had decreased. The results concluded that a child's illness or disability affected the mother's everyday life, and that leisure time is particularly influenced by becoming less of a priority.

Mothers of children with disabilities and coping strategies

Ray & Ritchie (1993) examined parents' perception of the stressfulness of managing the health care needs of a chronically ill child. Three themes were apparent in parents' coping strategies: 1) maintaining family strength and relationships; 2) maintaining a positive outlook; and 3) taking care of illness-related tasks. Parents reported beliefs and commitments, health and energy, problem-focused coping strategies, and emotion-focused coping strategies were personal factors that influenced their appraisal and coping. Parents closely linked their beliefs about positive outcomes, personal control and God to their coping strategies such as, maintaining hope and looking for positive meaning. Efforts for coping depleted their energy for other activities, although parents use of emotion-focused coping strategies were found to reduce stress levels. Parents made a significant effort to maintain a positive
outlook and reduced their stress by “living one day at a time” and getting a break from the caretaking regime.

Heaman (1995) compared mothers and fathers in her study, focusing on the perceived stressors and coping strategies of parents with children with developmental disabilities. Her results supported Ray & Ritchie’s (1993) study showing mothers and fathers share the greatest concern with the child’s future. In particular, mothers reported more stressors related to (in order) financial, physical and emotional health, time constraints and extra money for pleasures and discretionary activities. Mothers’ stressors were most related to having the right agencies to meet the child’s needs. Mothers used coping strategies in a variety of ways. Heaman was able to categorize these strategies as: seeking social support, problem solving and positive reappraisal. Concern for having fun and relaxation was more associated with the mothers rather than the fathers due to the increased amount of time the mothers spent in caregiving and home management activities. The ability of the family to respond to the ongoing daily demands dictated the perceived quality of the child and family’s life (McCarthy & Gallo, 1992).

Heaman (1995), Herman and Thompson (1995) and McCarthy and Gallo (1992) studied the impact of a child’s chronic illness on the family structure, parents’ level of stress and use of coping strategies, and the ongoing need and use of community and medical resources. They found
there was a need to educate all members of the family on the child’s diagnosis, treatment and daily needs, and that caring for a child with a disability can influence a family’s stress management, how they communicate with each other and seek supports. This indirectly would affect how a mother is able to find time for leisure.

Other studies by Olson and Esdaile (2000) and Segal (2000) have addressed mothers’ use of adaptive strategies with daily occupations and activities to meet the needs of a child with disability. Olson and Esdaile (2000) identified one major overarching theme that influenced the mothering of a child with a disability: “doing what I got to do.” Two subthemes identified from the data include: a) mothering as caring, and b) the impact of support systems (or lack thereof) on the occupations of mothers. Segal (2000) found that mothers of children with ADHD used three adaptive strategies to manage occupations in three different ways: enfolding, temporal unfolding, and unfolding occupations by inclusion. Enfolding occupation means performing more than one occupation at a time. In contrast, unfolding occupation means breaking up caregiving occupations into smaller tasks that can be performed at different times (temporal) and by different people. Mothers reported that these strategies helped them to care for their children, however they still had less time for other roles and occupations.
Segal & Frank (1998) also examined how mothers of children with attention deficit hyperactivity disorder (ADHD) used adaptive strategies to construct daily schedules within a time use pattern. Both studies examined how the mothers constructed schedules for homework and dinner and free time, taking into consideration their child's ability to concentrate, their emotional and physiological needs, and parental work schedules. Studies by Ray and Ritchie (1993) and Seideman and Kleine (1995) identified significant relationships between the use of coping strategies when parenting a child with a disability and the development of occupations for childcare, family/household management and stress management. Seideman and Kleine discussed the Transformed Parenting Model in which parents construct reality loops in response to their child's diagnosis and later seek out environmental supports, gather a mind set and then spring into action by implementing childcare strategies, routines and household management tasks.

Ray and Ritchie (1993) explored further the use of: 1) family support; 2) maintaining a positive outlook; and 3) ensuring that childcare activities were performed as the necessary coping strategies decreasing the stress mothers experienced when caring for a child with a chronic illness. The authors found that the presence of family support particularly a supportive spouse, and the cooperation with caregiving activities, was important for emphasis on positive outcomes. In addition, emphasis on a caring and
committed relationship with health professionals that promoted feelings of comfort was important for parents. Finally, the opportunity for breaks from the ongoing demands of caregiving activities helped parents, primarily mothers cope.

Leisure and Health

Edwards (1997) reported that leisure has long been characterized as time away from paid labor. Although unpaid labor continues to be recognized as a form of work, the conception of leisure is still based on the assumption that leisure is continuous and supplemental to work, paid or unpaid (Edwards, 1997). A second definition of leisure comes from its association with certain kinds of activity such as rock climbing, playing cards, or painting. This definition considers the nature of the activity rather than its relationship to work (Worpole, 1991). Edwards noted that this definition is problematic because leisure activities for one person may be work for another (i.e. sporting activities). A third definition of leisure incorporates the term "a leisurely approach" or the way any activity including work is approached. This approach combines attitudes and behaviors such as "taking one's time" and "going at one's own pace" (Edwards, 1997). He argued that leisure should be understood as a situation where all three of the above characteristics are met and that leisureliness can be pursued in all dimensions of life.
Pearson (1998) studied the influence of both job and leisure satisfaction on psychological health. He studied 189 adult men in the New Orleans area who were employed full-time. The Job Descriptive Index (JDI; Smith, Kendall, & Hulin, 1969) was used to measure job satisfaction and the Leisure Satisfaction Measure (LSM; Beard & Ragheb, 1980) was used to measure leisure satisfaction. Statistical analysis indicated that job satisfaction was the better predictor of psychological health; however, leisure satisfaction added to the prediction. Both job and leisure satisfaction were the highest correlates to psychological health and the correlation between job and leisure satisfaction was relatively low. Job satisfaction for professional workers was significantly higher than the satisfaction reported by blue-collar workers; however, the relationship of job satisfaction and leisure satisfaction with psychological health was not significantly different for blue-collar and white-collar professionals.

Coleman and Iso-Ahola (1993) reviewed literature on the social context of health to identify the ways in which leisure might contribute to health. The authors concluded from their literature review that stressful life circumstances contribute to physical and mental illnesses. However, research has shown that various coping processes, including leisure participation helps to moderate the impact of stressful life circumstances. Coleman and Iso-Ahola argued that leisure participation facilitates
coping with life stresses in two ways: availability of social supports and self-determination. First, leisure participation is usually social in nature and often organized around family groups and friendships. Leisure motivation studies documented by the authors reflect the social nature of leisure including, “establishing new friends,” “developing closer friendships,” “enjoying companionship,” “being with friends,” and “meeting new partners.” Iso-Ahola developed a model of leisure motivation that presents a “desire to seek and escape interpersonal situations” as one of the two dimensions of leisure motivation that reinforces the importance of social motives in leisure participation. Companionship in shared leisure activity appears to provide effective relief for people as they cope with the excesses of life stresses, thereby maintaining or improving health. Second, dispositions that reflect self-determination have also shown to contribute to people’s coping capacities and health. The literature studied by Coleman and Iso-Ahola indicated that personality dispositions involving self-determination (i.e. locus of control and hardiness) are often associated with the capacity to resist illness. The authors also noted that self-determination disposition is both a cause and an effect of leisure participation. Leisure participation allows a person freedom of choice and personal control and it is this characteristic that appears to be the buffer against stress and illness. Long-term positive effects on health
come from a person’s exploration of and participation in leisure activities that support feelings of self-determination.

Caldwell (2005) examined the ways in which leisure is therapeutic and how it may contribute to a person’s well-being and health. She believes that leisure may be restorative and beneficial, and move one towards health. She described three classes of leisure and health literature: prevention, coping and transcendence. First, Passmore (2003, cited by Caldwell) suggested that leisure activity may prevent poor health and certain risk behaviors before they occur. Passmore (2003) indicated that social leisure and leisure achievement significantly and positively influenced the mental health of Australian adolescents and that mental health was most strongly predicted by leisure-related competency, self-efficacy, and self-worth. Caldwell (2005) also examined a study by Hutchinson and Affifi (in progress) in which adolescents and parents reported participating in leisure to connect with others, affirm one’s identity and develop personal growth through new friendships and new leisure activities. Adolescents and parents were also helped by taking advice from friends, journaling, reading, and taking care of one’s self. Leisure may be therapeutic as a way to help deal with negative life events. Caldwell theorized that someone who has experienced a traumatic life event uses leisure to find a new meaning to life, and to realize one’s potential. Caldwell demonstrated that leisure participation is
meaningful and contributes to physical, emotional and cognitive health and is one of the more “free” moments in a person’s life that should be cherished.

Erlandsson and Eklund (2003) studied how a balanced pattern of daily occupations promoted health. They investigated the relationship of daily occupations and lifestyle factors to 100 Swedish working mothers’ health and well-being. The authors described the highs and lows as being “uplifts” and “hassles.” Working long hours and having a university diploma were found to be risk factors for experiencing more hassles. Risk factors for fewer uplifts were having two or more children and fewer leisure occupations. Women who reported experiencing less control over their time use constituted a risk of lower self-rated health and an additional high level of hassles impacting well-being. Women with university diplomas participated more often in leisure occupations than the women who had completed high school, with the most frequently reported leisure occupation being exercising at the gym. The study classified the total workload for women as daily chores such as self-care, care of children and home, remunerative work and leisure occupations. Women who experienced less control over time spent at work experienced more hassles and less time spent in leisure occupations. Experiencing more hassles and less control impacted on the experience of well-being and sense of coherence. Having more hassles constituted a
risk of experiencing lower quality of life and influenced the participation in
leisure pursuits and this disrupted the balance of daily occupations.

Shaw (1994) examined three approaches to analyzing women's
leisure. She referred to the first and dominant approach to understanding
women's leisure is analysis of how leisure is constrained. In this approach,
Shaw emphasized the ways in which women are disadvantaged or
oppressed within a patriarchal society and how their subordinate status
within society limits their access to and enjoyment of leisure. Shaw
reviewed literature that explained how women's lack of freedom for
leisure was related to the reality of their everyday lives, specifically time,
money, social structures, household obligation and family commitments.
Shaw believes that leisure activities are constrained to some degree by a
woman's roles and position in society. Second, she argued that certain
forms of leisure participation can be seen to emphasize women's
mothering roles within the family. For example, the encouragement of
"family leisure" functions and "family values" hides women's work in
creating family leisure time, thus placing constraints on women's personal
leisure choices and opportunities for time for themselves. The third
approach to analyzing women's leisure constraints is one that defines
women's leisure as offering possibilities for resistance to societal imposed
constraints. Leisure participation, especially self-determined leisure, can
empower women and help them resist cultural pressures to conform to
prescribed social roles and to traditional definitions of femininity (Shaw, 1994). She makes this argument for resistance based on two notions: the idea of agency (how women perceive and respond to social situations) and the idea of leisure as freely chosen, thereby exemplifying personal choice, control and self-determination. From her review of the literature, Shaw argued that women increasingly see free time and leisure as important and valued areas of social life and provided evidence that some women value and seek out personal leisure time as a time, which is separate and distinct from family leisure.

Summary of Literature Review

Most of the literature has focused on motherhood or maternal roles and their engagement in and perception of their occupations with particular attention to leisure. The literature reviewed for this study used the terms mothering and maternal work interchangeably. For the purpose of this study I chose the term mothering to refer to both.

Mothering is a phenomenon; historically and presently influenced by social and political agendas. Mothering a child is complex; an enfoldung activity that requires mothers to attend to a variety of activities at once. Mothering is for a lifetime, often changing, however never-ending. Mothers of typically developing children and mothers of children with disabilities devote much time to the care and nurturance of their children. Mothers seek to provide their children with activities to enhance
their child's development and social well-being. Mothers of children with disabilities take on additional roles such as advocate and developmental interventionist and use a variety of coping strategies to meet personal and familial needs while other roles such as hobbyist, friend, volunteer, worker and student may be eliminated. However, mothers' engagement in their own occupations (other than child rearing) as well as their own leisure pursuits are important for their own health and well-being and that of the family unit.

In summary, the research suggests that mothers are spending a lot of time on caregiving and "mothering" activities, leaving less time for their own leisure pursuits. Mothers of children with disabilities are particularly challenged to find time for themselves and may feel obligated to spend the free time that they have on family activities. They are expressing a strong desire to engage in preferred leisure pursuits and other occupations outside of time spent with family and caring for a child with disabilities. However, mothers are also finding it hard to make time for leisure. Mothers of children with disabilities face changes in their many roles when mothering a child with disabilities. They also rely on a variety of coping strategies in addition to participation in leisure to enhance feelings of well-being and success with mothering. Mothers also report feeling emotionally, physically and cognitively healthy when engaging in leisure.
The purpose of this research is to examine the meaning of leisure time experienced by mothers of children with disabilities, and their engagement in and satisfaction with their leisure pursuits. This research assists occupational therapists in understanding the value of mothering, and the role leisure occupations play in promoting a sense of emotional, physical, and balanced mental health and well-being for mothers of children with significant developmental disabilities and their families.
CHAPTER II

RESEARCH METHODS

Purpose of Study and Research Questions

The purpose of the study was to describe how mothers with children with significant developmental disabilities engage in and perceive leisure activities. The following research questions were addressed:

1. What kinds of challenges do mothers of children with significant developmental disabilities face related to engagement in leisure activities?

2. How does having a child with significant developmental disabilities influence a mother’s engagement in leisure activities?

3. For mothers of children with developmental disabilities, in what ways does engaging in leisure activities promote their overall sense of well-being?

4. How do mothers orchestrate their own leisure occupations with the demands of daily living?

5. What meanings and values do mothers of children with significant developmental disabilities place on their leisure occupations?
Qualitative research methods were used to address the study questions. Data were collected through in-depth interview (see Appendix A) with four mothers. Using a phenomenological approach as described by Creswell (1998), four mothers of children with significant developmental disabilities were interviewed and given the opportunities to share their experiences and feelings with respect to their leisure time and to describe the meanings and values they place on leisure engagement.

Phenomenology is one qualitative research approach designed as a means for investigating questions concerned with the lived experience (Benner, 1994; Peters, 1996). Open-ended, semi-structured interviews allowed me the flexibility to explore further individual differences, and to ask questions in hopes to better understand the topic. Phenomenological research aims to identify the essence of personal experiences through statements based on meaning. Interpretation of their stories helped to develop a conceptual understanding for how mothers of children with significant developmental disabilities engage in leisure activities. Phenomenologists do not impose an interpretive framework on data, but look for it to emerge from the information they obtain from their informants (DePoy and Gitlin, 1998). Common themes emerged from the data identifying their specific chosen leisure activities, addressing the challenges faced by mothers related to leisure engagement, the orchestration of mothers leisure time within their daily routines, and their
feelings and values related to engagement in leisure activities. Human participation in this study was approved by the Institutional Review Board of the University of New Hampshire (see Appendix D).

**Stance of the Researcher**

Qualitative methods allow the researcher to bring to the study his or her own values, beliefs and interests. He or she becomes part of the study rather than an objective collector of data (Creswell, 1998). The researcher brackets his or her own preconceived ideas about the phenomenon to understand it through the voices of the informants (Field & Morse, 1985). For this study, I have examined my own engagement in leisure activities, how I orchestrate my day to include leisure occupations, and have reflected on my own personal feelings, values and beliefs I associate with these activities. Personally, I greatly value leisure activities and incorporate leisure into my routine daily. For me, leisure comes in a variety of forms. I engage in passive leisure activities such as reading, crafting and listening to music. My "active" engagement in leisure includes going to the gym, gardening, walking the dogs, hiking and spending time with friends and family. I value leisure activities because it allows me to connect with my inner sense, engage in new experiences, become educated to new viewpoints and gain mental and physical health benefits. Leisure affords me the opportunities to reconnect with family and friends; people I greatly value and deeply respect. I engage in
leisure activities to feel better physically and emotionally and work hard everyday to understand my physical and emotional state, as it can fluctuate daily due to work, family, time and schedule demands. I re-evaluate my needs throughout the day and then match what I feel is the appropriate leisure activity to meet my needs.

I am currently an occupational therapist working with children with disabilities and their families, through early supports and services. My experience is primarily working with mothers with children with significant developmental disabilities in their homes. Being in their homes has allowed me to observe many aspects of mothering and motherhood. Being a mother is a complex, lifelong, engaging role. Working with mothers with a child with a significant developmental disability has afforded me an ongoing respect for the expansiveness of their intense caregiving, mothering, and nurturance and daily engagement in occupations. I hope that in talking with the mothers with whom I work, I help them see the value of leisure for increasing their sense of self and well-being. My observations of behavior, schedules and the emotional well-being of mothers coupled with listening to mothers talk about their desire and personal need to reinvent their leisure have prompted me to conduct this research. I believe that these mothers truly want to find ways to enhance their leisure time.
After each interview, I listened to the interview responses and wrote down my thoughts, questions and feelings. Reflecting on my own beliefs about leisure engagement, how I value leisure and the overall benefits I experience when engaging in leisure occupations, has helped me to understand how they were experiencing leisure and how my biases were influencing my interpretations of the data.

Data Collection

I interviewed each mother about her engagement in leisure activities, her feelings of well-being and satisfaction with leisure occupations, time management and her thoughts on motherhood. (See interview guide in Appendix A). Approximately 1-1.5 hours was spent with each mother. The interview sessions were audiotaped and later transcribed verbatim for analysis. During the transcription process, names were changed to maintain confidentiality. Informal notes were also taken during the interviews, and I wrote reflective notes after each interview, which contributed to data analysis.

Data Analysis

The first step in the data analysis process was reviewing my written notes from each of the interviews. Subsequently, as each interview was transcribed, I read the transcriptions at least 3 times. Following a traditional phenomenological approach, I then reviewed the interview responses and grouped the responses into “meaning units” (Creswell,
I used colored highlighters to color code the statements. The highlighted statements were then grouped together based on similarities and emerging themes were developed. Emerging themes were labeled and responses are then sorted into each theme. After taking a break from reviewing the data, I came back to my text to rework the grouping of the interview responses and content of the themes for further clarity. Dickie (2003) reminded us that this "shaping" of the data takes place because in the act of bringing them to order, certain events and stories are data and others are not. Making the data fit into specific themes was challenging for me. For example, many of the responses were relevant to changes in leisure definitions and finding time for leisure. There were many overlapping statements that related to one another; however, I felt strongly that separating these statements into two themes was important for a better understanding of the mothers' desire to engage in leisure pursuits. In order to increase the trustworthiness of these emerging themes, a second researcher, my research advisor who is experienced in qualitative research methods, also reviewed the text. We both found similar themes related to the research questions posed. The result of this analysis was a description of the leisure occupations of mothers of children with significant developmental disabilities, and the meaning of leisure for these women which are presented in the chapters that follow. They included four themes identified from the text:
a.) Defining leisure: Multiple Perspectives.
b.) Leisure occupations: Engagement and meaning.
c.) Never enough time.
d.) Level of satisfaction.

Participants

Mothers with a child with a significant developmental disability were recruited through word of mouth. Criteria included having a child with significant developmental disabilities. Colleagues helped to make initial contacts with interested families. Interested mothers returned their contact information. Six mothers volunteered. Two mothers were omitted because I had previously provided services to the child and family. All families were currently receiving intervention services through their local early supports and services program and area agency. I subsequently obtained informed consent forms from all participants prior to the interviews (see appendices B and C for consent forms). Mothers were selected based upon their willingness to participate and the age of their child (between 2-11 years old). Selection was also purposeful to obtain some diversity with respect to family make-up and age of the child with a disability.
Table 1  Demographics of Children and Their Mothers

<table>
<thead>
<tr>
<th>Mother's Name</th>
<th>Child's Name</th>
<th>Age</th>
<th>Marital Status</th>
<th>Employment Status</th>
</tr>
</thead>
<tbody>
<tr>
<td>Barbara</td>
<td>Shawn</td>
<td>6</td>
<td>Married</td>
<td>Works from home</td>
</tr>
<tr>
<td>Amy</td>
<td>Connor</td>
<td>11</td>
<td>Married</td>
<td>Employed full-time</td>
</tr>
<tr>
<td>Karen</td>
<td>Anna</td>
<td>3</td>
<td>Married</td>
<td>Homemaker</td>
</tr>
<tr>
<td>Kerrie</td>
<td>Ben</td>
<td>3</td>
<td>Married</td>
<td>Works from home</td>
</tr>
</tbody>
</table>

*Pseudonym

**Barbara**

Barbara is a 40-year-old married mother of two children. Their son Tim at the time of this study was 10 years old, and Shawn 6 years old. Barbara is currently working from home as a writer and her husband David works for the local newspaper. The family just moved into their newly renovated wheelchair accessible home. Barbara previously worked part-time outside of the home when the boys were younger and both boys attended a local day care. Barbara described her pregnancy as “great” and Shawn was born 4 days prior to his due date. There were no health concerns following delivery. Shawn appeared to be developing typically as an infant and concerns were first generated at 4 months of age when Shawn was not interested in watching his hands. A referral to Early Supports and Services was made and Shawn was assessed to be eligible for services due to developmental delays. He received home-based services until he was 3 years old and then transitioned into his local school district. Through metabolic testing, Shawn was diagnosed with a rare metabolic disorder characterized by a deficiency in the enzyme
responsible for the breakdown of complex fatty acids. This clinical presentation included muscle weakness, hypotonia, dystonia, global developmental delays, feeding and swallowing problems and other medical complications.

As Shawn’s medical and developmental needs increased, Barbara reduced her office work hours to 3 days/week to accommodate for the scheduling of many medical and therapy related appointments. At the time of the data collection, Shawn was attending ½ day kindergarten at his neighborhood school. Barbara and David were currently receiving home visiting services from the Visiting Nurses Association 3 days a week to assist with medical management and allow Barbara the opportunity to complete her freelance grant writing work and engage in other occupations. Barbara is an active member of the community taking part in volunteer opportunities and being involved in the boys’ school activities.

Amy

Amy is also the mother of 2 boys. Her son Connor, 11 years old, is by her first marriage and her son Zachary, 2 years old, is from her current marriage to her husband, Bill. At the time of the study, Amy was working 5 days a week outside of the home, and her son Zachary attended a community based childcare program. Connor received early supports and services until the age of 3 and then transitioned into the local school
district. He was currently in school full-time, where he receives special education and related services. Connor was born with microencephaly. Amy stated, "I have always disliked the term, "microencephaly" and she prefers to use the term cerebral palsy and quadriplegia to describe Connor's medical condition. Connor wears lower extremity ankle foot orthotics (AFOs), wrist splints and a body/back brace. He requires the support of special seating devices for proper positioning and mobility. Connor has a seizure disorder and is fed by a gastrostomy tube. Connor is non-verbal and he uses eye-gaze as well as an augmentative communication system consisting of picture symbols and computers to communicate his wants and needs.

Amy and Bill have received Visiting Nurses Association services (VNA) in the past to assist with meeting Connor's medical needs while at home for some respite. At the time of study, they were not receiving VNA services, but were connected to their local area agency, and received support and respite when desired.

Karen

Karen is a 33 year old married mother of two. Her son Scott at the time of this study was almost 5 years old, and her daughter Anna was almost 3 years old. They have family in the area and see them often. Karen previously worked full-time in a laboratory and her husband was employed by the Army and returned home from his deployment shortly
before Anna’s 2nd birthday. Anna previously attended a day care full-time and has been cared for by Karen at home for the past 2 years. Karen described her pregnancy with Anna as “going well” until 36 weeks when she went into early labor. Anna was delivered via C-section due to being in the breech position. Due to medical complications, Anna received genetic testing and was later diagnosed with Down syndrome. At the time of the study Anna and her family were participating in early supports and services, and she was beginning the transition process from early supports and services to preschool services.

Karen is currently not working outside of the home. She cares for Anna and Scott as well as her nephew who comes to the house before and after school. Karen is involved in a local Down syndrome parent support group and takes part in fundraising events for Down syndrome awareness.

Kerrie

Kerrie, in her mid 30s and her husband Ed, in his early 40s, have been married for 4 ½ years. Kerrie and Ed have a wonderful extended family support system and they see them often. Their dog, a Labrador, is also a very important part of the family! Kerrie and Ed own their own business. Ed has 2 older children from a previous marriage who visit regularly. At the time of the study, Kerrie was expecting her second child.
Kerrie described her pregnancy with her son Ben, as “normal.” An ultrasound at 30 weeks was fine. Kerrie was induced on her due date, however required an unplanned c-section because Ben’s “head was too big.” He was later transferred to another hospital and diagnosed with congenital hydrocephalus. He required shunting surgery before discharge home. Further genetic testing revealed a diagnosis of a rare genetic condition. Because of seizures, Ben wore a helmet and was on medication. Neurological testing indicated agenesis of the corpus callosum. Ben has frequent medical appointments for vision and hearing, neurology, urology, gastroenterology, orthopedics, chiropractic, as well as regular visits to his pediatrician. At the time of the study, Ben was receiving occupational, physical and speech therapies through his early supports and services program as well as outpatient physical therapy in the swimming pool to facilitate movement and range of motion.

Kerrie and Ed were looking at local preschools for Ben for his transition to preschool with special education services to begin the following spring. Kerrie had considered home schooling Ben, but decided it would be in Ben’s best interest to learn and socialize with other children in a setting outside of home. Kerrie was working part-time, and struggling to find time in her busy schedule to work from home and meet her deadlines. Kerrie also participated in a leadership course at a local
university that teaches parents of children with developmental disabilities how to be the best advocate for their child.
CHAPTER III

Results

The analysis yielded four themes that captured the mothers’ thoughts about leisure and their participation in leisure activities. These themes described how leisure has evolved over time for them, how they struggled to find time for leisure, and their satisfaction with their leisure engagement. The analysis also provided an understanding of the feelings that the mothers associated with leisure engagement, and how they orchestrated their time to meet family and work demands, and maintain an occupational balance. The four themes are titled:

a.) Defining leisure: Multiple perspectives.

b.) Leisure occupations: Engagement and meaning.

c.) Never enough time.

d.) Satisfied with leisure?

A.) Defining Leisure: Multiple perspectives

There was a lot of variability in the ways the mothers defined leisure, and each of the mothers shared more than one perspective on what she considered leisure. Mothers in this study defined leisure as an opportunity to be by themselves and “in the moment.” Leisure could be spent alone, with girlfriends, as time with their husbands and/or time spent with the
family. It was also viewed as an occupation of choice, or non-obligatory time and activities associated with physical fitness. Finally, of interest was that this definition of leisure changed over time.

First, many of the women believed leisure to be time spent doing activities alone. This "alone" leisure time included engaging in physical activity, spending time alone to read or crafting and cooking. For example, Amy consistently referred to leisure time as, "something I do without my family," "doing something I enjoy outside of my family...much needed time alone."

Three of the mothers included time spent with their girlfriends in their definition(s) of leisure, and believed that their leisure time ideally, should be balanced with family and friends as well as time alone. For example, Amy reported leisure for her was also getting out of the house on Wednesday evenings with her best friend, "end up in a restaurant eating, chit chatting and complaining about husband and kids." Kerrie reported leisure for her also included getting together with friends and "being a normal mother." Karen acknowledged that her definition of leisure also includes a "girls night" once a week.

Although the mothers often defined leisure as "time alone" or with their own girlfriends, they also included spending time with their spouses and kids as leisure time. For Karen this included spending time with her husband after the children have gone to bed. She stated, "after the kids
go to bed, this is our alone time, whatever we do (i.e. watch television, wrap Christmas presents), we do together...we do not split up because we only see each other for a couple of hours a day.” Karen also described planned events with her spouse “going kayaking, camping and hiking.” Although Barbara reported that for her leisure is a “day at the beach by myself,” she stated, “going with David (her husband) would be nice.” She acknowledged, “David and I go out to dinner...that is really nice.” Kerrie included spending time with her husband in her definition of leisure, this is also one of the many reasons she engages in leisure activities; “having time with my husband, couple time.” Amy talked about getting respite and “my husband and I will go to dinner or movie, this is time for us.”

All of the mothers reported the need for balanced leisure time. Barbara expressed the need for a “balance of both...alone time and time with family; definitely need time alone.” Karen reported her leisure needs included both time alone and time spent with her family. She stated, “I definitely think my definition of leisure and doing things I want to do would be met by doing things with my family.”

The idea of “choice” was prevalent among the mothers. Leisure pursuits were defined consistently as those activities that they were intrinsically motivated to engage in, not those they were obligated to do, or needed to do. For example, Karen stated leisure is “anything I want to
do, not something I have to do." Leisure for Amy is "being able to choose not to do anything."

Included in their definition of leisure was engaging in physical activities. For example, Amy talked about "gardening and walking" as preferred leisure activities. Kerrie stated, "I have always tried to stay active and workout...hiking and running." Barbara talked freely about leisure activities including, "going for walks, exercising and hiking." Karen liked to exercise and spend time gardening, kayaking and hiking.

All the mothers in this study reported significant changes in their definition of leisure, as they adjusted to being a new mother, and their roles and life routines changed over time. Their thoughts about what constitutes leisure continued to evolve as they encountered the many challenges of being a mother of a child with significant developmental disabilities. For example, Amy's definition of leisure changed after having her first son Connor who is significantly developmentally disabled. Before having her son, Amy defined leisure as "having all the time you needed to do what you wanted and doing what I wanted to do when I wanted." Now she views leisure differently, "totally different, having a child adds other responsibilities and demands on time, now you have mommy this, mommy that. With Connor, it is different, more meds, stretching, OT and PT. Laying on the couch just never happens." As she faced the many parenting challenges and routine changes, her definition of leisure shifted
from "having much time by yourself" to "much needed time away, to take a break from all the things that need to be done; stretching, range of motion, providing medication and household tasks." When her second son Zachary was born, Amy said her definition emphasized more alone time and being "outside of the kids, getting out by yourself." She also stated a need for her "own time, it does not come that often, however there are days if I had my choice, Connor being gone to his dad's house, my husband taking Zachary and me going to the store and buying plants, shrubs and then planting them, being by myself."

Before having kids, leisure for Karen was "my whole life before having a baby and everything you do is what you want to do." Leisure was "taking a day off from work to go skiing, taking a whole day to hike and not worrying about the house or when to come home." Her definition of leisure changed after having her son Scott due to the stress of being a new mother and caring for a child. After her second child Anna was born, Karen realized "just how much free time you had with one child." Karen talked freely about the change in her leisure engagement after having children. She mentioned that before kids, leisure meant, "anything I wanted to do for fun, time was not a factor and this allowed me to try new leisure activities." Karen talked about getting an hour to herself. "I might use this hour walking up and down the aisles at Shaws or completing a painting project for a friend." For Karen, this is leisure time, it
is not her first choice, that being hiking up and down a mountain, or spending time at the gym. However she stated, "this allows me to decompress and acts as a de-stressor." This helps Karen move towards her goal of being a more patient mom and a well-balanced person.

She stated:

the more I do here and there, I am a better mom, more patient. I do notice on the weeks when it is crazy and I am running around, I am less likely to stop and make a fort and play with them for an hour. I do notice that if I get time out to distress, take time for myself and have some time alone and to not be engaged constantly, I am much better for them.

Barbara defined leisure as "something that is relaxing and where I am not thinking about the next thing I have to do." Reflecting back, Barbara stated, "Having a child is a change regardless, I did not know it was leisure then. I took for granted having nothing to do on Sunday." She stated, "Leisure could also be an unstructured day with my boys....helping Shawn kick the soccer ball or holding him while he hits the ball off the tee or walking up and down our street helping Shawn steer his bike while he practices pedaling." Barbara has recognized that her definition of leisure not only includes finding time to be alone and do something that is relaxing, but includes time spent with her family and participating in activities that allows her meet her leisure needs.

All the mothers talked about how their roles have changed and how these changes have influenced their definition of leisure.
For example, Amy stated, “Connor requires medication, stretching, range of motion and 24 hour care...less of a typical parent role and more of a medical role.” This role change has changed her definition of leisure which now includes more “alone time, having down time” and “owning” her alone time. Kerrie reported feeling like a “healthcare provider” with all the medical appointments and having therapists coming in and out of her home. Kerrie acknowledged that leisure for her includes getting together with friends and saying, “hey I am just a normal woman, a normal mother being with friends.” Barbara has also taken on the role as advocate and researcher, “I need to be proactive and do research to find appropriate leisure activities that the whole family can engage in together and that meet everybody’s needs.”

The mothers in this study defined leisure in a variety of ways. They consistently defined leisure as time spent alone, as well as with family and friends. Leisure was viewed as time spent doing certain types of activities. They reported changes in the definition of leisure as they adjusted to being a new mother, then a mother of a child with significant developmental disabilities. As their roles and routines changed, definitions of leisure were adapted to meet their needs and the needs of their families.
B. Leisure occupations: Engagement and meaning:

All of the mothers in this study reported engaging in a variety of leisure activities and expressed the desire to participate in leisure that fits into their daily routines. This section begins by highlighting some of the leisure activities of the mothers.

Karen reported that she exercises for leisure. She tries to exercise 3 times a week and this is usually done in the house on her stationary bike or working out to a variety of videos. Karen structured her day so that her son goes to afternoon kindergarten and her daughter takes a nap in the afternoon. This time allows her to engage in exercise activities and paint. "When Emma naps, that's when I have an hour or two by myself. This is when I will work on a project, if I have one, or I will fit in some exercise."

Kerrie reported, "I like to hike, cook and read and have a girls night out for dinner." Kerrie talked about many of her favorite leisure activities as ones she would like return to. "Vacation, swimming, going to the beach, movies and travel. We did it a lot before Ben was born."

Barbara reported some of her leisure activities include, reading, going hiking and walking. Amy stated, "I like planting, gardening, reading and sitting down and watching the food network." Amy also talked about going to flower shows and taking long walks as some of her favorite leisure activities.
When asked whether or not they prefer leisure time alone or with others, the majority reported needing the time alone as well as time with family and friends; needing a balance between the two. For example, Barbara stated, "Alone, I do take walks by myself, also exercise and read. With my family, we take day trips and I like to get together with friends also. I definitely need a balance of both (alone time and with others), but I definitely need time alone." Kerrie who likes to cook and read reported, "I definitely like to do things on my own, I definitely like to be alone, be by myself." Karen talked about her leisure time as alone time; painting and exercising as well as spending time with her family. "When I am with my kids, my favorite thing to do is snuggle. We have a big chair and we snuggle and watch Good Morning America, it is great when you have a big blanket. We listen to music and dance, read books or play outside. We are really into making forts, so we will turn the livingroom into a fort."

Amy's leisure activities include spending time with her girlfriends and taking walks after dinner with her family. She reported, "getting out of the house on Wednesday evenings with my best friend. We end up in a restaurant eating, chit chatting, touch base with other women and complain about husband and kids." She also prefers spending time alone. Amy reported, "on an ideal day, my leisure would definitely not be with my husband or kids. I'm a little bit more selfish."
The mothers in this study reported they engage in leisure for a variety of reasons including, finding a balance between feeling “normal” and the daily routine of caring for a child with significant developmental disabilities. When they find time to engage in leisure activities the mothers are looking for moments of “normalcy” and the expectation of time away from day to day pressures. Kerrie engages in leisure for “normalcy, stress relief and time to sort out my thoughts.” Barbara reported for her engaging in leisure is for the “need and desire to break away from the regular schedule and day to day pressures.” For Barbara leisure engagement is recharging and is reflected in her choices: reading, hiking, going for a run or walk and getting together with friends. Barbara’s alone time is important to her just as much as time spent with her family. She considers some of her leisure engagement when with her children. For example, as Shawn learned to ride his adaptive tricycle, Barbara viewed this an opportunity to exercise as she walked along side Shawn as he pedaled to the end of the street. Barbara described a day at the pool as being in the pool with Shawn, helping him move through the water and remain supported in his float. Although she views this a leisure activity for her, she is aware that other mothers might not view the activity as leisure. She said, “I can never be one of those parents who brings her kids to the pool and then sits by the pool in her chair and reads a magazine.”
Kerrie seeks out some "normalcy" in her leisure time and she finds this when out with friends, "just a normal woman, normal mother being with friends."

All of the mothers engage in leisure activities to improve their mental health. Kerrie also engages in leisure for "stress relief and time to sort out my thoughts." Karen engages in leisure for "sanity...the more I can do here and there, I am a better mom, more patient." Karen talked about those busy days that turn into a busy week and how she is "less likely to build a fort and play for an hour with the kids." She reported that she is aware that when able to engage in leisure outside of the home, usually one night a week, she is much better for her kids. She has recognized the added stress she experiences in raising Anna, and she tries not to think about what it would be like if she was not born with Down syndrome. "In order to deal with the added stress and acquire the necessary patience for raising Anna, I need leisure activities. I now have a greater need for leisure activities."

As the mothers' definition of leisure has changed over time, so to has the types of leisure activities they engage in and the meanings they attach to their leisure pursuits. Each mother described how their engagement in leisure "fits" their changing views of definition of leisure. For example, Karen stated, "I now have a greater need for leisure activities, but I cannot do the things I used to do, ...as often as I would
like." Karen’s leisure activities, many of them being before children, have moved from being very active (i.e. hiking, kayaking and camping) to more passive activities such as painting, gardening and socializing over dinner at a friend’s house. Karen now searches for leisure activities that she can engage in at home or ones that require less time when outside of the home, that do not involve great expense and fit into structure of her day (i.e. nap times, school times). Karen calls these “at home” leisure activities. These activities include gardening, instead of kayaking, and riding her stationary bike and working out to exercise videos instead of joining a gym.

Kerrie also illustrated this change in leisure engagement when she explained that she preferred to seek out solitary activities such as reading a book. However, her commitment to running some road races this past summer with her brother made her feel like she had to go running. "I almost feel like if it were leisure then I should be doing it more. I would say to Ed, watch Ben, I have to go for my run." Kerrie was trying to fulfill the commitment to train and run with her brother and viewed it as something she needed to do and not necessarily something she wanted to do. She stated, "I feel like if it has a purpose, it is less leisurely." However, she also wonders if jogging and running road races is something she would have done prior to having Ben. Kerrie talked about how her leisure engagement has changed since having a child, "it involves more alone
time than before, before having a child, you take for granted the alone
time...I think that is not different than a lot of people with kids." Before
having a child, Kerrie and her husband Ed traveled a lot and often spent
time with friends going to dinner and the movies. After having a child with
significant developmental disabilities, Kerrie prefers to spend most of her
leisure time engaging in familiar leisure activities (i.e. cooking, reading and
journaling), and she now has a stronger desire to be alone. When Kerrie
and her husband spend time together, their activities are more active
such as short hikes. Kerrie and her husband talk frequently about returning
to some of their earlier leisure pursuits (i.e. traveling, hiking and going to
the beach), however she fears for Ben's medical fragility and being too
far away from home if something should happen.

Kerrie expresses her fear about traveling with Ben:

    We have talked about traveling with Ben and there are
    places we might not go because of his healthcare
    needs. He has had one shunt malfunction in his life. It is
    not like it is going to happen everyday, but I am thinking,
    it would be just my luck to have something happen while
    on vacation. We talk about hiking and I wonder is he
    ever going to be able to hike. Will he be able to come
    with us or not, we have questions like that.

    Her desire to return to some of the familiar leisure activities is offset
by her fear that Ben's shunt may fail and his medical needs cannot be
managed, and by finding people other than family members who she
can feel completely comfortable and trusting of to care for Ben. "There
are very few people that I trust to take care of Ben."

63

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Amy expressed a unique perspective on the change in leisure engagement. Her leisure activities include reading, gardening, planting, decorating and shopping. This is consistent with the way she has defined leisure, “doing something I enjoy outside of the kids.” Amy cherishes the time she spends with her family; going swimming, taking walks and day trips however, she also feels very strongly that alone time is just as important. When asked about a perfect or ideal “leisure day,” Amy was passionate about it being “my day” with no husband or kids. Her day consisted of all the leisure activities most important to her. She declared, “The whole day, this could be fun. I would stay in bed until 8am and would not have my kids or my husband with me. I think it would be my day. My leisure would definitely not be husband or kids. I’m a little bit more selfish.” Since having a child with significant developmental disabilities, her participation in leisure activities have changed, especially as Connor has gotten older. When Connor was younger, she had the “I can do it all attitude”, as he got older, she feels she now has more opportunity for leisure pursuits. Amy reports she is utilizing respite and feeling like she is “smarter now.” She has learned a lot about planning, routines and time management as Connor as gotten older. Her solitary or more passive activities are usually planned for the weekends instead of during the week.
According to Amy, the week is a time of being busy with household and school related tasks and working full-time outside of the home. Weekends for Amy and her family involve more family time that is now easier to plan. She reinforced this by her statement, “Connor is 11 years old now and a lot of things we have already worked through; what other people see as the need to plan for, for us it is just part of our routine.”

For Barbara, the change in leisure engagement changed after giving birth to her first son Tim. She views having a child is a change regardless, in routine, lifestyle and relationships with friends and family. “I didn’t know it was leisure then. I took for granted having nothing to do on Sunday.” Since having her second son Shawn, Barbara’s engagement in leisure activities changed more dramatically. There is more planning on a daily basis to meet Shawn’s medical and therapeutic needs. She described her oldest Tim as more “portable” when he was Shawn’s age. This made it easier to pick up and go together or to find babysitter for Tim so Barbara and David could spend some time alone. It is still easier to help Tim plan time away with friends and family.

Barbara talked about the differences in planning when Shawn was transitioned to g-tube feedings:

it never occurred to us...we could ship Tim off for these great adventures with friends of course, and we would be stuck at home. Shawn would want to do these great adventures also. His health has been so poor and eating was difficult. With his g-tube we pack and plan a lot. Wherever we go we have our cooler, meds for the
whole day, formula needs, oral eats and tons of snack. We incorporate that into our travel, we are still restricted, however more flexible.

With Shawn, his needs are greater from a medical and developmental perspective and more planning is needed. Since having Shawn, planning for leisure engagement individually and as a family is a constant reminder as to the complexity of the daily routines. She stated, "I have become more active, better about planning things to do which is more fun. Things became a little easier when Shawn was transitioned from oral feedings to g-tube feedings. His g-tube feedings can be incorporated into their travel, however Barbara commented that even though they have more flexibility, some restrictions remain.

The mothers in this study expressed the desire to participate in leisure that fits into their daily routines, and that gives them a break from specific caregiving activities. They chose activities that are meaningful and provide them with the opportunity to meet their physical, mental and emotional needs.

C. Never Enough Time

The most consistent reason for not participating in leisure as much as desired, was the challenge of finding enough time to do so. Other priorities included work outside of the home, meeting daily medical and developmental needs of their children, and meeting the regular routines of their lives and needs of the family. All of the mothers talked about the
need to balance all of their mothering occupations and that finding time for themselves was often given the lowest priority. Finding time for leisure often did not happen everyday and it often needed to be planned ahead of time.

Amy’s daily routine provides a good example of how a typical day might go for a mother with a child with special medical needs. She first begins by getting her son Connor out of bed, bathes him, dresses him, feeds him through his g-tube, puts him in his wheelchair and on the school bus, while anticipating the needs of her youngest son. She then goes to work. Once home from work, she is required to make dinner, do laundry, provide Connor with his medications and then put the kids to bed. She stated: “I then sit around on the couch checking out television while paying bills or making picture symbols. This is typically my time and it is spent not doing much of anything, this is some down time before the next thing needs to be done (i.e. the next load of laundry).” When asked what makes it difficult to engage in leisure activities, Amy responded simply, “it is time, fitting it in with everything else.” When her family is together, Amy stated, “we will go, if we stay home, I will be doing laundry and washing the floor, my husband knows that we have to go... to leave the house to do something together.” Because Amy’s week is busy with household tasks and working outside of the home, her leisure time is saved for the weekend. Amy makes a conscious effort to plan leisure time by herself or
with her family on the weekends. She views her "down time" as just what it is, time spent waiting to move onto the next task, it isn't a time exclusively for her.

Karen described having time for leisure is difficult because of the challenges she faces with two kids and finding somebody to watch the kids. Karen also acknowledges the personal struggle she has with being a stay-at-home mother and guilt she feels when she wants some time away for herself. She stated: "There is the whole guilt factor of I am putting in a movie for an hour for my kids so I can do something else. I feel like if I am going to be home I should be engaged with them." Karen's husband works full-time and often works late. Karen reported this is difficult, "I am spending my whole day with them....so then I am not having time for myself. It is a constant balance."

Finding the time to engage in leisure activities is a struggle for Karen as well as managing feelings of guilt for wanting to engage in activities for and by herself. She has found that leisure activities for her occur in quick bursts of time (i.e. while Anna is taking a nap or the kids are watching a movie) or she seeks out activities that she can do while simultaneously attending to her kids (i.e. gardening or painting outside while the kids play in the yard).

Another example of how daily routines are constructed without including leisure was presented by Barbara. She talked about her life
being structured by the needs of her son Shawn, his medication, feeding and sleep schedule. Barbara and her husband David have a tightly structured day based on Shawn's medical needs, which leaves little room and energy throughout the day for leisure activities. At night Barbara's husband David helps complete the evening routine of giving medications, cleaning up and preparing lunches and snacks for the next day. During this time, Barbara is helping with homework and preparing Shawn for bed. "I clean when I get a break or I do work. I am too tired at the end of the day for anything else." Barbara tries to provide herself some leisure time at the end of the day by reading, however she is often too tired and is always anticipating the next round of late night feedings, medications and Shawn's night wakings.

Barbara admitted having high standards for keeping Shawn engaged and this interferes with her finding time for other things. "I have high standards for keeping him engaged, keeping Shawn happy keeps me engaged all day, whatever gives him joy gives me joy, it is hard work on my part, however I do need a break from that or have somebody else do it."

Although Barbara talked strongly about finding time for her own leisure and described her ideal day as a "day at the beach by myself," and she also talked about her need for lots of family leisure pursuits to meet the needs of all family members. She works hard to have the
balance between individual leisure time and leisure time with her family. Barbara acknowledges that her high standards for keeping Shawn engaged interferes with any free time she may have to engage in preferred leisure activities.

Kerrie reported finding the time to engage in leisure activities is difficult due having a hard time finding people she trusts to care for her son Ben. "I used to go to the gym, now I would never take Ben to the daycare there. He would probably do just fine, but I would have to go in and explain everything like if he has a seizure, come and get, that kind of thing."

Karen stated, "my husband and I try to have a date night, once or twice a week...depending on how often we can get a babysitter." Karen also described a day kayaking with her husband Ron, "we had to find a babysitter, who could only watch the kids for 6 hours. We had to totally plan our time accordingly, a two hour drive round trip and then we could only paddle for two hours and then we had to turn around."

The mothers in this study want to engage in their preferred leisure activities, however feel their pursuits are constrained by time and feelings of guilt and concern for the care of their children. They express a desire to return to some of their previous leisure activities. However their time is constrained by time devoted to the caregiving needs of their
developmentally disabled child, working outside of the home and feelings of guilt for wanting to spend time alone.

*Satisfied with leisure?*

When discussing whether or not they were satisfied with their engagement in leisure activities the mothers provided varied responses, although the tended to emphasize factors that contributed to their dissatisfaction with leisure occupations. Most of the mothers expressed their dissatisfaction with their leisure engagement due to not having enough time as was discussed above. For example, Karen stated, “Although I love my hobbies that I have and the activities that I chose to do...I am not satisfied with how often I get to do them, again, time and fitting it in.” Karen is clear about what her expectations are for leisure and what type of leisure would be ideal. In an ideal world, if Karen could engage in the leisure activities she most prefers and as often as she would like, her satisfaction level would be different. Karen struggles with feelings of guilt when taking time for herself for leisure activities.

Karen feels stressed when not in control and she readily admitted:

the fact that Anna has a disability is out of my complete control and so I want to control as much as I can, especially how she learns. So it does factor into my need for leisure activities, instead of her being at daycare, I chose to be at home with her, so now I feel guilty when I try to do what I want to do and that makes it harder.
This impacts Karen's engagement in leisure and in turn her overall satisfaction with her leisure engagement because she feels guilty when she takes time for herself.

Amy talked about her satisfaction with her leisure time:

It is time, fitting it in with everything else, I work 35 hours a week, take care of 2 kids, getting Connor on the bus. My day starts at 5am and we are in bed by 9:30, which is early. I like planting, gardening and watching the food network, these are things I do not seem to get a whole lot of time for, however, this time in my life we are utilizing more respite so we have gotten more leisure time and we are smarter. Chris is 11 years old and everything is much easier now, I have more leisure time than I have ever had. Is it all that I want? Probably not, but it is good.

Although Amy recognizes that her life is different at this time, she is still seeking a higher level of satisfaction with her leisure pursuits. This is evident in her ideal day being "my day...would not have my husband or kids here."

Barbara has recognized that her engagement in leisure activities that promote alone or "me" time is limited and influenced by the structure of her day and caring for her significantly developmentally disabled son. Lack of time and energy influences Barbara's level of satisfaction with her preferred "alone time" leisure activities. "I can never be one of those parents who brings her kids to the pool and then sits by the pool in her pull-out chair and reads a magazine. It cuts down on other things I would like to do because I do not have the energy." When asked if she was
satisfied with her leisure engagement, she responded, "no, Shawn’s peers have more time than I do, it’s not going to get better." Maybe it is this reasoning Barbara is searching for family based leisure activities to hopefully meet her own leisure needs while providing her children with great learning opportunities. Barbara commented, “my leisure is me by myself or the whole family. As a family we need to be proactive and do research, this is important because Shawn will have to do this all his life. We are researching things, however the downside is the expense.” Barbara would like to try skiing with her family, however commented on how expensive skiing is and the need to modify the activity to meet Shawn’s physical needs as well as meeting the needs of her husband David and their son Tim.

Another factor influencing their engagement in and their satisfaction with their leisure activities was money. For example, Karen stated:

most leisure activities outside of the home cost money, I would love to join a gym or take a class and this would be an ideal use of my alone time. I could use the physical and mental stimulation. Instead I just use the time out of the house as quiet, alone time. It all helps. I can not afford to take up new leisure activities outside of the home, so I have had to change my definition of leisure. For example, when I get an hour to myself, I decompress walking up and down the aisles of Shaws. It is still not the ideal activity, but it acts as a de-stressor and allows for fun playtime later with the kids.
Kerrie is not satisfied with her engagement in leisure activities. She stated, “I do not have any time by myself because I am always with Ben.” Kerrie used the example of taking up running as a commitment she made to her brother. She doesn’t view this as leisure and often wonders if she would have done this before having her son Ben. She bought a jogging stroller so she could take Ben along. “I took up running, because it was something I could do with Ben.” Kerrie would like to spend more time by herself reading, cooking and more time with her family going on vacation and to the beach, however she is not as trusting to leave Ben with other caregivers because of his healthcare needs. She expressed, “through my leadership course, they are trying get me through my trust issues and fear, teaching me to be an advocate for myself and for Ben. The class has helped me to open up.” She hopes her participation in the Leadership Course through the local university will help her become more comfortable with advocating for her own needs. Until then, her satisfaction with her leisure engagement is compromised.

Most of the mothers in this study have found some meaningful leisure, and although they may not always be satisfied with the amount of alone time or they activities that they have chosen, they attached meaning and value to the activities they engage in. The mothers’ leisure exploration requires planning time away with and without family, finding appropriate resources (i.e. time, childcare and money) and dealing with
the guilt of leaving their child with other caregivers or providing them with another activity (i.e. movie on television) so they can take time alone. The mothers in this study had a clear picture in their minds of what they wanted to do and they did report engaging in meaningful activities.

Satisfaction with leisure may not have been as important to these mothers because of the satisfaction they received in their roles as mothers. The mothers in this study talked about "being a mother."

Amy talked about how being a mother has changed her:

being a mother is a great experience, it has been wonderful and I would not change it. With Connor, you do not look at the huge things, it is all the little things. It makes you slow down and appreciate the little things. Being a mother of a child with a disability is life changing, the people you meet, things you do, the relationships you develop and the experiences are much different than having a child without a disability because this is what happened first. I would not be the same person, it makes you a better mom for your other kids.

Kerrie reported, "Being a mother means everything to me. I have always wanted to be a mom. I never thought I would be a mom of a kid with a disability, it just did not occur to me. I think it has made me a good mom. I am right on top of things. I am always trying to get him out with other kids. It is sort of like my mom agenda."

Barbara expressed her joy in being a mother:

being a mother is just wonderful. It has broadened my world in terms of how much love I can carry for people and how hard I will work for them. My job is to nurture and protect my kids, nurture my children in a way that
they become open to the world and enthusiastic about learning while at the same time protect them and help them gain the skills to protect themselves.

The mothers seemed to gain some clarity through motherhood and have realized that time is precious. They expressed enjoyment in their mothering role which perhaps reduces the reliance on leisure activities for the purpose of life fulfillment (to some degree). They are learning and experiencing joy and happiness when they spend time "mothering" and caring for their children. It is this enjoyment in their mothering role that may be replacing their own leisure needs.
Mothers in this study defined leisure in multiple ways. All the mothers reported their definition of leisure changed after having their child, especially a child with significant developmental disabilities. Thus their engagement in leisure and their chosen activities changed. They strive to balance alone time, time with friends and family as well as engaging in preferred activities. The mothers in this study viewed their leisure pursuits as time spent away from the structure of their day, and a break from tasks that "need to be done." They became family-centered in their thinking and planning for leisure activities, and expressed a strong desire to plan their own leisure time. Argyle (1992) and Cassidy (1996) support the mothers' definition of leisure as involving free time, perceived autonomy or freedom of choice, and intrinsic motivation which reflects those behaviors which are enjoyable in themselves. The authors discussed leisure as time engaging in motivating activities outside of work. This is also supported by Edwards (1997) who defined leisure as "a period free from and outside the labours of work" (p. 69).

Mothers of children with significant developmental disabilities have special challenges related to their engagement in leisure. They faced
barriers to engagement in satisfying leisure activities such as financial and
time constraints, finding adequate babysitting, and feelings of guilt. Since
mothers often feel like they are the only ones who can care for their
children, this interferes with finding time for themselves to engage in
preferred leisure activities. They reported being challenged everyday to
find a balance between leisure time for themselves, and maintaining the
established daily routines which meet the needs of their families. Their
time is bound by the routine of caregiving, which includes providing the
care needed to meet the developmental and healthcare needs of their
children. Mothers in this study and their engagement in leisure activities
often changed from active (i.e. hiking, swimming, going on vacations) to
more passive activities (i.e. reading, visiting with friends and painting), and
occurred more often in the home rather than out in the community.
Reasons for pursuing leisure also changed once they began mothering a
child with significant developmental disabilities. In addition to moving to
more passive leisure pursuits, leisure became more family-oriented
(needing to rest and relax as a family) and is integrated with a home-
making or childcare tasks.

All the mothers reported that they needed to engage in leisure
activities to break away from their daily routines, and to feel like a “normal
woman.” They reported stress relief, and being able to be a better
mother when having the opportunity to engage in leisure and experience
some down time. Although the mothers reported not having as much opportunities to engage in their preferred leisure activities as they would like, they talked freely about what kinds of leisure activities they enjoyed the most and the meanings they attached to these activities. It remained important and beneficial. Participation in leisure was important for many reasons such as fulfilling a need to be alone and sort out thoughts, to recharge and develop of sense of understanding of who they are. Some enjoyed spending time connecting with other woman to chat about “normal things” such as husbands, children, house and work. This promoted feelings of being a normal mother, a normal woman. One mother described her desire for leisure engagement for “sanity.” It helps her gain more patience and be a better mom. The mother’s views are supported by Smith (1986) who found that even with increased childcare demands, mothers continue to value, and make time for leisure. Larson (2000b) found that mothers of children with disabilities who felt successful at managing child and family occupations experienced greater feelings of well-being and this sparked their desire to seek out and engage in preferred leisure activities or “down time.”

Each mother had a unique way of orchestrating her own leisure occupations within the demands of daily living. There was planned leisure time on weekends or a night out for dinner and although limited, some spontaneous use of free time for leisure. The mothers spent time planning
or thinking about their leisure and worked hard to make their leisure time “good leisure.” When asked what an ideal day would be, it did not take the mothers long to respond and it appeared as though they had given a lot of thought in the past regarding what they would do for leisure if given the time and freedom. One mother was specific about how her leisure time was constructed to fit into her daily routine. The balance between finding “me leisure time” vs. leisure intertwined with family is a delicate one as all the mothers reported needing time away. However, with their often regimented daily routine established to meet their child’s medical, developmental and self-care needs, their time is limited and they struggle with finding the much needed time to escape from the day to day demands of caring for their child with significant developmental disabilities. Mothers used the time spent with their children engaging in activities as a way to meet some of their leisure needs and engage in the activities they find helpful and that promote their well-being. Mothers also used their evolving definition of leisure to guide how their spend free time. McGuire et al. (2004); Olson and Esdaile (2000); Segal (2000); Crowe et al. (1997) also found that mothers had difficulty balancing their lives because caring for their children on a daily basis resulted in a decrease in the time they would devote to other occupations or giving up occupations they considered important such as their own leisure pursuits.
Being a mother is both challenging and rewarding according to the mothers in this study. They talked freely and passionately about the experience of being a mother of a child with a disability, and how that role has made them a better person, family member and mother to their other children. It has broadened their experiences and heightened their emotions and appreciation for the "little things." Each mom had a "mom agenda," including, nurturing and protecting their children, helping them to become open to the world and gain the skills needed to protect themselves, as well as, being in the moment and encouraging age-appropriate interactions for their children so they can be like one of their peers. Each mother viewed mothering and motherhood as life changing, an experience like no other, and something they would not change. In many ways the feelings of happiness and satisfaction achieved through mothering may reduce the need for these same feelings to be gained specifically through leisure.

**Implications for Occupational Therapy Practice**

Given the lack of literature about how mothers define and use their leisure time, it may be reasonable to think that some pediatric occupational therapists may not address this specific area when working with children and their families. Pediatric occupational therapists working within the home address all areas of the child's development often through play activities therefore, facilitating the "work" of the child.
Occupational therapists working with children also provide support to family members and caregivers. Occupational therapists suggest ways that parents and caregivers can play with, position and handle their children with disabilities and provide suggestions for activities to promote learning new skills and facilitating growth and development. Family-centered early supports and services strive to incorporate the needs of the entire family through evaluation, family-focused outcomes and ongoing support. However, occupational therapists may not fully recognize a mother's leisure engagement as an occupation that should be assessed and incorporated into the ongoing development of family-centered outcomes. However, this is important because when mothers are ‘happy,’ they are better able to ‘mother.’ Engaged parenting at home affects child outcomes. Family-centered early supports and services allows therapists the opportunity to enter into a close relationship with families that gives the therapists permission to address the needs of the parents and not just the child.

Occupational therapists who work in the home, have the opportunity to interact with the whole family and promote skills within the child’s most familiar environment. In the home, the child experiences ways of interacting with toys, siblings and their parents. The home is where routines and expectations are established and the child learns independence and how to engage in activities that facilitate growth and
development. It is where family members, in particular mothers, care for and nurture their children and adapt to being a mother, and more specifically, a mother of a child with disabilities. Pediatric occupational therapists working in the home focus on the needs of the child with a disability and interact with the parent who are most likely going to be carrying over strategies and suggestions, and who are most influential in their child’s life. Being in the home allows occupational therapists the opportunity to observe, interact and connect with mothers in ways that create close relationships, and allows therapists to identify and address a mother’s individual leisure needs and desires. Occupational therapists working with families have the opportunity to address a mother’s leisure engagement and its relation to feelings of health and well-being.

I have learned from this study that mothers need time for leisure and want to engage in leisure activities that promote a sense of well-being. They want time to themselves to escape the daily demands of caring for a child with disabilities, time to be “in the moment” and “time to get out of yourself.” Mothers are looking for ways to incorporate leisure both in and out of the house, while meeting the needs of their family and work demands. Occupational therapists can assist mothers with seeking out community resources such as respite care, childcare opportunities and ways to manage their time so they can engage in leisure activities.
The findings of this study also suggest that mothers of children with disabilities often feel more like a medical caregiver than a mother. This is one reason why they seek to spend time away from home and caregiving to renew the feeling that they are "just a normal woman, a normal mother." Some mothers express dissatisfaction related to leisure engagement, because of money and time constraints. In an ideal world, the mothers in this study would like to spend more time pursuing old and new leisure activities, and spend more time reading, painting and traveling. However they are constrained by time, the daily schedule of providing medications, g-tube feedings and other medical management. This is in combination with managing other household and work related tasks. Other mothers struggle with feelings of guilt for engaging their children in other activities (i.e. watching a movie) so they can be by themselves and doing what they want to do, however they are happy and feel blessed with being a mother.

Occupational therapists are uniquely suited to address the delicate and ongoing balance that mothers strive to achieve between all the occupations in which they engage throughout the day. It is important for occupational therapists working in the home to include a mother's leisure occupations as a continuous dialogue to provide support, resources and collaboration with other professionals. A mother's definition of leisure, her leisure occupations, what meanings and values she places on leisure and
lastly, what challenges she faces as a mother of a child with disabilities are areas occupational therapists need to consider as part of their family-centered work. Occupational therapists can assist mothers in finding practical solutions for finding leisure time such as helping mothers manage daily routines, find resources for childcare and respite and developing time management skills. Occupational therapists should address the needs of each mother individually because leisure needs and occupations are different for all mothers. Occupational therapists can provide support to mothers and help them process feelings of guilt and that it is okay to do for themselves while feeling comfortable with respite and childcare. Occupational therapists can help mothers explore when they feel successful at managing child and family occupations and if this motivates them to seek out and engage in preferred leisure activities.

Findings of this study provide insight and give a voice to mothers' sincere thoughts and feelings on mothering, leisure and occupational balance. This insight can assist occupational therapists to adapt activities and routines to create satisfying leisure experiences for mothers, that promote a sense of wellness, occupational balance and personal insight. Also, occupational therapists can help mothers to experience some playfulness, joy and fulfillment through caregiving tasks with their children. This may reduce the amount of time needed or desired for leisure away from family. Finally, occupational therapists understand how important a
variety of occupations are in a mother's life, and the values, meanings and emotions that are placed on leisure occupations, especially as their roles change and knowing that mothering a child with disabilities is often a lifetime commitment.

Study Limitations and Future Research

Data were collected from only four participants in the same geographical area, marital status and respite opportunities. All the participants had extended support systems of both friends and family. While the children were of different ages, and their developmental disabilities varied, all the children were significantly developmentally delayed. This study examined, through interview, mothers' definition of leisure, engagement and satisfaction with leisure and the challenges each faced mothering a child with disabilities. Future research into mothers' engagement in leisure should occur with a larger sample of mothers of children with developmental disabilities. A study that examines mothers engagement in leisure over a specified time frame would be helpful to mothers and therapists to examine how often mothers engage in leisure activities and what are the leisure constraints. A study focusing on families of a variety of cultures to broaden the understanding of how culture influences a mother's definition of leisure, how she values leisure and her engagement in the occupation of leisure would be helpful to occupational therapists providing services to mothers and their children.
within the home setting. The examination of the effectiveness of early supports and services specifically designed to promote leisure participation and satisfaction would also be helpful.
LIST OF REFERENCES


APPENDIX A

INTERVIEW QUESTIONS

1. What is your definition of leisure?
2. What do you like to do for leisure?
3. What are some of your favorite leisure pursuits?
4. What would be an ideal leisure pursuit (one you have not tried but would like to try)?
5. Why do you engage in leisure activities?
6. Do you engage in leisure activities alone or with others? Which do you prefer?
7. How does engaging in leisure activities benefit you (include how it feels to pursue leisure activities with others)?
8. What makes it difficult for you to engage in leisure activities?
9. Has your definition of leisure changed since having a child? If it has, how do you define leisure now?
10. How has your engagement in leisure activities changed since having a child?
11. What is a typical day for you (weekend and weekday)?
12. What would be a perfect/ideal day for you (weekend or weekday)?
13. How have you found out about different leisure activities?
14. Do you feel satisfied with your engagement in leisure activities?
15. How has your definition of leisure changed since having a child with developmental disabilities?
16. Tell me about being a mother.
Dear [Name],

I am a graduate student in the Occupational Therapy Post Professional Master’s Program at the University of New Hampshire and as part of my thesis I am conducting a research project to investigate the engagement in leisure activities of mothers of children with developmental delays and disabilities. I currently work in Early Supports and Services as an occupational therapist with children from birth to 3 years old. I have approximately 6 years experience working with children and their families and I am hoping this study will contribute to my understanding of the needs of families. I am writing to ask you to participate in the study.

If you agree to participate in this study, you will be asked to discuss your everyday activities and your engagement in leisure. I am particularly interested in leisure and how leisure activities relate to your other occupations and to your role as a mother. This will involve 1-2, one-hour interview sessions and perhaps brief phone calls for questions that may arise. The total time required will not exceed (is approximately) 3 hours. Interviews will be audiotaped and transcribed verbatim. If you wish, you may review transcriptions and make any changes. Names and other identifying information will be changed or abbreviated. All information used in this research study will be confidential and kept in a locked file cabinet. After transcription and completion of this research study, the tapes will be erased.

It is the intention of the researcher to maintain the confidentiality of all data and records associated with your participation in this research. You should understand, however that there are rare instances when the researcher is required to share personally-identifiable information. For
example, in response to a complaint about the research, officials at the University of New Hampshire, designees of the sponsor(s), and/or regulatory and oversight government agencies may access research data. You should also understand the researcher is required by law to report certain information to government and/or law enforcement officials (e.g. child abuse, threatened violence against self or others, communicable diseases).

You will not receive any compensation to participate in this study and participation is strictly voluntary. If you agree to participate and then change your mind, you may withdraw at any time during the study.

I will conduct this research. I am an Occupational Therapist working in Early Supports and Services at Community Bridges in Bow, NH as well as a student in the Post Professional Master’s of Occupational Therapy Program at the University of New Hampshire, Durham, NH.

If you have any questions about this research project or would like more information before, during or after the study, you may contact Judith Ward, OT Department who is the chair of my thesis committee. If you have any questions about your rights as a research subject/participant, you may contact the UNH Office of Sponsored Research at 603-862-2003 to discuss them in confidence.

I have enclosed two copies of this letter. Please sign one indicating your choice and return in the enclosed envelope. The other copy is for your records. Thank you for your consideration.

Sincerely,

Yes, I, __________________consent/agree to participate in the research study.
Date____

No, I, __________________do not consent/agree to participate in the research study.
Date____
Dear __________,

The purpose of this study is to explore the experiences of mothering a child with developmental disabilities/delays in relation to the orchestration of daily occupations, specifically the engagement in leisure activities.

You will be asked to describe your engagement in and satisfaction with your current leisure activities. You will be asked to discuss what leisure means to you and how it fits in the pattern of your daily occupations. There will be 1-2, one-hour interview sessions with further follow-up via home visit or telephone calls to clarify interview responses.

If you are interested in hearing more about this thesis study and your potential participation, please provide contact information below.

Thank you for your time and consideration.

Sincerely,

Contact Information:

I ____________________________, (please sign name) give my consent for the investigator to contact me at ___________________________(please include telephone number) to further discuss participation in this research study.
May 20, 2003

Jennifer Bellen
8 Walden Drive
Merrimack, NH 03054

IRB #: 2924
Study: Mothers of Children with Developmental Disabilities and the Occupation of Leisure
Approval Date: 05/20/2003

The Institutional Review Board for the Protection of Human Subjects in Research (IRB) has reviewed and approved the protocol for your study as Exempt as described in Title 45, Code of Federal Regulations (CFR), Part 46, Subsection 101(b). Approval is granted to conduct your study as described in your protocol.

Researchers who conduct studies involving human subjects have responsibilities as outlined in the attached document, Responsibilities of Directors of Research Studies Involving Human Subjects. (This document is also available at http://www.unh.edu/osr/compliance/irb.html.) Please read this document carefully before commencing your work involving human subjects.

Upon completion of your study, please complete the enclosed pink Exempt Study Final Report form and return it to this office along with a report of your findings.

If you have questions or concerns about your study or this approval, please feel free to contact me at 603-862-2003 or Julie.simpson@unh.edu. Please refer to the IRB # above in all correspondence related to this study. The IRB wishes you success with your research.

For the IRB,

Julie F. Simpson
Manager

cc: File
Shelley Mulligan