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Caregivers of Children with Disabilities: An Exploratory Study of Factors Influencing Occupational Therapy Home Programming Engagement

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CAREGIVERS OF CHILDREN WITH DISABILITIES: AN EXPLORATORY STUDY OF
FACTORS INFLUENCING OCCUPATIONAL THERAPY HOME PROGRAMMING
ENGAGEMENT

by

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Advisor: Anne M. Haskins, PhD, OTR/L

An Independent Study

Submitted to the Occupational Therapy Department

of the

University of North Dakota

In partial fulfillment of the requirements

for the degree of

Master's of Occupational Therapy

Grand Forks, North Dakota

May 11, 2013

This Independent Study Paper, submitted by Sara Joersz and Rebecca Polansky in partial fulfillment of the requirement for the Degree of Master's of Occupational Therapy from the University of North Dakota, has been read by the Faculty Advisor under whom the work has been done and is hereby approved.

Faculty Advisor

Date

Permission

Title	Caregivers of Children with Disabilities: An Exploratory Study of Factors Influencing Occupational Therapy Home Programming Engagement
Department	Occupational Therapy
Degree	Master's of Occupational Therapy

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Abstract

Purpose: Home programming for children with disabilities is prescribed frequently by occupational therapists as an effective adjunct to practice-setting occupational therapy. The effectiveness of home programming is largely influenced by the degree to which caregivers (and children) adhere to the home programming parameters. Numerous factors are thought to promote or limit home programming adherence but there is a lack of quantitative research addressing the relationships between these factors and home programming adherence. The purpose of this quantitative, independent study was to explore the factors that are correlated with or influence caregivers' adherence to their child's occupational therapy home program. A secondary purpose of this study was to analyze the reliability of the Multi-dimensional Occupational Therapy Home Programming Engagement Survey.

Methods: A prospective, exploratory online survey design was used to gather data to answer the research questions. Following IRB approval, convenience sampling was used to access respondents and gather data. Fifteen caregivers of children with disabilities completed a 44 question online survey. The Multi-dimensional Occupational Therapy Home Programming Engagement Survey was created by the researchers and was guided by the concepts within the Model of Human Occupation. Statistical analysis was used to analyze descriptive statistics, Pearson's correlations, Spearman rho's, tests of internal consistency, and ANOVAs to answer the research questions.

Results: The results indicated significant relationships between caregiver home programming adherence and the perceived benefits to the child, caregiver value for the home program, activities fitting within the families' daily routine, the frequency that the home program is recommended throughout the week, and the age of the child receiving occupational therapy home programming. Each of these factors contributed to greater caregiver adherence with implementing the child's home program. No statistical significance was reached for adherence related to the environment, child and caregiver performance capacity, demographics, and the child's ability to complete daily tasks within his or her home and school, as well as to socially interact. These factors were not related to home programming adherence.

Conclusion: Numerous factors influence caregiver and children's occupational therapy home programming adherence. In order to increase overall adherence rates to home programming, it is essential that occupational therapists consider and engage in discussion about these factors (i.e. caregiver value, benefits to child, daily routines, etc.) with caregivers when prescribing pediatric home programs. Finally, further quantitative research studies are needed to more fully understand the variables influencing familial home programming engagement and methods that occupational therapists may use to enhance home programming adherence.

Chapter I

Introduction

Chapter I: Introduction, includes the introduction to this independent study. Specifically, it includes the rationale, statement of the problem, purpose of the study, broad research questions, theoretical framework, assumptions, scope and delimitations, and the definition of key terms.

Rationale

It has been estimated that approximately 5.2 million children in the United States have some form of a disability (Brault, 2012). Many children with disabilities are seen by occupational therapists to maximize their ability to engage in occupations successfully. Traditional occupational therapy treatment requires home or clinic-based visits for hands-on intervention from a therapist (Novak & Cusick, 2006). Clinic-based and individual child to therapist treatment is not always feasible, cost-effective, or readily available for families to utilize, thus, home programs are a common intervention approach used by pediatric occupational therapists as a supplement or substitute to traditional therapy (Bazyk, 1989; Gajdosik, 1991; Hinojosa & Anderson, 1991; Novak & Cusick, 2006; Novak, Cusick, & Lowe, 2007; Segal & Hinojosa, 2006; Tetreault, Parrot, & Trahan, 2003).

Home programs have been shown to be effective when implemented, however, in some cases adherence to the program is limited (Hinojosa & Anderson, 1991; Novak, Cusick, & Lannin 2009; Ozonoff & Cathcart, 1998; Tang et al., 2001). Multiple

qualitative studies have indicated that certain factors contribute to successful adherence to home programming and have provided evidence that certain factors make adherence to home programming difficult (Novak, 2011; Segal & Beyer, 2006; Tetreault et al., 2003).

These factors have to do with the child with disabilities, the caregivers, the occupational therapists, and specific aspects of the home program. Each of the aforementioned factors could potentially impact the follow through of a home program (Segal & Beyer, 2006). According to Mayo (1981), parental involvement with intervention programming for their children was a key factor in eliciting success from these programs. There was largely a lack of quantitative literature available for review involving what factors are causally linked to adherence to home programs, which led to the development of this independent study.

Statement of the Problem

Through the literature review, it was noted that caregivers had difficulty implementing occupational therapy home programming consistently, yet it is common that occupational therapists prescribe home programs as an adjunct to traditional therapy. There is a disconnect between the child, caregiver, occupational therapist, and environmental factors that influence home program engagement. This incongruence could potentially lead to the child not getting the maximum benefits of the home program, caregivers becoming frustrated, and therapists becoming discouraged from prescribing future home programs. There is a lack of quantitative research addressing the aforementioned factors. More research is needed to help guide occupational therapists to develop evidence-based occupational therapy home programs that are more effective and client-centered, in order to enhance overall home programming adherence.

Purpose of Study

The purpose of this quantitative, independent study was to explore factors that may influence adherence to home programming for children with disabilities.

Specifically, the researchers surveyed caregivers of children with disabilities to identify time, context, and other variables that are perceived by caregivers to enhance or impair the home programming process. This study provides evidence to promote the development of client and family centered occupational therapy home programs, with consideration to the families' volition, habituation, performance capacity, and natural environment.

The results of this research support previous qualitative and quantitative studies. It can also be a guide for occupational therapists when designing and implementing home programs with children and their families. The researchers hope the outcomes of this study will provide valuable information for occupational therapists to consider when working with caregivers of children with disabilities.

Research Questions

In order to examine the multiple factors that facilitate or inhibit the adherence to occupational therapy home programming, the researchers created and disseminated the Multi-dimensional Occupational Therapy Home Programming Engagement Survey, for caregivers of children with disabilities to gather these perceptions. Throughout this study, the researchers hoped to answer a number of research questions. The broad research questions that guided this study were: What is the overall occupational therapy home programming adherence as reported by caregivers of children with disabilities? What child, caregiver, occupational therapist, and environmental variables, with

consideration for volition, habituation, and performance capacity, influence familial adherence to occupational therapy home programming? Refer to Appendix A for a comprehensive list of the research questions.

Theoretical Framework

Using a theoretical model is essential when considering research and future practice, as it increases the validity of research and allows for a guide that is evidence-based and grounded in previous research (Kielhofner, 2008). As a foundation for this independent study and survey development, the researchers utilized the Model of Human Occupation (MOHO) as a theoretical model. MOHO is an occupation based model and is used frequently in occupational therapy practice. The two main constructs within this model are the person and the environment (Cole & Tufano, 2008). Within MOHO, the person system is broken down into volition, habituation, and performance capacity (Kielhofner, 2008). The environmental subsystem involves both the physical and social environments (Kielhofner, 2008). Although temporal environment is not discussed as a key aspect within MOHO, temporal environment was used by the researchers throughout this study, as it became an evident factor affecting adherence within the results of this study.

MOHO is used to identify performance skills and patterns, individual patient factors impacting participation in occupations, and the environments that facilitate or inhibit performance (Baptiste, 2008; Kielhofner, 2008). A primary focus within this study was related to how the person and environment subsystems work together to facilitate occupational performance. Specifically, how these factors influenced caregivers with implementing an occupational therapy home program with their child

with disabilities. A detailed chart of each question involved in the Multi-dimensional Occupational Therapy Home Programming Survey and the aspect of MOHO it addressed is included in Appendix B.

Assumptions

Although the researchers anticipated that the respondents provided accurate and truthful responses to the questions within the online survey, the validity of these responses cannot be guaranteed. It was also anticipated that the varying demographics of the respondents would influence the results of this independent study. A theoretical model, MOHO, was used to guide the survey development, as well as the research questions. It was assumed that this evidence-based occupational therapy model was an appropriate fit for the variables under study.

Scope and Delimitation

The principal variables and constructs utilized and examined throughout this study were guided by MOHO. These included the concepts of volition, habituation, performance capacity, the environment, and occupational performance (Kielhofner, 2008). In addition to these concepts, the researchers studied the rate of adherence, as well as the factors that affected adherence, when considering pediatric occupational therapy home programs. These variables were addressed through questions implemented within the online survey.

The instrument, the Multi-dimensional Occupational Therapy Home Programming Engagement Survey, was developed by the researchers and was used to gather data. The survey was delimited to the variables studied, including the child, caregiver, therapist, and home programming factors, as these were the focus of the study.

These variables were identified throughout the literature review as factors that influenced home programming adherence.

This study was delimited to caregivers of children (under the age of 18 years) with disabilities. Additionally, the study was delimited to the seven organizations that the researchers identified as sources for potential respondents. The organizations were identified within the regions of North Dakota and Minnesota and, thus, the geographical location was a delimitation of this study. Time and money also set delimitations, as this study was completed for partial fulfillment of the requirements required for the degree of Masters of Occupational Therapy.

The researchers could have sent out the survey more frequently, it could have been posted for a longer period of time, reminders could have been sent out, and potential respondents could have been sought out at clinics or other practice settings. Each of these could potentially have attracted more participants and increased the overall response rate; however, the delimitations of the study prevented this.

This independent study was completed from June 2012 to April 2013. The data was gathered from January 1, 2013 to February 28, 2013. Potential respondents were given as long as needed to complete the online survey. Respondents were given the option to skip any questions that they did not want to answer. This may account for some of the missing data throughout the survey responses. Throughout the results section it was noted when respondents chose not to respond to the questions.

Definition of Terms

The following definitions are important to understanding aspects of occupational therapy, caregiving, children with disabilities, and home programming. These definitions

have been provided to ensure that readers have a consistent understanding throughout this study.

Activities of daily living – Refers to activities oriented toward taking care of one’s own body (adapted from Rogers & Holm, 1994, pp.181–202). ADL also is referred to as basic activities of daily living (BADL) and personal activities of daily living (PADL). These activities are “fundamental to living in a social world; they enable basic survival and well-being” (Christiansen & Hammecker, 2001, p. 156 as cited in AOTA, 2008).

Caregiver – Refers to “a person who, for evident reasons and on a regular basis, provides care for a care demanding person, in his/her immediate environment and who is not part of a formal or professional organization” (Van Durme, Macq, Jeanmart, & Gobert, 2012, p. 501). Throughout this independent study, caregiver is the term used to describe parents and/or caregivers of children with disabilities. While the majority of the survey respondents were parents, the survey demographics indicated parents were not always the primary caregiver, thus caregiver was the term used.

Compliance/Follow through/Adherence –Refers to the number of therapy sessions reported as a percentage of potentially expected therapy sessions prescribed (Khalil et al., 2012). These terms are used interchangeably throughout the literature, with adherence being primarily used.

Disability – Refers to “an umbrella term, covering impairments, activity limitations, and participation restrictions. An impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in

executing a task or action; while a participation restriction is a problem experienced by an individual in involvement in life situations” (World Health Organization, 2013, para. 1).

Environment – Refers to “the external physical and social environment that surrounds the client and in which the client’s daily life occupations occur” (AOTA, 2008, p. 670).

Family – “Structural definitions of the family characteristically define the characteristics of family members such as those who share a place of residence, or who are related through blood ties or legal contracts. A structural definition would contend that the children be related by blood or adoption, while a functional definition might define family as whoever is there to care for the child” (Wisconsin Family Impact Seminars, n.d., p. 21).

Habit – Refers to “automatic behavior that is integrated into more complex patterns that enable people to function on a day-to-day basis...” (Neistadt & Crepeau, 1998, p. 869 as cited in AOTA, 2008,).

Home program – “Occupational therapy home programs are individualized multimodal interventions that target body structure, activities, and participation problems identified collaboratively by the parents and therapist, informed by diagnoses and referral instructions” (Novak et al.2009, p. 607). “They are interventions specifically designed for implementation in the home and in the context of daily life by families” (Novak & Cusick, 2006, p. 252).

Independence – Refers to “a self-directed state of being characterized by an individual’s ability to participate in necessary and preferred occupations in a satisfying manner

irrespective of the amount or kind of external assistance desired or required”
(AOTA, 2008, p. 671).

Intervention – Refers to “the process and skilled actions taken by occupational therapy practitioners in collaboration with the client to facilitate engagement in occupation related to health and participation. The intervention process includes the plan, implementation, and review” (AOTA, 2008).

Model of Human Occupation – Refers to a conceptual practice model “specifically developed to focus theory, research, and practice on occupation. The concept, human occupation, refers to the doing of work, play, or activities of daily living within a temporal, physical, and sociocultural context that characterize much of human life” (Kielhofner, 2008, p. 5).

Occupation – Refers to “activities that people engage in throughout their daily lives to fulfill their time and give life meaning. Occupations involve mental abilities and skills and may or may not have an observable physical dimension” (Hinojosa & Kramer, 1997, p. 865 as cited in AOTA, 2008).

Occupational therapy – “The practice of occupational therapy means the therapeutic use of everyday life activities (occupations) with individuals or groups for the purpose of participation in roles and situations in home, school, workplace, community, and other settings. Occupational therapy services are provided for the purpose of promoting health and wellness and to those who have or are at risk for developing an illness, injury, disease, disorder, condition, impairment, disability, activity limitation, or participation restriction. Occupational therapy addresses the physical, cognitive, psychosocial, sensory, and other aspects of performance in a

variety of contexts to support engagement in everyday life activities that affect health, well-being, and quality of life” (AOTA, 2004a as cited in AOTA, 2008, p. 673).

Role – “Roles are sets of behaviors expected by society, shaped by culture, and may be further conceptualized and defined by the client” (AOTA, 2008, p. 674).

Routine – Refers to “patterns of behavior that are observable, regular, repetitive, and that provide structure for daily life. They can be satisfying, promoting, or damaging. Routines require momentary time commitment and are embedded in cultural and ecological contexts” (Fiese et al., 2002; Segal, 2004 as cited in AOTA, 2008, p. 674).

Self-efficacy – Refers to “...[t]he belief that one is capable of accomplishing a certain behavior” (Bandura, 2004 as cited in Braungart, Braungart, & Gramet, 2011, p. 61).

Summary

Chapter I was composed of an introduction to this independent study and included the rationale, statement of the problem, purpose of the study, research questions, theoretical framework, assumptions, scope and delimitations, and the definition of key terms. The purpose of this quantitative, independent study was to explore factors that influence adherence to home programming for children with disabilities.

Chapter II contains a complete and detailed examination of the literature regarding home programming with children with disabilities and included how caregiver, child, occupational therapist, and the home program factors all influence home programming adherence. Chapter III consists of a detailed explanation of the research

methodology used in this study. Specifically, Chapter III includes subject characteristics, sampling procedures, ethical considerations, research design, locale of the study, theoretical foundations of the survey design, and the tools and instruments used for data analysis. Chapter IV consists of the statistical analyses of the results from the online, Multi-dimensional Occupational Therapy Home Programming Survey. Chapter IV also includes the pre-analysis data screen, analysis of the reliability of the survey instrument, statistical analyses of the descriptive statistics, and inferential statistical analyses used to answer the research questions. Chapter V details the written discussion of the researchers' findings, the relationship between the results and the previous research, study limitations, and implications for occupational therapy practice and future research.

Chapter II

Literature Review

Chapter II: Literature Review includes a complete and detailed examination of the previous literature relating to home programming for children with disabilities.

Specifically, it includes how certain child, caregiver, occupational therapist, and home program factors influence home programming adherence.

Occupational therapy is an important discipline within healthcare, as occupational therapists work with a variety of diagnoses and disabilities, from newborn children to older adults, to help improve function and independence within an individual's meaningful occupations (American Occupational Therapy Association [AOTA], 2008). Brault (2012) examined data from the sixth Survey of Income and Program Participation (SIPP), which provided a general estimate of the prevalence of disability within the civilian non-institutionalized living in the United States in 2010, through questions about respondents' ability to perform specific sets of participatory and functional activities. According to Brault (2012), there were 62.2 million children under the age of 15 years old living in the United States in 2010. Of this population of children, approximately 5.2 million (8.4 percent) had some form of a disability and half of these children (2.6 million children) were identified as having severe disabilities (Brault, 2012). Additionally, 0.8 % of these children required assistance with one or more of their activities of daily living (ADLs) (Brault, 2012).

The operational definition of “disability” was dependent on the child’s age (Brault, 2012). For example, a child younger than three years old was considered to have a disability if he or she had a developmental delay or had difficulty moving his or her upper or lower extremities. For children three to five years old, disability was classified as having a developmental delay and/or having difficulty ambulating (i.e. walking, running) or playing. Among the children aged 6 to 14 years old, disability was described with consideration for a wider range of impairments and activities (Brault, 2012).

Similar to Brault (2012), Boyle et al. (2011) conducted research to determine the prevalence of children in the United States with developmental disabilities, as well as to examine the changes in the occurrence of developmental disabilities in children over time. The researchers utilized data on children, ages 3 to 17 years old, from the *1997-2008 National Health Interview Surveys* (NHIS), which were comprised of continuous national representative samples of the households in the United States. The following parent-reported diagnoses were included in the surveys: intellectual disabilities, attention deficit hyperactivity disorder (ADHD), autism, cerebral palsy, hearing loss (moderate to profound), seizures, learning disorders, stuttering, blindness, and/or other developmental delays (Boyle et al., 2011). The occurrence of any developmental disability was approximately 13.87% with a significant increase in the prevalence of developmental disabilities over time (Boyle et al., 2011). Of each of the child diagnoses examined, autism and ADHD had the greatest increase over time (Boyle et al., 2011). On the basis of parent report, Boyle et al. (2011) found that nearly 10 million children (approximately 15% of children 3 to 17 years of age) had a developmental disability in 2006-2008, approximately 1.8 million more than a decade earlier.

Children with developmental disabilities and other diagnoses often require occupational therapy services to increase their overall function and independence with everyday activities. The prevalence of disabilities in children in the United States and the needs of these children support the need for specialized health services, such as occupational therapy (Boyle et al., 2011).

AOTA (2008) asserted that “supporting health and participation in life through engagement in occupation” (p. 626) is the domain of occupational therapy. The term *occupation* was described by AOTA (2008) as any activity of daily living in which one engages. Thus, when occupational therapy practitioners collaborate with clients, they consider the variety of occupations or activities in which each client is engaged.

Occupational therapy’s domain of practice includes “areas of occupation—activities of daily living (ADLs), instrumental activities of daily living, rest and sleep, education, work, play, leisure, and social participation” (AOTA, 2008, p. 630).

The definition of children’s occupations can be different from adults’ occupations. Important occupations that children participate in include school, education, and play. These areas of occupation are often affected by the problems associated with the presence of a disability in children. It is important that occupational therapists are involved in treatment of children to assist them in an attempt to increase function and independence. In many cases with children, these services may involve individual occupational therapy treatment sessions, as well as the use of occupational therapy home programs (Bazyk, 1989; Gajdosik, 1991; Hinojosa & Anderson, 1991; Novak & Cusick, 2006; Novak, Cusick, & Lowe, 2007; Segal & Hinojosa, 2006; Tetreault, Parrot, & Trahan, 2003).

Use of Home Programs

Traditional occupational therapy treatment requires home or clinic-based visits for hands-on intervention from a therapist (Novak & Cusick, 2006). However, clinic-based and individual child to therapist treatment is not always feasible, cost-effective, or readily available for families to utilize. In such cases, home programs are a common intervention approach used by pediatric occupational therapists as supplements or substitutes for traditional therapy (Bazyk, 1989; Gajdosik, 1991; Hinojosa & Anderson, 1991; Novak & Cusick, 2006; Novak et al., 2007; Segal & Hinojosa, 2006; Tetreault et al., 2003).

Home programs are used as interventions to treat children and adolescents who have been diagnosed with a disability or disorder (Novak & Cusick, 2006). They are individualized, multimodal interventions or activities that are specifically designed to be implemented within the context of one's daily life and home environment (Novak & Cusick, 2006; Novak, Cusick, & Lannin, 2009; Segal & Hinojosa, 2006). Specifically, home programs for children are implemented with the assistance or supervision of a caregiver to help facilitate opportunities for the child to practice and integrate skills into his or her daily life and achieve the child's desired therapeutic outcomes (Bazyk, 1989; Gajdosik, 1991; Hinojosa & Anderson, 1991; Segal & Hinojosa, 2006).

Home programs focus on an individual's meaningful activities, body structure, and participation limitations, which are all identified through collaboration with the caregivers, therapist, and referring physician (Novak et al., 2009). Occupational therapists typically complete an evaluation (using observation, screening tools, or standardized assessments), provide the evaluation results to parents, facilitate parental understanding of the pertinent problems, and provide possible intervention suggestions

for parents to implement with their children (Novak et al., 2009). Occupational therapists collaborate with parents to design an individualized home program that will meet the child's and family's goals (Novak et al., 2009). Home programs are intended to actively engage parents in their child's treatment program, in order to increase the child's overall participation and growth in treatment. In addition, home programs are thought to be cost efficient (Hinojosa & Anderson, 1991). Of these characteristics of home programming, parental involvement with intervention programming for their children is reported to be a key factor in eliciting success from these programs (Mayo, 1981).

Effectiveness of Home Programs

As the frequency of home programming prescription has increased, researchers have begun to examine the effectiveness of home programs through formal research methods, although occupational therapy home programming research is in its infancy (Novak et al., 2009; Ozonoff & Cathcart, 1998; Tang et al., 2001). The existing evidence has indicated that home programs are effective (Novak et al., 2009; Ozonoff & Cathcart, 1998; Tang et al., 2001; Wuang, Ho, & Su, 2013).

In a randomized control study of 36 children with cerebral palsy, Novak et al. (2009) found that home programs had clinical effectiveness when they were used 17.5 times over a one month span for approximately 16.5 minutes per session. Clinical effectiveness in occupational therapy is defined as improvement that increases function, regardless of statistical significance (AOTA, 2004). When home programs were implemented in the treatment group, measures of satisfaction and performance, using the Canadian Occupational Performance Measure (COPM), were statistically greater than the control group on a waiting list (Novak et al., 2009). On the Goal Attainment Scale and

Quality of Upper Extremity Skills Tests, the home program group demonstrated more improvement than the control group (Novak et al, 2009). These results led the researchers to conclude that home programs assisted with improvements in children's functioning, upper extremity movement, and parental satisfaction (Novak et al, 2009).

Home programs can also be used with families that include a child with autism. Over a four-month period, Ozonoff and Cathcart (1998) administered a home program and parent education program specifically focused on skills essential for school success, including academic ability, cognitive activities, and prevocational skills. The group that participated in the home program showed significant improvement in imitation, gross motor, fine motor, and nonverbal conceptual skills, as measured by the Psychoeducational Profile-Revised (Ozonoff & Cathcart, 1998). On the outcome tests, the group receiving home programming showed three to four times more developmental progress than the control group, which indicated that home programs are an effective way to support childhood development (Ozonoff & Cathcart, 1998).

Novak et al., (2007) conducted a pilot study to determine the effectiveness of a home program for 20 children with cerebral palsy, using a single-group pretest-posttest design to evaluate the efficacy of the intervention. A questionnaire designed by the investigator and three outcome measures were used (Goal Attainment Scaling, The Pediatric Evaluation of Disability Inventory, and the Quality of Upper Extremity Skills Test). A home program log was also developed to measure parental implementation of the home program. Parents and their children were seen by an occupational therapist three times during the study (Novak et al., 2007). These sessions were focused on devising a home program and providing activities, instructions, and training, as well as

follow-up sessions in the middle and end of the six-month period. There was a positive difference between the children's baseline and post-intervention measures on all three outcome measures. These improvements indicated that the implementation of a home program was effective for these children (Novak et al., 2007).

Tang et al. (2001) also found clinical effectiveness with home programs. In a randomized control trial of children with global developmental delays, the control group received 45 minutes of institution-based therapy, once a week, and the treatment group received 30 minutes of institution-based therapy, supplemented by 15 minutes of guidance and training for the home activity program (Tang et al., 2001). Following the training session, the parents of the children in the treatment group were asked to complete the program once daily. The children in the treatment group, which received the supplemental home program, showed greater improvement in developmental level, as well as statistically significant improvements for language, cognition, motor, and social skills (Tang et al., 2001).

Despite the promising gains of the children in the treatment group, Tang et al. (2001) did not find a strong correlation between the participants' developmental outcomes and strict adherence to the home program. This may suggest that strict adherence is not crucial to the success of home programs. However, the average adherence rate to the program in Tang et al.'s (2001) study was 80% (the range was from 76.7% to 83.8%). The adherence rate of the treatment group in Tang et al.'s (2001) study may be higher than average home programming adherence, as the average rate has been documented as less than 50% (Law & King, 1993). Gajdosik (1991) found that the average family adherence to home programs was from 47-67% over a four week span. In

a study of a physical therapy home program with caregivers of children with disabilities, only 44% of the caregivers reported complete adherence (Rone-Adams, Stern, & Walker, 2004). In a study by Stieber et al. (2012), adherence to the home program fluctuated from 0 to 100 % with only two of the families fully complying with the suggested intervention program (Stieber et al., 2012). It is plausible that successful outcomes in home programs are influenced by a high execution rate. Novak et al. (2007) also reported the frequency of home program participation was not significant, although, similar to Tang et al. (2001), the adherence rates were high throughout the study (average participation of 14.22 minutes, 27 days a month).

Research has supported the premise that home programs are effective for improvement in many areas of impairment for children with disabilities, when used as prescribed (Novak et al., 2009; Ozonoff & Cathcart, 1998; Tang et al., 2001; Wang et al., 2013). However, there are many factors that influence caregiver and child adherence to these programs, which can decrease their effectiveness. The factors that affect execution of home programs for children with disabilities are essential for occupational therapists to address with families prior to implementing a home program in order to increase overall adherence to home programming (Novak et al., 2009; Segal & Beyer, 2006; Tang et al., 2001).

Factors Affecting Familial Adherence to Home Programming

Throughout the literature, compliance and adherence appear to be used interchangeably. “Adherence implies support of or commitment to a plan of care” while “compliance implies obedience or passive acceptance of the healthcare regimen” (Richards & Digger, 2011, p. 201). Occupational therapy is based on client-centered care

and a collaborative partnership between the therapist and client, thus adherence will be the term used throughout this study. Home programs have been shown to be effective when implemented, though in some cases, adherence to the home program was limited (Hinojosa & Anderson, 1991; Novak et al., 2009; Ozonoff & Cathcart, 1998).

Limited quantitative research regarding factors linked to adherence to home programming has been published, although the results of multiple qualitative studies have indicated that certain factors contribute to successful adherence to home programming (Novak, 2011; Segal & Beyer, 2006; Tetreault et al., 2003). Following a 14-week long exercise program for children with developmental disabilities, Fragala-Pinkham, Haley, Rabin, and Kharasch (2005) implemented a 12-week home exercise program with these children. Higher levels of subject adherence were noted during the exercise program than during the home program (Fragala-Pinkham et al., 2005). Greater improvements in outcomes were also observed during the group program when compared with the home program, which indicated that improvement was linked to adherence (Fragala-Pinkham et al., 2005). When designing home programs, it is important that occupational therapists recognize factors that affect familial adherence with home programming. Factors involving the child with disabilities, the caregivers, the occupational therapist, and aspects of the home program all influence the success and implementation of the home programming process.

Child factors in home programming adherence.

The child is the center of the home program and how he or she responds to the program is a key aspect of familial adherence to the home programming process (Segal & Beyer, 2006). In one study, children's pain, discomfort, and negative responses to a

brushing program led to parents discontinuing the program (Segal & Beyer, 2006). Key factors in parental subjects choosing to discontinue with a brushing home program included if the child had a negative response to the brushing or if the child had a stressful response to the brushing (Segal & Beyer, 2006). Hinojosa and Anderson (1991) found that implementing activities that were viewed as stressful for the child decreased the use of home programming interventions.

Ensuring that the child participated in the suggested activities was also a major difficulty for parents attempting to use a home program (Tetreault et al., 2003). Adverse effects typically decreased adherence; likewise, positive benefits and effects increased participation (Escolar-Reina et al., 2010). If a child did not enjoy the activities, familial adherence to the home program was impacted (Segal & Beyer, 2006; Stieber et al., 2012).

Home programs that are beneficial for children and cause noticeable improvements are more likely to be implemented by parents and caregivers (Segal & Beyer, 2006; Tetreault et al., 2003). The level of the child's delay or impairment may impact familial adherence to home programs (Mayo, 1981). Mayo (1981) found that with children with severely delayed motor development, there was a statistically significant higher rate of familial compliance compared to the adherence of families with children with moderate delays.

Caregiver factors in home programming adherence.

In a study of adherence to a home program with adults with a disability, the two main factors that led to not carrying out the home program were illness and lack of caregiver support (Khalil et al., 2012). The caregiver of a child is often a parent and, subsequently, the factors that influence the ability of a parent to facilitate a home

program influence the child's engagement in the home program. Law and King (1993) reported that parents' understanding and skill with a home program were the only predictors of change in the child's hand function. Parents are typically the key caregivers for children and are typically responsible for implementation of the home programs, with mothers being mostly responsible (Tetreault et al., 2003). Tetreault et al. (2003) found that 90.3% of participants were mothers. According to Segal and Beyer (2006), caregiver commitment to the home program was a key factor in the execution of the interventions at home. Caregiver factors that influenced adherence to home programming included: caregiver beliefs and values (Novak, 2011; Segal & Beyer, 2006), caregiver self-efficacy and roles (Novak, 2011; Segal & Beyer, 2006), and caregiver stress (Rone-Adams et al., 2004; Segal & Beyer, 2006).

Caregiver beliefs and values.

Since parents are often the main caregivers and typically responsible for the child's home program, parents' beliefs, values, and attitudes impact adherence to home programming recommendations (Novak, 2011; Segal & Beyer, 2006). Segal and Beyer (2006) reported that familial and parental values affected successful implementation of prescribed programming. In a correlative study of 45 families with a child with global developmental delays, parents who were highly motivated, confident, and hopeful had more positive feelings about implementing home programming recommendations (Tetreault et al., 2003). Caregivers who believed the home programming activities could be realistically incorporated into their daily schedules, as well as caregivers who were at ease with the home program, had more positive feelings (Tetreault et al., 2003).

Caregivers who completed successful facilitation of home programs believed they were doing something worthwhile (Novak, 2011). Caregivers' beliefs that home programs were beneficial varied between a group of parents who adhered to home programming and a group that did not (Tetreault et al., 2003). Tetreault et al. found that 77% of parents who believed home programs were a good way to work with their child at home, adhered to the home program. Conversely, only 57% of parents in the non-adherence group believed the home program was good for their child (Tetreault et al., 2003). Some parents had more negative feelings, including feelings of burden, guilt, deception, and discouragement, which led to not using the home programs (Tetreault et al., 2003).

Caregiver self-efficacy and roles.

Caregiver self-efficacy about doing the home program also influenced adherence (Novak, 2011; Segal & Beyer, 2006). In interviews, parents reported worrying about whether they had the skills and abilities to help their child (Novak, 2011). Other parents mentioned that they would rather have a professional do the activities because of a lack of confidence (Novak, 2011). Hinojosa and Anderson (1991) used interviews to collect data from eight mothers of children with cerebral palsy in order to examine the mothers' experiences and perceptions in relation to home programming. All of the mothers that were interviewed expressed that they did not feel adequate with implementing a formal program; however, each of the mothers developed their own methods of implementing therapeutic activities into their child's daily life (Hinojosa & Anderson, 1991).

Acknowledging caregiver feelings regarding their competence with implementing home programs is a factor that could lead to better adherence to therapists'

recommendations (Segal & Hinojosa, 2006). Tetreault et al. (2003) found that parents had more positive feelings about their child's home program when they felt confident in their abilities to do the activities. In another study, parents mentioned that throughout the implementation of home program activities they gained self-confidence in their own ability to help their child develop (Stieber et al., 2012). Despite the benefits of parents' confidence in their role of completing a home program with their child, Novak (2011) cautioned that some parents may find role confusion regarding balancing parental and therapist roles. Hinojosa and Anderson (1991) reported that the mothers who participated stated that they would rather not assume a "therapist-like" role with their child. Novak (2011) asserted that it is important for parents to be able to maintain their roles as parents when implementing a home program, rather than feel as if they have to assume a therapist-like role.

Caregiver stress.

In addition to caregiver values, beliefs, self-efficacy, and roles, caregiver stress is another factor occupational therapists should consider when developing home programs (Segal & Beyer, 2006). One parent in Segal and Beyer's (2006) study responded that some home programs may not be appropriate for certain families if the home programming demands are overwhelming for the caregivers' abilities and resources. If the burden of care is high or there is a lack of support, caregivers appear to struggle with home programming adherence (Segal & Beyer, 2006). In a correlational study, a relationship was found between caregivers' level of stress and their adherence with home programs (Rone-Adams et al., 2004). With increased family and caregiver problems there was decreased adherence with the home programming (Rone-Adams et al., 2004). Rone-

Adams et al. (2004) found an inverse relationship between the adherence score and family problems, which indicated that as caregiver and family problems increased, the level of program adherence decreased. Occupational therapists need to be aware of perceived caregiver stress that may result from the home programs prescribed. The level of stress could determine whether caregivers adhere with the suggested activities and regimen (Rone-Adams et al., 2004).

In a qualitative study of eight parents of children with cerebral palsy, parents reported difficulty completing the home program during the initial adjustment to a diagnosis (Piggot, Hocking, & Paterson, 2003). They reported feeling overwhelmed by the new situation, which limited their abilities to adhere to the home program (Piggot et al., 2003). Occupational therapists must be aware of potential familial problems that may interfere with home programming adherence. Occupational therapists should also assist parents or caregivers in identifying resources they could utilize to better cope with the identified problems (Rone-Adams et al., 2004). Also, occupational therapists need to be aware of the responsibility that home programming entails, as more responsibility has been found to decrease the familial satisfaction and adherence to home programming (Tetreault et al., 2003).

Occupational therapist factors in home programming adherence.

Authors of multiple qualitative studies have focused on what occupational therapists can do to assist families with home programming adherence (Hinojosa & Anderson, 1991; Novak, 2011; Segal & Beyer, 2006). Occupational therapists may enhance adherence to home programming through education to caregivers (Escolar-Reina et al., 2010; Segal & Beyer, 2006), development of rapport (Novak & Cusick, 2006),

learning family routines (Segal & Beyer, 2006), monitoring caregiver adherence (Novak, 2011), and providing support to families (Tetreault et al., 2003).

Education for caregivers.

Caregiver education has been shown to be important in home programming adherence (Segal & Beyer, 2006). More specifically, education of the rationale for the program, how to do the activities in the program, and how to incorporate the therapeutic components into activities have shown promising outcomes (Novak, 2011; Segal & Beyer, 2006). Stieber et al. (2012) noted that the caregivers appreciated the ability to use their knowledge to adapt the activities to better fit the child (i.e. the “just-right challenge”). Escolar-Reina et al.’s (2010) participants noted that education, consisting of adequate instruction and exercise training, was essential to the home programming experience. It was necessary for therapists to invest time in educating parents on the essential skills required to implement the interventions at home (Segal & Hinojosa, 2006). Specific reminders, such as written instructions and verbal instructions, can also be beneficial in increasing home programming adherence (Escolar-Reina et al., 2010).

Development of rapport.

When developing home programs it is important for occupational therapists to understand that “their values as professionals and their belief in occupational therapy interventions may not be shared by the families” (Segal & Beyer, 2006, p. 509). Occupational therapists need to be family-centered while implementing home programs. Promotion of family-centeredness has been described by Novak and Cusick (2006) in five steps. Establishing rapport and a collaborative relationship with the patient and his or her caregiver is the first step. Mutual goal-setting and development of the home

program are the second and third steps. The final steps involve the therapist supporting the implementation of the home program and evaluating the program outcomes (Novak & Cusick, 2006).

This model is consistent with Piggot et al.'s (2003) research in which it was suggested that occupational therapists that do not have a trusting relationship with caregivers find it difficult to obtain accurate reports of adherence to home programming. Specifically, their findings indicated that caregivers who did not have a trusting relationship with the therapist were reluctant to report their level of adherence (Piggot et al., 2003). Piggot et al. (2003) further suggested that therapists should work on developing rapport while recommending home programs in order to encourage adherence. Caregivers also reported that they felt overwhelmed in the early stages of diagnosis and suggested that therapists provide additional support and higher levels of input (Piggot et al., 2003). Occupational therapists can provide additional support by being aware of and integrating family routines into the home programming process.

Learning family routines.

Multiple studies have pointed to the importance of home programs being implemented into family routines (Novak, 2011; Segal & Beyer, 2006; Segal & Hinojosa, 2006; Stieber et al., 2012; Tetreault et al., 2003). The organization of a program into a routine was considered more important than the amount of time spent doing the interventions (Segal & Beyer, 2006). In a comparative study, both groups (the adherence and non-adherence group) reported it was difficult to make the program a part of daily life, although, the adherence group was more able to put the activities into daily routines (Tetreault et al. 2003).

Transitioning from therapy in an occupational therapy setting to a home program was made easier by incorporating the families' everyday habits and routines into the home programming activities (Escobar Reina et al., 2010). Segal and Beyer (2006) suggested that occupational therapists learn families' daily routines so the program could be implemented in a way that minimized disruption to family routines. Parents felt more positive about a home program that they could incorporate into everyday activities, such as getting ready in the morning or getting ready for bed (Segal & Beyer, 2006).

Occupational therapists must understand the importance of incorporating home interventions into the child and family's daily routines; additionally, therapists should be available to provide assistance with adapting therapeutic tasks so the tasks can be better integrated into these daily routines (Segal & Hinojosa, 2006). Discussions with parents to determine what times would work best to implement the home interventions, as well as providing visual aids (such as a calendar to allow parents to track use of the program) were two strategies that assisted in improving familial home programming adherence (Segal & Beyer, 2006). Other families found that implementing home programming activities into other daily tasks (i.e. cooking) or making the home program a part of homework time with the child's siblings made doing the program easier for the family (Novak, 2011). These results were consistent with Hinojosa and Anderson's (1991) findings that parents appreciated activities that were able to be implemented within the context of different home activities. Jaffe, Humphry, and Case-Smith (2010) noted the importance of integrating therapeutic strategies into a child's daily activities, as the best learning occurs in a child's natural environment.

When home programs were too rigid or too great of an inconvenience, caregivers struggled to follow through with program completion (Novak, 2011; Segal & Beyer, 2006). Also, if the programs were lengthy or complex, there was less adherence (Tetreault et al., 2003). In a correlative study of parents who adhered to home programs and those who did not, Tetreault et al. (2003) found that 57% of families who had difficulty adhering to the home program struggled to make it a part of their daily lives. Home programs that were flexible and adaptable were viewed positively and were more easily incorporated into families' daily routines (Segal & Beyer, 2006).

During interviews with parents of children with disabilities, Novak (2011) noted that when home programs were a part of daily life for families, they were easier to implement for the family. Having the home program as a part of a daily routine helped normalize the families' activity and reduce their feelings of burden (Novak, 2011). Parents reported that with more flexibility in the home program it was easier to adapt it to their unique child and family routines (Novak, 2011). Novak (2011) also noted that interdisciplinary home programs were helpful; separate disciplines could integrate multiple home programming goals into one holistic program. In addition to building rapport and incorporating home programming into family routines, occupational therapists can provide support to families by monitoring and encouraging adherence.

Monitoring familial adherence.

Occupational therapists have suggested utilizing charts to track adherence and the child's progress towards goals to evaluate efficacy of the home program, as well as sharing and discussing this information with caregivers to support adherence (Segal & Beyer, 2006). Multiple researchers found participants' adherence increased when their

care provider “checked in” and monitored how the exercises were progressing (Escolar-Reina et al., 2010; Segal & Hinojosa, 2006). Khalil et al. (2012) found that weekly phone calls from therapists encouraged familial adherence to the home program.

Consistent “check-ins” from therapists have not been supported by all research findings as a strategy that increases home programming adherence. Mayo (1981) found no statistical difference between adherence to a home program between mothers who received a home visit from a therapist and the other mothers who did not receive a home visit, though the group that received the home visit showed an overall higher adherence rate (Mayo, 1981).

Occupational therapists’ approach can also have a negative impact on adherence (Novak, 2011; Tetreault et al., 2003). When occupational therapists chose the child’s goals and put pressure on the parents for adherence, the parents reported they found the experience too rigid, less motivating, and less satisfying (Novak, 2011).

Support from therapists.

Support and guidance from the therapist may influence home programming adherence with more positive results. Escolar-Reina et al. (2010), Hinojosa and Anderson (1991), and Segal and Hinojosa (2006) found that aspects of the care providers’ style in teaching and supporting clients and families were factors that influenced familial adherence. Parents in Novak’s (2011) study reported professional support such as a visit at home, a follow-up phone call, or training made them feel comfortable and increased their feelings of optimism, ability to cope, and confidence. According to Gajdosik (1991), having frequent contact with the child’s caregiver to review the home program and providing instruction and guidance on how to identify the child’s improvements are

strategies that therapists can use to help support parents with the implementation of home programs for their children. Gajdosik (1991) also found that providing positive reinforcement to the caregivers improved the caregivers' self-confidence and ability to adhere to the home program. When parents felt alone and without the support of a therapist, they reported feeling overwhelmed by responsibility (Novak, 2011). In a comparative study, Tetreault et al. (2003) found that a lack of therapist support was found in 36% of the parents in the group that struggled to adhere to the home program, compared to 3% of the parents in the group that had stronger adherence.

Home program factors in home programming adherence.

Factors and outcomes of the home program itself also impacted caregiver adherence to the intervention (Segal & Beyer, 2006). These home programming factors included the effectiveness of the home programs (Segal & Beyer, 2006), personalization of the home programs (Segal & Hinojosa, 2006), and readability of educational materials (Badarudeen & Sabharwal, 2010; Freda, 2005; Johnson & Stern, 2004).

Effectiveness of home programs.

Caregiver motivation to complete the home programming activities decreased if the program was not effective or if it did not help the child meet his or her goals (Segal & Beyer, 2006). When parents, using the Wilbarger protocol, noticed an immediate, positive effect of the brushing and compression home program they were using, they reported it was easier to continue the program (Segal & Beyer, 2006). One parent commented, “[i]t worked, which is why we stuck with it, of course” (Segal & Beyer, 2006, p. 505). Occupational therapists need to consider the effectiveness of the home

programs they prescribe, as this is often a factor that positively influences home programming adherence.

Personalization of home programs.

It is the duty of the occupational therapist to collect pertinent information from each client prior to suggesting or developing home programming (Huntley, 2008). This should include information about the client's lifestyle, such as meaningful activities, hobbies, and productivity that the client engages in. The program should be tailored to the child's special needs, with consideration to his or her strengths and areas for growth (Segal & Hinojosa, 2006). When considering implementing home programming with children, it is essential for occupational therapists to gather information regarding both the child's and family's meaningful occupations and environments. By collecting this information, the home program given to each family can be individualized to match the desires and needs of the entire family (Huntley, 2008). Another aspect of personalization of home programming is taking into account each client's ability to read (i.e. readability) and understand the materials they are given.

Readability of educational materials.

“Readability is an essential concept for patient education materials” (Freda, 2005, p. 1) and is “the ease with which written or printed information can be read” (Bastable, 2011, p. 232). As many occupational therapy home programs require reading, it is imperative that occupational therapists create home programs that are understandable to a broad population. The average American reading ability is at approximately an eighth grade level (Bastable, 2011). Subsequently, written materials for home programs should be written at no more than an eighth grade level (Badarudeen & Sabharwal, 2010; Freda,

2005; Johnson & Stern, 2004). Occupational therapists must consider the educational level of the caregiver when home programming education is provided, in order to ensure comprehension.

Despite the presence of recommendations regarding the readability level at which written materials should be created, research has shown that many educational materials are too complex for a broad consumer population (Badarudeen & Sabharwal, 2010; Freda, 2005; Johnson & Stern, 2004). Using two methods of patient education material analysis, Freda (2005) discovered that approximately half of the materials in the American Academy of Pediatrics patient education brochures were in the acceptable range (less than or equal to eighth grade level) with one method; with the other, none of the materials were acceptable. Similarly, Johnson and Stern (2004) discovered that of the cardiac rehabilitation education materials in rural and urban settings, only 9% of the urban materials and 14% of the rural materials were at or below the eighth grade level. The average readability of the cardiac materials was at least two grade levels higher than the average American reading level (Johnson & Stern, 2004).

In an article pertaining to health literacy in orthopedics, Badarudeen and Sabharwal (2010) stated that health related information has to be customized to each patient's literacy level in order to maximize the usefulness of the material. They also suggested that integrating other aids, such as videos, charts, or examples may increase patients' understanding of educational materials (Badarudeen & Sabharwal, 2010). When occupational therapists provide home programs they must be aware of the readability of the materials and provide materials that families can not only read, but also understand.

Summary

Published evidence exists to support the efficacy and use of occupational therapy home programs (Bazyk, 1989; Gajdosik, 1991; Hinojosa & Anderson, 1991; Novak & Cusick, 2006; Novak et al., 2007; Segal & Hinojosa, 2006; Tetreault et al., 2003). Despite the beneficial outcomes and frequent use of home programming in pediatric occupational therapy practice, limited adherence has been reported and adherence varies greatly (Rone-Adams et al., 2004; Stieber et al., 2012). While there is qualitative research that suggests there are factors that contribute to the execution of home programming, including child factors (Hinojosa & Anderson, 1991; Segal & Beyer, 2006; Stieber et al., 2012), caregiver factors (Novak, 2011; Segal & Beyer, 2006; Tetreault et al., 2003), occupational therapist factors (Hinojosa & Anderson, 1991; Novak, 2011; Segal & Beyer, 2006), and home program factors (Huntley, 2008; Segal & Beyer, 2006; Segal & Hinojosa, 2006), there is a dearth of quantitative research that has examined these factors in relation to successful home programming. Quantitative research is lacking on this topic and it is an important topic to address with a larger sample size and more objective data. Furthermore, a great deal of the published research that supports the use of home programs is outdated. In addition, use of an occupational therapy model to serve as a theoretical foundation from which to consider the factors that influence occupational therapy home programming adherence by families is needed.

Kielhofner's (2008) Model of Human Occupation (MOHO) was used as an occupation based model throughout this study to examine how child factors, caregiver factors, occupational therapist factors, and home program factors all contribute to successful engagement in occupations, as well as adherence to home programming. In

order to contribute to the body of knowledge on the topic of pediatric occupational therapy home programming, the following broad research questions were proposed: (a) What caregiver factors correlated with increased adherence to the child's home programming? (b) What child factors correlated with increased adherence to home programming? (c) What occupational therapist factors correlated with increased adherence to their client's home programming? (d) What home program factors correlated with increased familial adherence to home programming?

Chapter II included a review of literature pertaining to caregiver adherence to home programming including the child, caregiver, occupational therapist, and home program factors that impact adherence. The review of literature involving these factors and use of an occupation based model as a guide, led to the development of the research questions and research study. Chapter III is comprised of the research methodology used to gather and analyze survey data used in this research study. Included are the details of the subject characteristics, sampling procedures, ethical considerations, research design, instrument development, theoretical basis for development, and statistical analysis.

Chapter III

Methodology

Chapter III: Methodology consists of the process of gathering and analyzing survey data used within this research study. Included are the details of the respondents' characteristics, sampling procedures, ethical considerations, research design, locale of study, instrument development, theoretical basis for development, and the tools and instruments used for statistical analyses.

Subject Characteristics

The target population had the following inclusion criteria: (1) caregivers who serve or have served as a primary caregiver for a child (birth through 17 years old) with a disability, (2) the child must be receiving occupational therapy services or may have received occupational therapy services in the past; specifically, an occupational therapy home program, and (3) the respondents had to be able to read and comprehend English. There were no exclusion criteria, other than having to meet the aforementioned inclusion criteria. Overall, 15 caregivers of children with disabilities completed the informed consent and online survey.

Sampling Procedures

A sample of convenience was used to gather respondents, due to the specific inclusion criteria and the characteristics of the population. No randomization was instituted due to a limited number of respondents. This process was consistent with

previous research studies, as limited response rates are common in survey research (Forsyth & Kviz, 2006). Most existing research relating to this topic was conducted in a qualitative manner, with less than 20 participants (Novak, 2011; Segal & Beyer, 2006; Tetreault, Parrot, & Trahan, 2003). There was limited existing survey research on this topic. A majority of the participants involved had been interviewed or questioned directly by the researchers (Rone-Adams et al., 2004). Processes were established apriori to institute random selection if the respondent sample reached 150 participants; however, due to a small number of respondents, random selection was not implemented.

Potential respondents for this study were accessed through four separate processes that involved members of seven state and national organizations. Refer to Appendix C for the request letter that was sent to these organizations for potential respondents. The researchers used four different avenues for recruiting respondents, in order to enhance the external validity of the study results. The four methods of accessing respondents included: (1) the use of direct email invitation from the organization to the membership—National Alliance on Mental Illness (NAMI) of Minnesota, (2) the posting of an electronic invitation by the organization to the organization’s listserv—Family Voices of North Dakota, Inc., (3) the posting of an electronic invitation by the researchers to the organization’s listserv—Minnesota STAR Program, and (4) invitations provided in the organizations’ newsletters—Disability is Natural, Minnesota Brain Injury Alliance, Rocky Mountain ADA Center, and Pathfinder Parent Center. Overviews of the aforementioned organizations, their mission statements, and contact information have been provided in Appendix D. Refer to Appendix E to view the email messages that confirmed the organizations’ willingness to post an invitation to partake in this study. A

link to the online survey, which included informed consent, was provided to each of these organizations. A brief overview of the study was posted in the invitation, as well as the web address to the online survey.

Ethical Considerations

The University of North Dakota's Institutional Review Board (IRB) approved this study on November 29, 2012 (case number: IRB-201211-141). Refer to Appendix F for the official IRB approval letter. Following IRB approval, the survey was reviewed by the NAMI research review board before the survey was sent to the members of that organization. Each respondent provided informed consent prior to being allowed access to the online survey. Refer to Appendix G to view the detailed informed consent form. Respondents' identifying information was not gathered to ensure anonymity. Confidentiality was guaranteed through the use of Qualtrics for survey dissemination. Qualtrics is a secure online server through the University of North Dakota which provides an option, used in this study, which prohibits tracking of internet provider addresses in order to maintain confidentiality.

Research Design

A prospective, exploratory survey design was used to access respondents and gather data to answer the research questions. An online survey format was used and potential respondents were contacted by either direct email invitation from the organization to the membership, posting of an electronic invitation by the organization to the organizations' listservs, posting of an electronic invitation by the researchers to the organizations' listservs, or invitations provided in the organizations' electronic newsletters. Each of these methods of contact provided the potential respondents with a

link to the URL to access the survey, which decreased issues of the respondents having to copy a lengthy link to the survey and increased ease of access to the survey.

A survey design contributed to the ability to collect data on multiple respondent variables and subsequently, complete broad statistical analyses of the collected data (Forsyth & Kviz, 2006). Despite numerous benefits to the use of a survey to answer the research questions, there were limitations. A survey design may contain nonresponse bias as the individuals who choose to respond to the survey may have different characteristics than those who choose not to respond (Forsyth & Kviz, 2006). In addition, of those who do respond, there may have been response bias including: inability to correctly remember information, respondents interpreting the meaning of a question differently than intended, and/or having response choices that do not represent the respondent's opinion (Forsyth & Kviz, 2006). Online survey research also presents concerns of only including populations that have internet access, which can create sampling bias (Forsyth & Kviz, 2006). Online survey research is becoming more commonly used, as it is an efficient method of gathering data, has limited costs associated with distribution, and provides seamless transfer of the data to a statistical analysis package (Forsyth & Kviz, 2006).

Locale of the study.

The surveys were completed by respondents in an online format at a location of the respondents' choice. With IRB approval, data collection began January 1, 2013 and ended on February 28, 2013. The respondents were able to use any device that allowed them to access the Internet and respond to the online survey (i.e. computer, mobile device, I-pad, etc.). The survey and responses were initially housed in the University of North Dakota's, SSL encrypted, Qualtrics program. To counter concerns about privacy

and confidentiality using online research the researchers took precautions by using a confidential server to disseminate the surveys and store the data. The researchers did not ask any questions that involved identifying characteristics and did not track any of the respondents who chose to participate in the survey. The consent form was written at a sixth grade level and required completion before respondents could begin the study. The consent form described these measures for the respondents in detail.

Instrument: Multi-dimensional Occupational Therapy Home Programming Engagement Survey.

One survey, the Multi-dimensional Occupational Therapy Home Programming Engagement Survey, developed by the researchers, was used to gather data in this study. The Multi-dimensional Occupational Therapy Home Programming Engagement Survey was composed of demographic questions and Likert-type statements or questions, which were designed to gather information regarding caregiver perceptions of their child's home programming variables. The survey was composed of eight subscales, including: Child Benefits, Caregiver Value, Habituation, Caregiver's Performance Capacity, Child's Performance Capacity, Temporal Environment, Physical Environment, and Social Environment.

The researchers designed the survey for data collection; therefore, the measure had not been formally tested on the psychometric properties of validity and reliability. However, internal reliability measures of the subscales were completed on the survey instrument to identify the consistency of the instrument. To determine the reliability of the instrument, the researchers used statements with varying directionality. Two examples included: "Carrying out my child's home program is part of our daily routine"

with the reversal “My child's home program is difficult to fit into my family's schedule” and “My child's home program is important to me” with the reversal “I do not understand the importance of the home program.” Using a process outlined by Forsyth and Kviz (2006), the researchers clarified the survey variables, created questions, and formatted the survey. The final step, piloting of the survey was not completed due to time restrictions (Forsyth & Kviz, 2006).

The survey development was guided by the Model of Human Occupation (MOHO), evidence regarding home programming for children with disabilities, and literature on successful survey development. The survey respondents consented using an online consent form that did not allow initiation of the survey without consent. The online Multi-dimensional Occupational Therapy Home Programming Engagement Survey consisted of 44 questions that included Likert-type Scale questions, multiple response questions, and demographic questions. These questions were related to volition (motivation), habituation (routines and schedules), performance capacity (ability of the parent and child), and environmental factors; each of these areas are within MOHO (Kielhofner, 2008).

The Multi-dimensional Occupational Therapy Home Programming Engagement Survey questions pertained to the child, parent/caregiver, occupational therapist, and home program factors that influence the home programming process. Refer to Appendix H to view the survey. The survey was designed for the parents/caregivers to complete in approximately 15-20 minutes. Following the respondents' completion of the survey, the data was stored in the University of North Dakota Qualtrics system (a SSL encrypted program) to be analyzed.

Theoretical Foundation: The Model of Human Occupation

Using a theoretical model is essential when considering research and future practice as it increases the validity of research and allows for a guide that is evidence-based and grounded in previous research (Cole & Tufano, 2008). MOHO is an occupation based model that is used frequently in occupational therapy practice. The two main constructs within this model are the person and the environment (Kielhofner, 2008). MOHO is a theoretical model that is used to identify performance skills and patterns, individual client factors impacting participation in occupations, and the environments that facilitate or inhibit performance (Baptiste, 2008; Kielhofner, 2008). A primary focus within this study was related to how the person and environment subsystems work together to facilitate occupational performance. Specifically of importance is how these factors influenced caregivers with implementing an occupational therapy home program with their child with disabilities.

Within MOHO, the person system is further broken down into volition, habituation, and performance capacity (Kielhofner, 2008). The environmental subsystem involves both the physical and social environments (Kielhofner, 2008). A detailed chart of each question involved in the survey and the aspect of MOHO it addressed is included in Appendix B.

Person.

Volition.

The first aspect of the person subsystem is volition, which is an individual's source of motivation to engage in occupations; this guides what individuals do and how they experience situations (Kielhofner, 2008). Volition is further divided into personal

causation, values, and interests (Kielhofner, 2008). Personal causation refers to a person's capacity for self-efficacy; it examines an individual's feelings of competence and awareness of his or her abilities (Kielhofner, 2008). The concept of personal causation was addressed in the survey through questions similar to: "I feel confident carrying out my child's home program" and "I can complete the home program with my child as good as anyone."

Values—beliefs about what is important, right, and good to engage in that influence one's actions and goals—are another component of the person subsystem (Kielhofner, 2008). Questions such as, "My child's home program is important to me" and "I do not understand the importance of the home program" examined the value that parents and caregivers placed on the home program. The benefits observed from the home program for the child, including physical benefits, psychological benefits, and increased independence may also be of value to caregivers. The Likert statements: "My child likes doing therapy at home" and "The home program causes my child discomfort" addressed the caregiver perceptions of the child's outcome and the focus on the child as a part of the program.

Interests—another aspect of the concept of volition—are what a person finds satisfying, pleasing, and enjoyable (Kielhofner, 2008). These interests and factors of motivation were addressed through the following questions: "I am motivated to complete the home program with my child" and "I am hopeful that the home program will help my child."

Habituation.

The next aspect of the person subsystem within MOHO is habituation (comprised of two parts—habits and roles), which helps individuals organize patterns or routines within their daily lives (Kielhofner, 2008). Habits are referred to as automatic and repetitive behaviors that shape how individuals behave and use their time on a daily basis (Kielhofner, 2008). The importance of a familial routine and the significance of incorporating a home program within this daily routine were noted throughout the literature review. The questions used to address routines included: “Carrying out my child’s home program is part of our daily routine,” “My child’s home program is difficult to fit into my family’s schedule,” and “The home program has activities my child would do anyway.” Other questions about habits and routines were: “My child’s home program takes too much time” and “My child’s home program has to be done too often.” Familial habits and routines were incorporated throughout the survey when considering the amount of time families have to complete the home program, as well as the ability of each family to form a habit of completing the home program on a regular basis.

Performance capacity.

The last component of the person system is performance capacity (Kielhofner, 2008). Performance capacity refers to the physical and mental skill abilities that influence occupational performance (Kielhofner, 2008). The concept of performance capacity was addressed through the following question: “I am able to help my child do the activities as well as anyone else.”

Occupational performance.

In MOHO, occupational performance is defined as participation in a goal-directed action (Kielhofner, 2008). Throughout this study, the action the researchers addressed was familial participation in a home occupational therapy program. Caregivers were asked about specific factors that facilitated engagement or that were barriers to implementing a home program for their child. They were also asked who was involved with developing the program and if the caregivers' input was utilized throughout the home program development. The average adherence, or the ability to complete the program, was examined. Additional questions were concerned with the child's ability to participate in the home program. These concepts were addressed throughout the following questions: "What is your child's ability to do everyday tasks in relation to other children?", "What is your child's ability in school settings in relation to other children?", and "What is your child's ability to interact with other children?"

Environment.

Environment is the last category within MOHO and involves the social and physical components and contexts within one's life (Kielhofner, 2008). More specifically, the physical environment encompasses the natural and built spaces, as well as the objects within these spaces (AOTA, 2008; Cole & Tufano, 2008). The social environment incorporates the relationships, expectations, and the presence of people, organizations, and populations (AOTA, 2008). Each of these environmental components was addressed throughout the Multi-dimensional Occupational Therapy Home Programming Engagement Survey.

The physical environment was considered through questions such as “We have enough space in our home to carry out the home program,” “We have the right equipment to carry out the home program,” and “My child and I are not able to do the activities in our home.” The social environment was examined through the following questions: “There is too much going on in our home to do the suggested activities,” “Doing the home program activities negatively affects other family members,” and “Family support helps us do the activities at home.”

Summary of theoretical basis.

MOHO is a client centered and evidence-based conceptual model that focuses on the internal factors of the person and how the external factors of the environment influence participation and engagement in meaningful occupations (Kielhofner, 2008). The Multi-dimensional Occupational Therapy Home Programming Engagement Survey was designed to gather information about the aspects of MOHO, including the person (volition, habituation, and performance capacity), occupational performance (of caregiver and child), and environment (physical, social), as well as to address client-centeredness. The researchers used existing literature to guide the development of the Multi-dimensional Occupational Therapy Home Programming Engagement Survey and addressed aspects that caregivers of children with disabilities identified as essential to the overall home programming process.

The Multi-dimensional Occupational Therapy Home Programming Engagement Survey was also client centered, as it was designed with consideration for clients with varying reading comprehension. Once the initial survey was drafted, the researchers analyzed the readability of the survey using the Flesch-Kincaid scale, which can be used

to examine the average sentence length, in words, and average word length, in syllables (Bastable, 2011). These two variables are calculated to form the reading ease (RE) score (Bastable, 2011). The RE of the survey was 6.3. Lastly, the length of the survey considered respondents' busy lifestyles by taking only 15 to 20 minutes of their time to complete it.

Tools for Data Analyses

Data was analyzed using SPSS 20.0 and included descriptive statistics analyses and inferential analyses of numerous variables, to answer the research questions. A pre-analysis data screen was completed prior to beginning data analysis. Analysis of the reliability of the Multi-dimensional Occupational Therapy Home Programming Engagement Survey was completed. Following the reliability analysis of this instrument, statistical analyses of the descriptives were completed for the demographics and survey responses. Lastly, inferential statistical analyses were conducted on the data that was collected.

Summary

Chapter III consisted of the methodology, which included the process of gathering and analyzing survey data that was used in this research study. The details of the subject characteristics, sampling procedures, ethical considerations, research design, locale of the study, instrument development, theoretical basis for development, and statistical analyses were included. Chapter IV consists of the results and statistical analyses of the data that was gathered.

Chapter IV

Results

Chapter IV: Results consists of the statistical analysis of the results from the online survey of caregivers of children with disabilities. Chapter IV also includes the pre-analysis data screen, analysis of the reliability of the survey instrument, statistical analyses of the descriptive statistics, and inferential statistical analyses used to answer the research questions.

Data was downloaded from the Qualtrics server into a Microsoft Excel Spreadsheet. The data was then entered into SPSS 20.0 for data analysis. A pre-analysis data screen was completed prior to beginning data analysis. Analysis of the internal reliability of the survey instrument, the Multi-dimensional Occupational Therapy Home Programming Engagement Survey, which was created by the researchers, was completed. Following the reliability analysis of the instrument, statistical analyses of the descriptives were completed for the demographics and survey responses. Lastly, inferential statistical analyses were conducted on the data that was collected.

Pre-Analysis Data Screening

To ensure accuracy of the results, a pre-analysis data screen was conducted (Mertler & Vannatta, 2005). The pre-analysis screen included examining the missing data, as well as eliminating cases that initiated the survey but did not provide informed consent. A total of 33 respondents accessed the online survey. Of these 33 cases, 15 had a complete data set and thus were analyzed. Within the original data set, the following

cases were excluded from data analysis: Cases 4, 14, 15, 16, 17, 18, 21, 22, 23, 24, 25, 26, 28, 29, 30, 31, 32, and 33.

Instrument Reliability: Multi-dimensional Occupational Therapy Home Programming Engagement Survey

The reliability of the Multi-dimensional Occupational Therapy Home Programming Engagement Survey was analyzed using SPSS 20.0. The results from Cronbach's Coefficient Alphas are presented throughout the following sections for instrument reliability.

The Multi-dimensional Occupational Therapy Home Programming Engagement Survey was composed of eight subscales, including: Child Benefits, Caregiver Value, Habituation, Caregiver's Performance Capacity, Child's Performance Capacity, Temporal Environment, Physical Environment, and Social Environment. Each subscale included specific questions from the online survey that correlated with the appropriate subscale topic. The survey also included demographic questions. The purpose of using combined subscale scores was to determine factors that impact caregiver adherence to occupational therapy home programming.

All subscales were analyzed to determine the surveys internal reliability. The Cronbach's Coefficient Alphas ranged from .304 to .944. The subscale with the highest internal reliability was physical environment and the subscale with the lowest internal reliability was child's performance capacity. The total score for the Multi-dimensional Occupational Therapy Home Programming Engagement Survey demonstrated a Cronbach's Coefficient Alpha of .557; this demonstrated moderate internal reliability. Due to the moderate internal reliability of this survey, the researchers chose to use the

individual subscales for comparison, as there were higher internal reliability scores when the subscales were analyzed individually.

Table 1
Internal Reliability (Cronbach's Coefficient Alpha) Results for the Multi-dimensional Occupational Therapy Home Programming Engagement Survey

Subscales	Number of Items	Cronbach's Coefficient Alpha
Child Benefits	6	.452
Caregiver Values	3	.789
Habituation*	3	-2.375
Caregiver Performance Capacity	3	.870
Child's Performance Capacity	3	.304
Temporal Environment	3	.769
Physical Environment	2	.944
Social Environment	3	.562
Adherence	**	**
Total Internal Reliability	22	.557

*Habituation was not included in the total internal reliability score

**Only one question was analyzed

The Cronbach's Coefficient Alpha came up as a negative number for the subscale of habituation, which cannot be analyzed with the total. Habituation was removed from the instrument reliability test, as the conflicting responses violated the assumptions of the test. The total internal reliability of the instrument also included the question on overall programming adherence, which was not analyzed individually for internal reliability, as it was only one question.

Table 2

Subscales Created from Survey Instrument

Scale	Operational Definition	How Quantified
Child Benefits	Reported factors that motivated caregivers to implement the home program	Sum of frequency responses of items regarding: Child's mood; Child's physical capacity; Child's independence; Child's enjoyment; Child's discomfort; & The "just-right" challenge
Caregiver Values	Reported factors that are important to the caregiver when completing the home program	Sum of frequency responses to items regarding: Importance of home program; Motivation to complete; & Hope that it will help child
Habituation	Reported factors that involve the families' habits and routines	Sum of frequency responses to items regarding: Program is part of routine; Difficult to fit in schedule; & Uses everyday activities
Caregiver's Performance Capacity	Reported factors that are related to the caregivers' confidence and ability to complete home program	Sum of frequency responses to items regarding: Able to change activities; Confidence in ability; & Self-efficacy with performance
Child's Performance Capacity	Reported factors of caregiver perceptions about child's independence	Sum of frequency responses to items regarding: Activities of daily living; School performance; & Socialization
Temporal Environment	Reported factors that involve caregivers' perceived time for completing the home program	Sum of frequency responses to items regarding: Program takes too much time; Program is done too often; & Program is stressful
Physical Environment	Reported factors that are non-human (i.e. objects and space) within the home environment	Sum of frequency responses to items regarding: Have enough space in home & Have right equipment
Social Environment	Reported factors that are human (i.e. people, interactions) within the home environment	Sum of frequency responses to items regarding: Too much going on; Negatively affects family; & Family support helps

Research Question Analysis

Research analysis began with the analysis of the demographics and descriptive statistics, including frequencies, means, and standard deviations. Next, correlations were completed between the subscales and caregiver adherence. Various analyses were used on SPSS 20.0, including Pearson's Correlation Coefficients, Spearman's *rho*, t-tests for independent data, and analyses of variance (ANOVAs).

Demographic analysis.

Of the 33 people who viewed the first page of the online survey, 15 provided informed consent and completed the survey. The frequencies and percentages for the respondents' gender were calculated and revealed that 93.3% (n = 14) of the respondents were female. There was one respondent who elected not to respond to this question, which accounted for 6.7% of the cumulative percentage. When examining the marital status of the respondents, 80.0% (n = 12) identified that they were married, 6.7% (n = 1) were separated, and 13.3% (n = 2) elected not to respond to this question.

Frequencies and percentages were also calculated to determine each child's primary caregiver. The respondents' responses were in three categories for this question; 20.0% (n = 3) identified that the mother was the child's primary caregiver, 66.7% (n = 10) of the respondents identified that both parents assist with the care giving responsibilities, and 6.7% (n = 1) acknowledged that there was another caregiver, other than the parents, caring for their child. One respondent (6.7% of the sample) elected not to answer this question.

The frequencies and percentages were calculated for the age of the children who have received, or who were currently receiving, occupational therapy services. There

was one person who elected not to respond and, thus, 14 caregivers responded to this question. There were 26.7% (n = 4) of the children that were 1 day to 2 years old, 6.7% (n = 1) of respondents identified that their child was 3 to 4 years of age, 20.0% (n = 3) identified that their child was 5 to 8 years old, 26.7% (n = 4) of the respondents identified that their child was 9 to 12 years of age, and 13.3% (n = 2) of the respondents' children were 13 to 17 years of age. In addition, the gender of the children who had previously received or were currently receiving occupational therapy services was identified. Of the 14 responses, 40.0% (n = 6) of the children were males, 46.7% (n = 7) of the children were females, and 6.7% (n = 1) of the caregivers elected not to respond to this question.

The frequencies and percentages for the respondents' employment status were calculated. Fourteen of the fifteen respondents elected to respond to this question; 66.7% (n = 10) identified that they were employed full time outside of their home, 13.3% (n = 2) were employed part-time outside of their home, 6.7% (n = 1) were employed part-time but worked from their home, and 6.7% (n = 1) were not employed in a job outside of their home. In addition to this, respondents were asked to identify their annual household income. One individual elected not to respond. The results indicated that 6.7% (n = 1) of respondents identified that their income was less than \$30,000, 6.7% (n = 1) had an annual household income of \$40,000-49,000, 13.3% (n = 2) of the respondents had an annual household income of 50,000-59,000, 6.7% (n = 1) identified that their annual household income was between \$60,000 and \$69,000, 6.7% (n = 1) had an annual household income of \$70,000-79,000, 6.7% (n = 1) acknowledged that their annual household income was between \$80,000 and \$89,000, 6.7% (n = 1) had an annual

household income of \$90,000-99,000, and 26.7% (n = 4) identified that their annual household income was at or above \$100,000.

The frequencies and percentages were calculated for the length of time the respondents had carried out their child's occupational therapy home program. Fourteen of the 15 respondents replied to this question; 6.7% (n = 1) identified that they had carried out the home program for less than 1 month, 13.3% (n = 2) had implemented their child's home program for 7 months to 1 year, and 73.3% (n = 11) of the respondents acknowledged that they had been carrying out their child's home program for more than 1 year.

The frequencies and percentages were calculated for the number of children (under the age of 18 years) currently living in the respondents' homes. Respondents with one and two children living in the home were represented evenly, as each of these items were 26.7% (n = 4) of the cumulative sample. Respondents with three children living in the home represented 20.0% (n = 3) of the sample. There were 13.3% (n = 2) of the respondents who reported having four children living in their home, and 6.7% (n = 1) reported that they had five or more children currently living in their home. One respondent elected not to answer this question; this accounted for 6.7% (n = 1) of the cumulative sample.

When considering the frequencies and percentages of the varying conditions of each child, there was an opportunity for the respondents to choose more than one possible condition, as many children may have more than one. Additionally, respondents were able to add in their child's condition if it was not already presented. The following data

represents 14 of the 15 total respondents; one person elected not to respond to the question regarding his or her child's condition.

Of the caregivers who responded, 33.3% (n = 5) reported that their child had autism; 26.7% (n = 4) reported their child had attention deficit hyperactivity disorder (ADHD); 13.3% (n = 2) identified that their child had cerebral palsy; 53.3% (n = 8) of caregivers reported their child had developmental delays; 20.0% (n = 3) of the caregivers identified that their child had a genetic condition; 20.0% (n = 3) of the caregivers reported their child had anxiety; 13.3% (n = 2) of caregivers reported their child was diagnosed with depression; both oppositional defiant disorder and bipolar disorder were identified as the child's condition by 6.7% (n = 1) of the respondents. Caregivers were provided with the option to fill in "other" conditions their child may have; 40.0% (n = 6) chose to do so. The other conditions reported were: dyslexia, epilepsy, presence of a feeding tube, sensory problems, specific learning disorder, and spinal muscular atrophy—type II; each of these conditions were identified by 6.7% (n = 1) of the respondents.

The frequencies and percentages were determined for the specific states in the United States which the respondents were from. This question could have been confusing, as some of the respondents may have identified where they were initially from rather than where they were currently residing. North Dakota residents composed the largest portion of the sample, as 66.7% (n = 10) of the respondents were from this state. Minnesota was the next largest and composed 13.3% (n = 2) of the sample. Alabama and Oregon were equal; both states comprised 6.7% (n = 1) of the cumulative percentage.

Frequencies and descriptives.

Caregiver volition was examined by several questions. Multiple caregivers agreed or strongly agreed that their child felt better physically, following the program (n=9, 60.0%) with no caregivers disagreeing or strongly disagreeing (n=0, 0.0%). A majority also agreed or strongly agreed that the home program caused their child discomfort (n=9, 60.0%) but the same number reported their child liked doing therapy at home (n=9, 60.0%). Four caregivers reported their child did not like doing the program at home (n=4, 26.7%). A majority of the caregivers agreed or strongly agreed that the home programming activities provided the “just right” challenge (n=9, 60.0%) and helped increase their child’s independence (n=9, 60.0%). Every caregiver either agreed or strongly agreed that the home program was important to them (n=15, 100%) and that they were hopeful it would help (n=15, 100%). Most were also motivated to do the home program (n=13, 86.7%), however, many reported that they did not understand the importance of the program (n=12, 80.0%).

Table 3
Frequencies and Percentages of Caregiver Volition (Child's Benefits and Caregiver Values)

Factor	Strongly Agree		Agree		Neither Agree nor Disagree		Disagree		Strongly Disagree	
	n	%	n	%	n	%	n	%	n	%
Child Benefits										
Child's mood is better	0	0.0	7	46.7	7	46.7	1	6.7	0	0.0
Child feels better physically	1	6.7	8	53.3	6	40.0	0	0.0	0	0.0
Child likes doing therapy at home	1	6.7	8	53.3	2	13.3	3	20.0	1	6.7
Causes child discomfort	1	6.7	8	53.3	4	26.7	2	13.3	0	0.0
Home program gives child "just right" challenge	2	13.3	7	46.7	3	20.0	3	20.0	0	0.0
Child can do more for self after home program	3	20.0	6	40.0	3	20.0	3	20.0	0	0.0
Caregiver Values										
Child's home program is important to me	5	33.3	10	66.7	0	0.0	0	0.0	0	0.0
I am motivated to do it	4	26.7	9	60.0	1	6.7	1	6.7	0	0.0
I am hopeful it will help	5	33.3	10	66.7	0	0.0	0	0.0	0	0.0

Caregivers' reports of habitation in regard to home programming showed that many of the 15 caregivers either agreed or strongly agreed (n=9, 60.0%) that the program was a part of their daily routine. Other caregivers (n=5, 33.3%) found that it was difficult to fit into the family's schedule.

Table 4
Frequencies and Percentages of Caregiver Habitation

Factor	Strongly Agree		Agree		Neither Agree nor Disagree		Disagree		Strongly Disagree	
	n	%	n	%	n	%	n	%	n	%
Home program is part of daily routine	1	6.7	8	53.3	1	6.7	5	33.3	0	0.0
Difficult to fit into family schedule	0	0.0	7	46.7	3	20.0	5	33.3	0	0.0
Has activities child would do anyway	1	6.7	7	46.7	2	13.3	4	26.7	1	6.7

Caregiver performance capacity examined the beliefs that caregivers have about their own abilities to assist their child with completing the home program. Most caregivers felt confident doing the home program (n=11, 73.4%), that they could change their child's home program as needed (n=10, 66.7%), and that they had high self-efficacy in doing the program (n=10, 66.7%).

Table 5
Frequencies and Percentages of Caregiver Performance Capacity

Factor	Strongly Agree		Agree		Neither Agree nor Disagree		Disagree		Strongly Disagree	
	n	%	n	%	n	%	n	%	n	%
I feel confident to carry out program	1	6.7	10	66.7	1	6.7	2	13.3	0	0.0
I can change program with ease	2	13.3	8	53.3	2	13.3	2	13.3	0	0.0
I can help my child do the activities as well as anyone	3	20.0	7	46.7	2	13.3	2	13.3	0	0.0

The temporal environmental factors were examined. Most of the caregivers (n=10, 66.7%) believed the home programming had to be done too often and that it took too much time (n=7, 46.7%). Although most caregivers reported high confidence and self-efficacy, only 4 of 15 reported that they did not feel stressed about implementing the home program (n=4, 26.7%).

Table 6
Frequencies and Percentages of Temporal Environment

Factor	Strongly Agree		Agree		Neither Agree nor Disagree		Disagree		Strongly Disagree	
	n	%	n	%	n	%	n	%	n	%
Takes too much time	0	0.0	7	46.7	6	40.0	1	6.7	1	6.7
I am stressed about doing home program	1	6.7	5	33.3	5	33.3	4	26.7	0	0.0
Has to be done too often	3	20.0	7	46.7	3	20.0	2	13.3	0	0.0

The physical environment examined the non-human variables (i.e. objects and space) within the home environment. While 10 of the 15 respondents reported that they were not able to do the activities within their home (66.7%), the same number of respondents reported that they have enough space and the correct equipment in their home to carry out the home program (n=10, 66.7%).

Table 7
Frequencies and Percentages of Physical Environment

Factor	Strongly Agree		Agree		Neither Agree nor Disagree		Disagree		Strongly Disagree	
	n	%	n	%	n	%	n	%	n	%
Have enough space in home for program	2	13.3	8	53.3	2	13.3	2	13.3	0	0.0
Have right equipment to carry out program	2	13.3	8	53.3	3	20.0	0	0.0	1	6.7
Not able to do the activities in home	4	26.7	6	40.0	2	13.3	2	13.3	0	0.0

The social environmental variables included the human factors within the home environment (i.e. people interactions). The home programming tended to negatively affect other family members, as a majority of the respondents strongly agreed or agreed (n=9, 60.0%) to the following statement: “Home program negatively affects other family members.” Family support was reported to help with the home programming from most respondents (n=11, 73.4%).

Table 8
Frequencies and Percentages of Social Environment

Factor	Strongly Agree		Agree		Neither Agree nor Disagree		Disagree		Strongly Disagree	
	n	%	n	%	n	%	n	%	n	%
Too much going on in home to do	3	20	3	20	4	26.7	4	26.7	0	0
Program negatively affects other family members	4	26.7	5	33.3	3	20	2	13.3	0	0
Family support helps do the home program	1	6.7	10	66.7	1	6.7	1	6.7	1	6.7

In a checklist format, caregivers were asked to select factors that made adherence to the home programming difficult. They were able to select as few or as many factors as they wanted. Busy family life and busy work/school schedule were the most common, with 12 of the 15 respondents selecting them as a factor that made adherence difficult (80.0%). The next most common problematic factors were budget and the length of the program, with both being selected by 2 of the 15 respondents (13.3%). Not understanding the purpose of the home program, lack of directions from the therapist, the therapist not understanding needs, and a confusing home program were all selected once (n=1, 6.7%). The child factors of the activities not focusing on the child and the activities being too difficult were not selected by any respondents as factors that made the home programming difficult (n=0, 0.0%).

Table 9
Frequencies and Percentages of Factors that Made Adherence to Home Programming Difficult

Factor	Makes Difficult		Not Selected	
	n	%	n	%
Caregiver Factors				
Budget	2	13.3	13	86.7
Busy family life	12	80.0	3	20.0
Busy work/school schedule	12	80.0	3	20.0
Not understanding how it helps	1	6.7	14	93.3
Child Factors				
Activities did not focus on child	0	0.0	15	100.0
Activities were too hard for child	0	0.0	15	100.0
Occupational Therapist Factors				
Lack of directions from therapist	1	6.7	14	93.3
Therapist does not understand needs	1	6.7	14	93.3
Home Program Factors				
The program is too long	2	13.3	13	86.7
The program is confusing	1	6.7	14	93.3

In a checklist format, caregivers were asked to select factors that made adherence to the home programming easy. Results for factors that made the home programming easy were numerous, involving caregiver, child, occupation therapist, and home programming factors. More than half of the respondents identified that the following factors made the programming easier: being involved in the goal setting (n=8, 53.3%),

the therapist providing good education (n=9, 60%), having clearly written instructions (n=9, 60.0%), practicing the home program with the therapist (n=9, 60.0%), and that the program used everyday activities (n=9, 60.0%). Other factors were also selected, but by less than half of the respondents and included: the child enjoying the home program (n=7, 46.7), the therapist being motivating (n=5, 33.3%), the therapist checking in regularly (n=6, 40.0%), and using photographs in the home program (n=7, 46.7%).

Table 10
Frequencies and Percentages of Factors that Made Adherence to Home Programming Easy

Factor	Makes Easy		Not Selected	
	n	%	n	%
Caregiver Factors				
Being involved in the goal setting	8	53.3	7	46.7
Child Factors				
Child enjoys home program	7	46.7	8	53.3
Occupational Therapist Factors				
Provided good education	9	60.0	6	40.0
Clearly written instructions	9	60.0	6	40.0
Practiced program with child and parent	9	60.0	6	40.0
Therapist is motivating	5	33.3	10	66.7
Therapist checks in to monitor progress	6	40.0	9	60.0
Home Program Factors				
The program uses everyday activities	9	60.0	6	40.0
Photographs were used	7	46.7	8	53.3

The children’s occupational performance was limited in the areas of everyday living, school, and social participation. There were various degrees of impairment noted, with some children having multiple areas of impairment. Twelve children were reported as having less than or much less than ability compared to their peers in the area of everyday living (n=12, 80%). Ten children were reported as having less than or much less than ability compared to their peers in the school setting (n=10, 66.7%). Ten children were reported as having less than or much less than ability to socially interact, compared to their peers (n=11, 73.3%).

Table 11
Frequencies and Percentages of Child’s Occupational Performance

Performance In Relation to Other Children of Similar Age							
Performance Area	Much less than others		Less than others		Similar to others		
	n	%	n	%	n	%	
Completing every day tasks	5	33.3	7	46.7	3	20.0	
Ability in school setting	3	20.0	7	46.7	2	13.3	
Interacting with other children	2	13.3	9	60.0	3	20.0	

The occupational therapist was most frequently involved with developing the home program (n=12, 80%), followed by the caregiver being involved in a majority of the cases (n=11, 73.3%). Teachers were occasionally involved (n=5, 33.3%), as well as doctors (n=4, 26.7%). Four respondents selected “other” and listed physical therapy (n=3, 20.0%), speech therapy (n=2, 13.3%), and the whole facility being involved in the

development of the home program (n=1, 6.7%). The child was involved in two cases (n=2, 13.3%).

Table 12
Frequencies and Percentages of Individuals Involved in Designing Home Program

Individual Involved	Was Involved		Not Selected	
	n	%	n	%
Caregiver	11	73.3	3	20.0
Child	2	13.3	12	80.0
Occupational Therapist	12	80.0	2	13.3
Teacher	5	33.3	9	60.0
Doctor	4	26.7	10	66.7
Other	4	26.7	10	66.7

The child clients received occupational therapy services at a variety of locations with the clinic being the most common (n=8, 53.3%), closely followed by their home (n=7, 46.7), school (n=6, 40.0%), and the hospital (n=2, 13.3%).

Table 13
Frequencies and Percentages of Location of Occupational Therapy Services

Location	Received Services		Not Selected	
	n	%	n	%
School	6	40.0	8	53.3
Hospital	2	13.3	12	80.0
Clinic	8	53.3	6	40.0
Home	7	46.7	7	46.7

Respondents were asked to indicate their adherence to the home programming by the following percentages: 0-25%, 25-50%, 50%-75%, and 75-100%. The most frequently selected option was 50-75%, with six respondents selecting it (40.0%). Only 3 respondents selected 75-100% (20.0%) and 3 respondents selected 25-50% (20.0%). Two of the respondents reported a level of adherence at 0-25% (13.3%).

Table 14
Frequencies and Percentages of Adherence to Home Programming

Adherence	n	%
0-25%	2	13.3
25-50%	3	20.0
50-75%	6	40.0
75-100%	3	20.0

Over half of the respondents reported their home program was recommended daily (n=8, 53.3%). Other respondents reported being asked to do the program three times a week (n=3, 20.0%), two times a week (n=2, 13.3%), and four times a week (n=1, 6.7). No respondents reported having the program recommended at one time a week, five times a week, or six times per week (n=0, 0.0%).

Table 15
Frequencies and Percentages of Recommended Frequency of Home Programming Implementation

Frequency	n	%
1 time per week	0	0.0
2 times per week	2	13.3
3 times per week	3	20.0
4 times per week	1	6.7
5 times per week	0	0.0
6 times per week	0	0.0
Daily	8	53.3

Correlations between subscales and caregiver adherence.

In order to run correlational analyses on the data, subscales were created to identify the overall areas that influence adherence to occupational therapy home programming. The means, standard deviations, and middle scores of the subscales were calculated throughout the analysis of the research questions. Refer to Table 16 to view the means, standard deviations, and middle subscale scores for the Multi-dimensional Occupational Therapy Home Programming Engagement Survey.

Table 16
Multi-dimensional Occupational Therapy Home Programming Engagement Survey Mean Scores, Standard Deviations, and Middle Scale Scores

Subscale	Actual Mean Scores (<i>n</i> = 15)	<i>SD</i>	Middle Scale Score
Multi-dimensional Occupational Therapy Home Programming Engagement Survey			
Child Benefits	20.00	± 2.78	15
Caregiver Values	12.73	± 1.53	7.5
Habituation	9.40	± 1.12	7.5
Caregiver Performance Capacity*	11.21	± 2.42	7.5
Child Performance Capacity*	5.79	± 1.53	7.5
Physical Environment*	7.71	± 2.33	5.0
Social Environment*	8.57	± 2.44	7.5
Temporal Environment	7.80	± 2.31	7.5

*Denotes analysis in which 14 respondents answered the relevant questions

Correlations were calculated to answer multiple research questions. These questions explored the relationships between variables from the subscales and overall caregiver adherence to occupational therapy home programming, as well as adherence related to respondents' demographics. When one variable was measured on an ordinal scale, a Spearman *rho* was utilized (Kielhofner, 2006). A Pearson correlation coefficient was used when both variables were measured on a ratio or interval scale (Kielhofner, 2006).

Correlation coefficients represent positive or negative relationships that can be considered weak, moderate, or strong (Cronk, 2010). A weak correlation has an absolute value less than 0.3 (Cronk, 2010). A moderate correlation has an absolute value between 0.3 and 0.7 (Cronk, 2010). A strong correlation has an absolute value greater than 0.7 (Cronk, 2010).

Parametric inferential statistics were calculated to answer certain research questions. An independent-samples *t* test was used to compare the means of two independent samples where the dependent variable was on a ratio or interval scale and the independent variable had two discrete levels (Cronk, 2010). Analyses of variance (ANOVAs) were used to compare the means of two or more groups when the dependent variable was at a ratio or interval level (Cronk, 2010). For the purposes of this research study, an alpha level of $<.05$ was selected as an appropriate level to reject the null hypothesis (Kielhofner, 2006).

Pearson correlation coefficients.

A Pearson correlation coefficient was calculated to answer the following research question: Is there a relationship between perceived child benefits and home programming adherence? A moderate positive correlation was found ($r(13) = .520, p < .05$), indicating a significant linear relationship between the two variables. Caregivers were more likely to adhere to the home program if they perceived it was benefitting their child.

A Pearson correlation coefficient was calculated to answer the following research question: Is there a relationship between caregiver value of the home program and home programming adherence? A moderate positive correlation was found ($r(13) = .515, p <$

.05), indicating a significant linear relationship between the two variables. Caregivers were more likely to adhere to the home program when they valued the home program.

A Pearson correlation coefficient was calculated to answer the following research question: Is there a relationship between habituation and home programming adherence? A moderate positive correlation was found ($r(13) = .526, p < .05$), indicating a significant linear relationship between the two variables. Caregivers were more likely to adhere to the home program when the home program activities fit within their daily routines.

Notably, the internal reliability for the subscale of habituation was flawed. The statement, “The home program fits into our daily routine” was analyzed individually with respect to the relationship between routines and adherence. A Pearson correlation coefficient was calculated to answer the following research question: Is there a relationship between daily routine and home programming adherence? A strong positive correlation was found ($r(13) = .767, p < .05$), indicating a significant linear relationship between the two variables. Caregivers were more likely to adhere to home programming when the home program activities fit within their daily routines.

A Pearson correlation coefficient was calculated to answer the following research question: Is there a relationship between perceived caregiver performance capacity and home programming adherence? A moderate positive correlation that was not significant was found ($r(12) = .475, p > .05$). Perceived caregiver performance capacity was not related to home programming adherence.

A Pearson correlation coefficient was calculated to answer the following research question: Is there a relationship between perceived child performance capacity and home

programming adherence? A weak negative correlation that was not significant was found ($r(12) = -.094, p > .05$). Perceived child performance capacity was not related to home programming adherence.

A Pearson correlation coefficient was calculated to answer the following research question: Is there a relationship between the temporal environment and home programming adherence? A moderate negative correlation that was not significant was found ($r(13) = -.402, p > .05$). Temporal environment was not related to home programming adherence.

A Pearson correlation coefficient was calculated to answer the following research question: Is there a relationship between a supportive physical environment and home programming adherence? A moderate positive correlation that was not significant was found ($r(12) = .385, p > .05$). Physical environment was not related to home programming adherence.

A Pearson correlation coefficient was calculated to answer the following research question: Is there a relationship between the social environment and home programming adherence? A weak negative correlation that was not significant was found ($r(12) = -.273, p > .05$). Social environment was not related to home programming adherence.

A Pearson correlation coefficient was calculated to answer the following research question: Is there a relationship between the number of times per week the home program was recommended and home programming adherence? A moderate positive correlation was found ($r(13) = .554, p < .05$), indicating a significant linear relationship between the two variables. Caregivers were more likely to adhere to the home program the more it was recommended throughout the week.

A Pearson correlation coefficient was calculated to answer the following research question: Is there a relationship between length of time caregivers have implemented a home program and home programming adherence? A moderate positive correlation that was not significant was found ($r(12) = .328, p > .05$). Length of time caregivers have implemented a home program was not related to home programming adherence.

A Pearson correlation coefficient was calculated to answer the following research question: Is there a relationship between the number of children currently residing in the home and home programming adherence? A weak positive correlation that was not significant was found ($r(12) = .273, p > .05$). The number of children residing in the home did not affect home programming adherence.

A Pearson correlation coefficient was calculated to answer the following research question: Is there a relationship between the total household income and home programming adherence? A weak positive correlation that was not significant was found ($r(12) = .218, p > .05$). Household income did not affect home programming adherence.

Spearman rho correlation coefficients.

Due to the child performance capacity subscale item having a low internal reliability (.304), the following items were analyzed separately: the child's performance with everyday tasks, the child's performance in the school setting, and the child's ability to socially interact with other peers. A Spearman *rho* correlation coefficient was calculated to answer the following research question: Is there a relationship between caregivers' perceptions of their child's ability to do everyday tasks and home programming adherence? A weak negative correlation that was not significant was found

($\rho(13) = -.215, p > .05$). The caregivers' perception of their child's ability to complete everyday tasks was not related to home programming adherence.

A Spearman ρ correlation coefficient was calculated to answer the following research question: Is there a relationship between caregivers' perceptions of their child's ability to complete school tasks and home programming adherence? A weak positive correlation that was not significant was found ($\rho(12) = .019, p > .05$). The caregivers' perception of their child's ability to complete school tasks was not related to home programming adherence.

A Spearman ρ correlation coefficient was calculated to answer the following research question: Is there a relationship between caregivers' perceptions of their child's ability to interact socially with others and home programming adherence? A moderate negative correlation that was not significant was found ($\rho(12) = -.315, p > .05$). The caregivers' perception of their child's ability to socially interact was not related to home programming adherence.

Independent-sample t tests.

An independent-samples t test was calculated comparing the mean score of respondents who assisted with designing the child's home program to the mean score of respondents who did not assist with designing the child's home program. No significant difference was found ($t(12) = -.907, p > .05$). The mean score of the respondents who assisted with designing the child's home program ($m = 2.73, sd = 1.10$) was not significantly different from the mean score of respondents who did not assist with designing the child's home program ($m = 2.00, sd = 1.73$).

An independent-samples t test was calculated comparing the mean score of adherence for the group of female children receiving the home program and the mean score of adherence of the male children receiving the home program. No significant difference was found ($t(11) = .764, p >.05$). The mean adherence to the home program with male children ($m = 2.83, sd = .75$) was not significantly different from the mean adherence with female children ($m = 2.29, sd = 1.60$).

One-way univariate ANOVAs.

The mean adherence rates to the child's home program were calculated for respondents who identified their marital status as either married, divorced, separated, single, in a partnership, widowed, or never married and were compared using a one-way ANOVA. No significant difference was found ($F(2,11) = .124, p >.05$). The respondents who were married had a mean adherence rate of 2.50 ($sd = 1.31$). Respondents who were separated had a mean adherence rate of 3.00. The standard deviation was not calculated for "separated" due to only one response. No other responses regarding marital status were identified by the respondents.

The mean adherence rate to a child's home program was calculated for respondents who identified their employment status as: employed full time outside the home, part-time outside the home, full time from home, part-time from home, or not employed in a job outside the home. These variables were compared using a one-way ANOVA. No significant difference was found ($F(3,10) = .818, p >.05$). The respondents who were employed full time outside of the home had a mean adherence rate of 2.80 ($sd = .92$). Respondents who were employed part-time outside of the home had a mean adherence rate of 2.00 ($sd = 2.83$). Respondents who were employed part-time from the

home had a mean adherence rate of 1.00. Respondents who were not employed outside of the home had a mean adherence rate of 3.00. Standard deviations were not calculated for the previous two responses, as only one caregiver responded to each item. No other responses regarding employment status were selected.

The mean adherence rate to a child's home program was calculated for respondents who identified their yearly household income as: less than \$30,000; \$40,000-49,000; \$50,000-59,000; \$60,000-69,000; \$70,000-79,000; \$80,000-89,000; \$90,000-99,000; and at or above \$100,000. These variables were compared using a one-way ANOVA. No significant difference was found ($F(8,5) = .431, p > .05$). The respondents who made less than \$30,000 a year had a mean adherence rate of 3.00. Respondents who made \$40,000-49,000 had a mean adherence rate of 4.00. Respondents who made \$50,000-59,000 had a mean adherence rate of 2.00 ($sd = 1.41$). Respondents who made \$60,000-69,000 had a mean adherence rate of 2.00. Respondents who made \$70,000-79,000 had a mean adherence rate of 3.00. Respondents who made \$80,000-89,000 had a mean adherence rate of 3.00. Respondents who made \$90,000-99,000 had a mean adherence rate of 4.00. Respondents who made \$100,000 or more had a mean adherence rate of 2.50 ($sd = 1.29$). No other responses regarding annual household income were selected. When only one caregiver responded to an item, the standard deviation was not calculated.

A one-way ANOVA was computed comparing the adherence rate of a child's home program to the age of the child. A significant difference was found among the ages of the children ($F(4,9) = .407, p < .05$). The data was unable to be analyzed using a post hoc test due to groups with only one sample. The standard deviation was not calculated

for the group with one sample. The respondents who had a child under the age of two had a mean adherence rate of 3.25 ($sd = .50$). Respondents who had a child from three to four years old had a mean adherence rate of 1.00. Respondents who had a child from five to eight years old had a mean adherence rate of 1.67 ($sd = 1.53$). Respondents who had a child from 9 to 12 years old had a mean adherence rate of 3.50 ($sd = .58$). Respondents who had a child from 13-18 years old had a mean adherence rate of 1.50 ($sd = .71$).

The mean adherence rate to a child's home program was calculated for respondents who identified the number of children in their household as: one, two, three, four, or five or more. These variables were compared using a one-way ANOVA. No significant difference was found ($F(4,9) = .454, p >.05$). The respondents who had one child in their home had a mean adherence rate of 2.50 ($sd = 1.29$). Respondents who had two children in their home had a mean adherence rate of 2.00 ($sd = 1.83$). Respondents who had three children in their home had a mean adherence rate of 2.67 ($sd = .58$). Respondents who had four children in their home had a mean adherence rate of 3.50 ($sd = .71$). Respondents who had five or more children in their home had a mean adherence rate of 3.00. The standard deviation was not calculated for the latter group, as only one caregiver responded to this item.

Summary

Chapter IV consisted of the statistical analyses of the results from the Multi-dimensional Occupational Therapy Home Programming Engagement Survey. The results were analyzed with a pre-analysis data screen, followed by analysis of the reliability of the survey that was developed, the Multi-dimensional Occupational Therapy Home Programming Engagement Survey. Next, statistical analyses of the descriptives were

calculated for the demographics and survey responses. Inferential statistical analyses were also conducted on the data that was collected. These findings are examined further in Chapter V.

Chapter V

Discussion

Chapter V: Discussion details the written discussion of the researchers' findings. Chapter V also includes the relationship between the results and the previous research, study limitations, implications for practice, and recommendations for future research.

Occupational therapy home programs are commonly used within pediatric occupational therapy practice. They have been shown to be effective when followed as recommended, however, there tends to be limited adherence to pediatric occupational therapy home programming (Law & King, 1993; Tang et al., 2001; Wuang, Ho, & Su, 2013). Occupational therapists must consider adherence to occupational therapy home programming when designing and implementing home programming with children who have disabilities, as this is a crucial piece of the success of their therapy.

Many child, caregiver, occupational therapist, and home programming factors influence adherence and have been noted in the literature. However, there have been a small number of quantitative studies conducted in which researchers have examined the correlations or relationships between adherence and these factors (Fragala-Pinkham, Haley, Rabin, & Kharasch, 2005; Rone-Adams, Stern, & Walker, 2004; Tetreault, Parrot, & Trahan, 2003). Each of the aforementioned factors were addressed and incorporated in the questions in the Multi-dimensional Occupational Therapy Home Programming Engagement Survey, in hopes of gaining a more family-centered view of the factors that

influence adherence to home programming. This study contributes to the existing body of evidence regarding how adherence to occupational therapy home programming is influenced by these factors. By gaining a more holistic understanding of these factors, the researchers hope that occupational therapists will consider these when they develop individualized home programs, in order to increase the overall adherence and effectiveness of home programming. Fifteen caregivers of children with disabilities participated in this online survey research. A majority of these respondents were female (n=14), while most of the respondents considered both parents as the primary caregiver for their child (n=10). Most of the previous research had been done with mothers, as mothers have typically been in the primary caregiver role. Factors that influenced the overall adherence rate to home programming included: child factors, caregiver factors, occupational therapists factors, and home programming factors. These have been further described in the following sections.

Adherence to Home Programming

Adherence rates to home programming that were found throughout this study were consistent with previous research. Adherence tends to vary greatly with home programming. Stieber et al. (2012) reported a fluctuation of adherence rates from 0 to 100%; Rone-Adams et al. (2004) reported 44% adherence; and Tang et al. (2001) reported an average of 80% adherence. Gajodosik (1991) found an average from 47-67% adherence and Law and King reported an average of less than 50% adherence. The respondents in this study had varied rates of adherence as well. Of those surveyed, 13.3% of the caregivers reported an adherence rate of 0-25% of the time, 20% reported a 25-50% adherence rate, a majority of the respondents (40%) reported a 50-75% adherence

rate, and 20% reported a 75-100% adherence rate. The self-reporting nature of this survey may have influenced accurate reporting, however, the survey was anonymous, which likely increased veracity. This research study was also completed by graduate students who were not directly associated with the occupational therapy treatment, and thus no penalties could be associated with telling the truth, which could have increased respondents' honesty.

Child factors.

When considering benefits of the home programming to the child, caregivers' responses varied in regard to the perceived improvements in their child's mood and physical well-being. Approximately half of the respondents reported benefits to their child in either mood or physical well-being. Throughout this study, it was identified that the home programs targeted multiple diagnoses and conditions, which could account for the varying effects of the home programming on the child's overall performance. Depending on the diagnosis and symptomology of the child, the caregivers and child may have been recommended home programming activities that were more difficult and time consuming, compared to activities that would be used with other diagnoses or identified problems. Thus, these activities may have been more difficult to implement or the benefits to their child may have been less obvious.

In this study, all of the caregivers reported the activities focused on the child and were the "just right" challenge, indicating that occupational therapists were able to design home programs to fit the child's specific needs. While 60% of the caregivers identified that their child enjoyed doing therapy at home, the same number reported the home programming caused the child discomfort. This should be interpreted with caution as

discomfort and enjoyment are subjective measures and, thus, caregivers may attribute different meanings to these terms.

When the home program was perceived as being beneficial for the child, the caregivers were more likely to adhere to the home programming. The child benefits that were analyzed included: the child's physical improvements, mood improvements, enjoyment of the home program, discomfort with the program, and having the "just right" challenge. This finding is consistent with Segal and Beyer (2006) and Tetreault et al.'s (2003) findings, which noted that when there were noticeable improvements for the child, greater home program adherence was present.

Seven of the 15 respondents (46.7%) reported that when the child enjoyed the program, the activities were easier to adhere to compared to when the child did not enjoy the programming activities. In previous research, similar findings were identified. Specifically, the child's enjoyment with the home programming activities was noted in interviews with caregivers as being a factor that increased their ability to adhere to the home program (Segal & Beyer, 2006; Stieber et al., 2012).

Child performance capacity was analyzed within multiple areas of occupation, which included the caregivers' perceived ability of their child to complete activities of daily living, school activities, and socialization. This analysis revealed results contrary to Mayo's (1981) finding in which higher rates of adherence to home programming were correlated with children who had more severe impairments. There was no difference noted in the results between the level of perceived impairment and adherence rates. However, this result could have been impacted by the low Cronbach's Coefficient Alpha score (.304) for the child performance capacity subscale, as the questions may not have

accurately represented the original subscale. The subscale contained three questions pertaining to: child's independence in everyday activities, child's ability in school settings, and child's ability in social situations which are three separate areas of occupation. This may have accounted for the low internal consistency as it is possible that children may be more independent in one area while less independent in another. Due to the low internal reliability of the subscale, the items were analyzed separately. Only weak correlations that were not statistically significant were found, indicating that child's ability does not influence adherence rates. Caregiver perspectives' of the child's ability is a subjective measure of performance, thus the caregivers may have had biased responses. Additionally, when considering the child's ability within his or her school environment and social situations, caregivers may not have observed their child constantly. Caregivers may not have had a full understanding or representation of their child's abilities within these contexts, which may have skewed the results related to this question.

Caregiver factors.

Caregivers, who were typically parents, were seen as a major factor that contributed to the success of home programming (Khalil et al., 2012; Law & King, 1993). Throughout the current study, 100% of the caregivers identified that the home programming was important to them and that they were hopeful it would help their child. A majority of respondents also identified that they did not understand the importance of the home program. These conflicting results could be due to response set error, in which respondents neglected to notice question reversals.

When analyzed within a subscale, caregiver values were found to influence adherence. The subscale for caregiver value included the responses to the questions that involved: the perceived importance of the home program, motivation to complete the program, and hope that it would be beneficial. When caregivers were found to value the home program they were more likely to adhere to it. Tetreault et al.'s (2003) research supported these findings, as caregivers who believed the home program was valuable, caregivers who were motivated to complete it, and those whom were hopeful that it would help their child, had higher rates of adherence than the group that had negative feelings towards the home program, such as guilt and discouragement. Novak (2011) also found similar results; parents who believed that they were doing something worthwhile were more likely to complete home programming successfully.

Throughout this study, it was noted that being involved in the goal setting process was beneficial; 53.3% of caregivers reported this made adherence to the home program easier. This supports the need to incorporate goal setting and engage caregivers in discussion of potential benefits and gains when designing home programs. The more that caregivers and their child were involved in the development of the home program, the better they understood and valued it because they were able to provide their personal input. This would essentially lead to increased adherence, as those that valued the home program had increased adherence rates.

Perceived caregiver performance capacity, including the caregiver's ability to modify activities, confidence in their ability to complete the home program, and self-efficacy, was not significantly linked to adherence. There was a moderate positive correlation between performance capacity and adherence, but it did not reach a level of

significance. No previous research had quantifiably measured caregivers' levels of self-efficacy and confidence, although many caregivers verbalized worries about their ability to complete the home programming activities as well as a professional (Novak, 2011). This finding was similar to Hinojosa and Anderson's (1991) research in which mothers verbally reported not feeling adequate to implement a formal home program. Yet all of the mothers in Hinojosa and Anderson's (1991) study had developed their own methods for completing daily therapeutic activities with their children. This finding demonstrates that caregivers may not report high levels of confidence and self-efficacy, but they may still be able to adhere to the program successfully.

Occupational therapist factors.

When developing home programming, it is essential for occupational therapists to consider the family's habituation, which includes how easily the program can be integrated as a part of their daily routine and the degree to which the program includes everyday activities. Caregivers were more likely to adhere to the home program when the activities were a part of their daily routine. However, the internal reliability of the habituation subscale was flawed, and thus, further data analysis of the individual statement: "Carrying out my child's home program is part of our daily routine" was completed. There was a strong positive correlation, which was significant, between this statement and adherence. This indicated that designing home programs that fit within a family's routines is essential to increase overall adherence and caregiver satisfaction.

Habits and routines are commonly recognized as a crucial focus within occupational therapy treatment (AOTA, 2008) and can be utilized to facilitate adherence to occupational therapy home programming. Multiple studies supported this finding and

included integrating the activities into daily routines, understanding what times work best for the family to implement the program, and integrating the activities into the natural context of the child's daily activities (Jaffe, Humphry, & Case-Smith, 2010; Novak, 2011; Segal & Hinojosa, 2006; Stieber et al., 2012). Throughout this study, 60% of the caregivers reported that when the program used everyday activities, it was easier to adhere to, compared to when the activities were not incorporated within everyday tasks.

Throughout the literature, occupational therapists have been noted to enhance overall programming adherence by providing education, supporting families, and monitoring adherence (Escolar-Reina et al., 2010; Novak, 2011; Segal & Beyer, 2006; Tetreault et al., 2003). Caregivers who responded to this survey also noted occupational therapist factors that made adherence to the home programming easy, although these results were analyzed for frequencies, not for correlations. Sixty percent of caregivers reported that the occupational therapist factors that made adherence easier were: providing good education, providing clearly written instructions, using photographs, and practicing the home programming activities with the caregiver and child.

Caregivers were more likely to adhere to the home program when the occupational therapist recommended it more often. This demonstrates another way that occupational therapists can influence adherence to home programming. By highlighting the importance of the home programming, the therapist is able to relate the value of the home program to the recommended weekly frequency (i.e. recommended daily compared to one time per week). Occupational therapists should consider recommending home programs with higher frequencies that are incorporated within the family's daily routine. However, with an increased frequency, it is important that occupational therapists

decrease the amount of recommended time to spend on the home programming activities each day (i.e. done more frequently throughout the week but spending less time each day).

Home program factors.

Previous literature revealed that occupational therapists also need to take the home programming environmental factors into account when recommending home programs. These environmental factors included: the temporal, physical, and social environments (Kielhofner, 2008; Novak, 2011; Segal & Beyer, 2006). Interestingly, the results from this research study did not reveal any significant differences between groups that had high adherence or low adherence, based on any of the environmental factors. There was a moderate negative correlation between the temporal factors (i.e. taking too much time, having to be done too often, and the program being stressful) and adherence. Nearly half of the respondents identified that the home program took too much time and had to be done too often. This finding suggested that when programs are viewed as a temporal burden they are adhered to less, however, this result did not reach the significant level. The most frequent barriers to completing home programming, identified by caregivers, were a busy family life and a busy work/school schedule; each were selected by 80% of respondents. Occupational therapists need to engage in discussion with families regarding their schedules when recommending home programming frequency.

The physical environment subscale included questions related to: having enough space in the home and the right equipment to complete the home program. This result had a moderate positive correlation but did not reach a level of significance. This may have been due to only 13.3% of the respondents reporting they did not have enough space

and only 6.7% of the respondents reporting that they did not have the right equipment to carry out the program. However, nearly 66.7% of the respondents felt they were not able to complete the activities in their home. This result could be due to a response set error as this was a question reversal. This response was not consistent with caregivers' previous responses regarding their adherence rate of home programming related to the physical environment.

The social environment subscale included questions related to: having too much going on, the program negatively affecting the family, and familial support. Throughout the results of this study, social environment was not found to impact adherence. This contradicted the previous literature in which Rone-Adam et al. (2004) noted a negative correlation between family problems, perceived support, and adherence. Notably, 73.4% of the caregivers reported that family support did help with implementing the home programming activities, however 60% reported the home program negatively affected other family members. It is unclear whether the caregivers were receiving the family support or just assuming it would help. It is also unclear how the home programming was negatively affecting the other family members, due to the method of research used for this study. Despite conflicting research outcomes, occupational therapists should engage in discussion with caregivers about potential family dynamics that could be affected throughout the home programming process. This will ensure a more family-centered approach to home programming.

In regard to demographics, only the age of the child impacted adherence to the home programming. While a significant difference was found between the ages of the caregivers' children, a post hoc test (to better understand which group had high

adherence) was not possible due to the small sample size in this study. Further research must be conducted to better understand this result. Multiple factors, including child, caregiver, occupational therapist, and home programming factors influence caregiver adherence to occupational therapy home programming. Although these results have added to occupational therapy's body of research knowledge, they need to be interpreted with cautions as multiple limitations were identified throughout this study.

Limitations

Several limitations were evident in this study. First, survey research is a level four research design and subsequently cannot show causation, only correlation relationships between variables (Kielhofner, 2006). Secondly, the method used to gather respondents was limited to the list serves the researchers chose and did not encompass all therapy services within the area. Third, the method used to gather data was an online survey. Using this type of survey limits the sample to people who have access to technology. Additionally, with a survey design, there is a risk of response set error, which could have impacted the interpretation of the results. A follow up request for potential respondents to access and complete the survey was not completed. This is often done with survey research, thus this was a limitation of this study.

A fourth limitation throughout this study was that the Multi-dimensional Occupational Therapy Home Programming Engagement Survey, used within this study, was designed by the researchers and had not yet been pilot tested. The internal reliability for the subscales was varied. The overall reliability was .557; within health care, a .750 internal reliability score is the gold standard for research. A fifth limitation was the small sample size, which reduced rigor and generalizability. Limited geographical areas were

represented since there were only respondents from four different states. Of the respondents who reported their gender, all were females; the gender of the caregiver who elected to not respond could not be assumed. Lastly, a limitation was the exploratory nature of this study; cause and effect could not be applied to the findings.

Application to Occupational Therapy Practice

Throughout this study, it appeared that occupational therapists were incorporating the child's needs, which included the "just right" challenge and activities the child enjoyed, into home programming. This research can be applied to occupational therapy practice, as home programming is a common adjunct to traditional therapy.

Recommendations from this study for occupational therapists are listed below.

- Adherence to pediatric home programming is impacted by multiple factors. It is important that occupational therapists consider the following when developing home programs.
 - Home programs must be beneficial to the child—positive effects from the home program must be seen in order to increase overall adherence rates.
 - Caregivers' values must be taken into account—the more they value the home programming, the more often they will implement the home programming activities with their child.
 - Caregivers' motivation, value, and hope that the program will be effective are specific aspects to consider when developing home programs for children.

- Implementing home programming activities within the family's daily routines is essential—occupational therapists must learn the family's routines and design the home program to fit within their daily lives.
 - From this study, the researchers found that therapists should highlight the importance and value of the home program through their recommendation of how often to implement it within the week (i.e. the more frequently it is recommended, the more caregivers adhere to it).
 - Although the frequency should be recommended more often, the amount of time the activities take each day should be minimized, as programs that are too long decrease overall adherence.
 - Occupational therapists should consider families' daily schedules when designing home programs. Caregivers and families often have other obligations to attend to within their personal lives and, thus, home programming activities should be easy to implement within their daily schedules.
- In addition to the aforementioned factors of the temporal environment, it is essential to address individual family's physical and social environments, as family dynamics are a complex process and are individualized to each family.
- Occupational therapists should provide good education about the home program, provide clearly written instructions, use photographs, and practice the home programming activities with the caregiver and the child.

- These factors identified throughout this study were reported to facilitate the ease of home programming engagement and adherence.
- Occupational therapists must consider engaging in discussion with caregivers and their child (if able) about all of the aforementioned factors in order to promote increased adherence to pediatric occupational therapy home programming.

By gaining a better understanding of the family's needs, occupational therapists will be able to develop more individualized home programs. This will essentially increase overall adherence rates, as these programs will be more meaningful to these families.

Future Research

A great deal of qualitative research has previously been done on the topic of caregiver adherence to home programming; however, there was a lack of quantitative research on this topic. While this study adds to occupational therapy's existing body of knowledge on the topic of pediatric home programming, the limitations of this study support the need for further research. A larger study, including a sample size with varying demographics and geographical locations could be conducted using the Multi-dimensional Occupational Therapy Home Programming Engagement Survey. The method of gathering potential respondents could be expanded to incorporate more potential sites (i.e. hospitals, clinics, schools); this would lead to greater response rate and generalizability. This survey could also be enhanced and tested to improve internal reliability through pilot testing and modification of the subscale questions. The survey methodology could also be expanded to other formats (i.e. paper and pencil, telephone) in

lieu of the online survey. Due to the design level of this study, it is recommended that more research be conducted using an experimental design to increase the rigor and efficacy of the results and recommendations so both can be better applied to occupational therapy practice.

Summary

Chapter V detailed the written discussion of the researchers' findings, which included the relationship between the results and the previous research. Study limitations were also addressed and further recommendations for future research were made. The implications for occupational therapy practice were identified and discussed in detail. There are many factors that occupational therapists need to consider when recommending home programming within pediatric practice. These include: child, caregiver, occupational therapist, and home programming factors. Taking these factors into consideration will lead to greater adherence and potentially more effective outcomes for the client and his or her family.

Appendices

Appendix A

Research Questions

Broad questions:

1. What is the overall occupational therapy home programming adherence as reported by caregivers of children with disabilities?
 - a. How many times a week it is recommended
 - b. How often are you able to complete the home program
2. What child, caregiver, occupational therapist, and environmental variables, with consideration for volition, habituation, and performance capacity, influence familial adherence to occupational therapy home programming?

Questions related to volition:

3. Is there a difference between home program engagement and the perceived benefits of the home program?
 - a. My child's mood is better after doing the home program
 - b. My child feels better physically if we do the home program
 - c. My child can do more for himself or herself after doing the home program
4. Is there a difference between home program engagement and how much the child enjoys the home program?
 - a. My child likes doing therapy at home
 - b. The home program causes my child discomfort
 - c. The home program activities give my child the just right challenge (not too hard, not too easy)
5. Is there a difference between home program engagement and the value placed on the home program by parents?
 - a. My child's home program is important to me
 - b. I do not understand the importance of the home program
6. Is there a difference between home program engagement and parental motivation?
 - a. I am motivated to complete the home program with my child
 - b. I am hopeful that the home program will help my child
7. Is there a difference between home program engagement and parental confidence with the home program?
 - a. I feel confident carrying out my child's home program
 - b. I am able to help my child do the activities as well as anyone else

Questions related to habituation:

8. To what extent does the fit of the home program with the familial routine influence home programming adherence?
 - a. Carrying out my child's home program is part of our daily routine
 - b. My child's home program is difficult to fit into my family's schedule
 - c. The home program has activities my child would do anyway

Questions related to performance capacity:

9. Is there a difference in reported home program adherence between parents who were involved in designing the home program and those who were not?
10. To what extent does caregiver's perceived confidence in his or her ability to carry out the home program influence home programming adherence?
 - a. I am able to change my child's home program with ease
 - b. I feel confident carrying out my child's home program
 - c. I am able to help my child do the activities as well as anyone else

Questions related to environment:

11. Does the practice setting in which the home program was issued influence home programming adherence?
12. Is there a difference between home program engagement and amount of time parents perceive they have for the home program?
 - a. My child's home program takes too much time
 - b. My child's home program has to be done too often
13. Is there a difference between home programming adherence when considering the physical environment of the home?
 - a. We have enough space in our home to carry out the home program
 - b. We have the right equipment to carry out the home program
 - c. My child and I are not able to do the activities in our home
14. Is there a difference between home program engagement and the social environment where the home program is done?
 - a. There is too much going on in our home to do the suggested activities
 - b. Doing the home program activities negatively affects other family members
 - c. Family support helps us do the activities at home

Questions related to percentages:

15. What variables do caregivers identify as being beneficial to home program adherence?
16. What variables do caregivers perceive as barriers to carrying out home programs?

Correlational Questions:

17. Is there a relationship between the length of time the child has been using the home program and adherence to the home program?
18. Is there a relationship between the number of children in the home and overall home programming adherence?
19. Is there a relationship between the age of the child and overall home programming adherence?
20. Is there a relationship between income and overall home programming adherence?
21. Is there a relationship between home program adherence and caregiver perception of child's independence in the areas of ADLs, education and socialization?
 - a. What is your child's ability to do everyday tasks
 - b. What is your child's ability in school settings
 - c. What are your child's interactions with other children

Questions related to demographics:

22. Is there a difference between home program engagement and marital status of the parent/caregiver?
 - a. What describes your marital status
23. Is there a difference between home program engagement and the employment status of the parent/caregiver?
 - a. What describes your employment status
24. Is there a difference between home program engagement and the socioeconomic status of the parent/caregiver?
 - a. What describes your income
25. Is there a difference between home program engagement and the age of the child?
 - a. What is the age of the child receiving the services

26. Is there a difference between home program engagement and the gender of the child?
- a. What is the gender of the child receiving the services
27. Is there a difference between home program engagement and the amount of siblings a child has?
- a. How many other children live in the house

Appendix B

Charts of Theoretical Basis for Survey Development



Caregivers' Occupational Performance

- How many times per week is your child's home program recommended?
- How often are you able to complete the home program?
- Mark the items that make your child's home program hard:
 - Budget
 - Busy family life
 - Busy work and/or school schedule
 - I don't understand how the activities are helping
- Mark the items that make carrying out your child's home program easy:
 - We were involved in the goal-setting process
 - I helped design my child's home program



Childs' Performance Capacity

- What's your child's ability to do everyday tasks in relation to other children?
- What's your child's ability in school settings in relation to other children?
- What's your child's ability to interact with other children?



Therapists' Occupational Performance

- Mark the items that make carrying out your child's home program hard:
 - Lack of directions by the therapist, The program is too long, The home program is confusing, The therapist does not understand my family's needs
- Mark the items that make carrying out your child's home program easy:
 - The therapist provides good education, Instructions are clearly written, Photographs are provided to help us remember how to do the activities, Practicing the program with my child and the therapist, Using everyday activities for the home program, The therapist is motivating, My child's therapist checks in with us to monitor progress
- The therapist designed the home program

Physical Environment

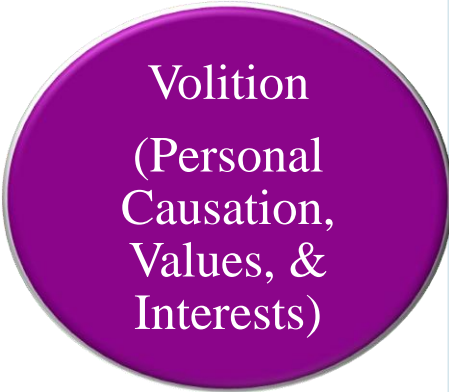
- We have enough space in our home to carry out the home program.
- We have the right equipment to carry out the home program.

Social Environment

- There is too much going on in our home to do the suggested activities.
- Doing the home program activities negatively effects other family members.
- Family support helps us do the activities at home.


Temporal Environment

- My child's home program has to be done too often.
- My child's home program takes too much time.
- The home program is stressful.



Volition
(Personal
Causation,
Values, &
Interests)

- My child's mood is better after doing the home program.
- My child feels better physically if we do the home program.
- My child likes doing therapy at home.
- The home program causes my child discomfort.
- The home program activities give my child the "just right" challenge (not too hard, not too easy).
- My child can do more for himself or herself after doing the home program.
- My child's home program is important to me.
- I am motivated to complete the home program with my child.
- I am hopeful that the home program will help my child.



Habituation
(Habits,
Roles, &
Routines)

- Carrying out my child's home program is part of our daily routine.
- My child's home program is difficult to fit into my family's schedule.
- The home program has activities my child would do anyway.



Performance
Capacity

- I am able to change my child's home program with ease.
- I feel confident carrying out my child's home program.
- I am able to help my child do the activities as well as anyone else.

Appendix C

Letter to Organizations

To Whom It May Concern,

Greetings. We hope this letter finds you well. We are occupational therapy graduate students in the Department of Occupational Therapy at the University of North Dakota, School of Medicine & Health Sciences in Grand Forks, ND. To complete our degrees, we are planning a research study in which we survey parents or caregivers of children with disabilities. We would like to gather caregiver perceptions of therapy home programs, the barriers they may face, and what helps them complete the home program activities with their child.

In order to complete our research, we are looking for willing parents and caregivers to fill out our surveys. Would you be willing to help us contact parents and caregivers of children with disabilities (if so, please see "RE: [REDACTED] & [REDACTED] Study" below to fill in the blank and send this back to one of these emails: [REDACTED] [REDACTED])? We would like to email potential subjects to share a link to an online and secure survey. Some organizations have list serves that allow each of their members to be contacted as a group. Would it be possible to contact members of your organization?

The survey contains questions about the use of a home program in the family, how it fits with family routines, how confident the caregiver is in providing the home program, and factors that both improved or lessened the quality of the home program provision. The survey will take about 15-20 minutes to complete.

We will not be contacting any potential participants or gathering any data until we receive approval from the University of North Dakota Institutional Review Board. Our work on this research project is also being supervised by our advisor, Anne [REDACTED], PhD, OTR/L. You may contact us or our advisor with any questions. Our contact information is listed below. Thank you for your time and consideration. We look forward to hearing from you.

RE: [REDACTED] & [REDACTED] Study

For the University of North Dakota Institutional Review Board,

The organization of _____ is willing to provide email addresses of potential survey respondents for Sara [REDACTED] and Rebecca [REDACTED]'s

research study at the University of North Dakota. We understand that this study will be supervised by the students' advisor, Anne [REDACTED].

We understand that no persons will be contacted until the Institutional Review Board at the University of North Dakota has approved the research study. We understand that each recipient will have the opportunity to choose to participate and will be asked to provide consent before participating.

Sincerely,

Sara [REDACTED] and Rebecca [REDACTED], MOTS
Occupational Therapy Program
University of North Dakota
School of Medicine & Health Sciences

Sara [REDACTED], MOTS / 701. [REDACTED] / [REDACTED]@my.und.edu

Rebecca [REDACTED], MOTS / 701. [REDACTED] / [REDACTED]@my.und.edu

Anne [REDACTED], PhD, OTR/L / 701. [REDACTED] / [REDACTED]@med.und.edu

Appendix D

Sources for Survey: Mission Statements and Contact Information

Organization	Contact Information	Brief Description and Mission Statement
Minnesota STAR Program	Jennie [REDACTED] 358 COB, 658 Cedar Street St Paul, MN 55155 651 [REDACTED] [REDACTED]@state.mn.us http://www.starprogram.state.mn.us	The MN STAR Program is a federally funded program that states it's mission is "to help all Minnesotans with disabilities gain access to and acquire the assistive technology they need to live, learn, work and play."
Disability is Natural	Kathie [REDACTED] [REDACTED]@msn.com www.disabilityisnatural.com	Disability is Natural is a website as a part of a family owned small business. The mission is "to encourage new ways of thinking about developmental disabilities, in the belief that our attitudes drive our actions, and changes in our attitudes and actions can help create a society where all children and adults with developmental disabilities have opportunities to live the lives of their dreams, included in all areas of life.
Minnesota Brain Injury Alliance	Christina [REDACTED] LSW, CBIS Resource Facilitation and Education Manager 34 13th Ave. Northeast, Suite B001 Minneapolis, MN 55413 Phone 612 [REDACTED] Toll-Free 800 [REDACTED] Fax 612 [REDACTED] www.braininjurymn.org	The MN Brain Injury Alliance is a state wide nonprofit organization with the mission "to enhance the quality of life and bring the promise of a better tomorrow for all people affected by brain injury."
National Alliance on Mental Illness (NAMI) of Minnesota	Sue [REDACTED], MPH Executive Director NAMI Minnesota 800 Transfer Road, Suite 31 St. Paul, MN 55114 651 [REDACTED] 1-888-NAMI-HELPS www.namihelps.org	The National Alliance on Mental Illness (NAMI) of Minnesota is a non-profit organization. They are "dedicated to improving the lives of adults and children with mental illness and their families" by offering education, support and advocacy.
Rocky Mountain	Maggie [REDACTED] ADA Information Specialist	The Rocky Mountain ADA Center is a member of the

ADA Center	Rocky Mountain ADA Center 800-██████████ (V, TTY) www.adainformation.org	National Network of ADA Centers. Their mission is “to provide information on the Americans with Disabilities Act (ADA) to individuals and organizations in Colorado, Utah, Montana, Wyoming, North Dakota, and South Dakota.”
Family Voices of North Dakota, Inc.	Donene ██████ FVND Executive Director Family Voices of North Dakota, Inc. 312 2nd Avenue P.O. Box 163 Edgeley , ND , 58433 (888) ██████ (701) ██████ http://www.fvnd.org	Family Voices of North Dakota is the Family Voices State Affiliate Organization. This organization is aimed at achieving family-centered care for all children and youth with disabilities and/or special health care needs. This organization provides families with tools to make informed decisions, advocates for enhanced private and public policies, builds partnerships among families and professionals, and serves as a dependable resource for health care.
Pathfinder Parent Center	Cathy ██████ Executive Director Pathfinder Parent Center 1600 2nd Avenue SW Ste 30 Minot, ND 58701 1. ██████ http://www.pathfinder-nd.org/	The Pathfinder Parent Center is a statewide non-profit organization that serves over 2000 parents of children (from birth to 26 years old) that are at-risk due to disabilities and/or learning problems. The Pathfinder Parent Center’s mission is “to unite families and educators by giving them the resources to build positive futures for and with children, students, and young adults with learning differences or challenges.”

Appendix E

Email Correspondence

Email Confirmations
<p>Hi Rebecca,</p> <p>Thank-you for contacting us. Unfortunately, we are not able to provide you email addresses of potential subjects. You could, however, subscribe to STAR Points (see below, our assistive technology listserv) and then post an announcement about your research. If people are interested, they will respond directly to you (we do not facilitate them being involved). Hope this helps. If you have further questions, please feel free to contact me again.</p> <p>Jennie</p> <p>Jennie [REDACTED] Minnesota STAR Program 358 COB, 658 Cedar Street St Paul MN 55155 651 [REDACTED] direct dial [REDACTED]@state.mn.us http://www.starprogram.state.mn.us</p> <p>The content of this email message is educational in nature. It should not be assumed that the identification of any product, individual, or agency implies endorsement by the State of Minnesota, STAR, or the U.S Department of Education.</p> <p>Subscribe, unsubscribe, or manage your STAR Point email list preferences at https://webmail.mnet.state.mn.us/mailman/listinfo/starpoint</p>
<p>Thanks so much...I'll be happy to spread the word about your survey via my newsletter (www.disabilityisnatural.com).</p> <p>My best, Kathie</p> <p>Kathie [REDACTED] ([REDACTED]@msn.com) Disability is Natural</p>
<p>The Minnesota Brain Injury Alliance could post information on this study on our Enews, bi-weekly e publication.</p> <p>Christina [REDACTED] LSW, CBIS Resource Facilitation and Education Manager 34 13th Avenue Northeast, Suite B001 Minneapolis, MN 55413 Phone 612 [REDACTED] Toll-Free 800 [REDACTED] Fax 612 [REDACTED] www.braininjurymn.org</p>
<p>National Alliance on Mental Illness (NAMI) of Minnesota Request for Research Announcement 2012</p>

Introduction

Persons wishing to recruit research participants through NAMI Minnesota must make their request in writing. The research must be consistent with the mission and goals of NAMI and potentially produce results that help improve the treatment (medication, therapy peer support, complementary therapies) of mental illnesses or attitudes towards people with mental illnesses and family members.

Please note the following conditions:

- NAMI Minnesota does not release its membership database to researchers. If your request is approved, NAMI will send a recruitment announcement to its members in an email, and post a message on its website.
- NAMI Minnesota does not directly endorse research projects; our role is to announce research opportunities that are consistent with the NAMI mission and goals.
- All requests for NAMI Minnesota to make research announcements available to its membership must be submitted to the NAMI Research Committee using the attached application form; the NAMI Research Committee will review the completed form in order to decide whether the request meets our criteria.
- NAMI Minnesota will not make a research announcement unless Institutional Review Board (IRB) approval has been received by the researcher.
- Please allow four weeks from the date all request materials are received by NAMI Minnesota for the NAMI Research Committee to complete its review. You will be notified in writing of the Committee's decision.
- In the event that NAMI Minnesota agrees to announce this research opportunity, the researcher must submit a draft announcement that includes a brief statement of the purpose of the research study, and the role of the participant. NAMI Minnesota will work with the researcher to finalize the most appropriate announcement.

Send requests with all required information to:

NAMI Minnesota
Attention: NAMI Research Committee
800 Transfer Road, Suite 31
St. Paul, MN 55114

Sue [REDACTED], MPH
Executive Director
NAMI Minnesota
800 Transfer Road, Suite 31
St. Paul, MN 55114
651 [REDACTED]
1-888-NAMI-HELPS
www.namihelps.org

I cannot give you any emails of families, that would be a violation of HIPAA
However....I can utilize with contact information and send out to the list serv in the event that
families may want to be a part of your study then they can contact you directly.

But we can never share our mailing list or emails

Thanks

Donene [REDACTED]

FVND Executive Director

Donene,

Thank you for your response. Once we obtain IRB approval for our research study we will be in
contact with you about this offer (i.e. contacting families to see if they would be interested in
participating in our study). Have a wonderful weekend and I look forward to discussing this
option with you in the near future.

Thanks again,

Sara [REDACTED], MOTS

Good afternoon, Sara. Thanks for your email.

We are more than happy to share the link to your survey in an upcoming issue of our
electronic newsletter. Maggie [REDACTED], our newsletter editor, is the primary contact for
that.

However, due to the confidential nature of our relationship with our customers, we will
not be able to provide you with a list of private emails.

When your IRB is complete, please let us know!

Jana [REDACTED], PhD

Project Director

Rocky Mountain ADA Center

A Member of the ADA National Network

800/[REDACTED] (V, TTY)

719/[REDACTED], ext. [REDACTED]

www.adainformation.org

From: Candice [REDACTED]

Sent: Thursday, November 08, 2012 1:52 PM

To: Jana [REDACTED]

Subject: FW: University of North Dakota Students Requesting Your Help

I found this more appropriate to send to you. Can you please see below and respond? Thanks!

Candice

From: [REDACTED], Sara [mailto:[REDACTED]@my.und.edu]

Sent: Wednesday, November 07, 2012 3:54 PM

To: Candice [REDACTED]

Subject: University of North Dakota Students Requesting Your Help

To Whom It May Concern,

Greetings. We hope this letter finds you well. We are occupational therapy graduate students in the Department of Occupational Therapy at the University of North Dakota, School of Medicine & Health Sciences in Grand Forks, ND. To complete our degrees, we are planning a research study in which we survey parents or caregivers of children with disabilities. We would like to gather caregiver perceptions of therapy home programs, the barriers they may face, and what helps them complete the home program activities with their child.

In order to complete our research, we are looking for willing parents and caregivers to fill out our surveys. Would you be willing to help us contact parents and caregivers of children with disabilities (if so, please see "RE: [REDACTED] & [REDACTED] Study" below to fill in the blank and send this back to this email: [REDACTED]@my.und.edu)? We would like to email potential subjects to share a link to an online and secure survey. Some organizations have list serves that allow each of their members to be contacted as a group. Would it be possible to contact members of your organization?

The survey contains questions about the use of a home program in the family, how it fits with family routines, how confident the caregiver is in providing the home program, and factors that both improved or lessened the quality of the home program provision. The survey will take about 15-20 minutes to complete.

We will not be contacting any potential participants or gathering any data until we receive approval from the University of North Dakota Institutional Review Board. Our work on this research project is also being supervised by our advisor, Anne [REDACTED], PhD, OTR/L. You may contact us or our advisor with any questions. Our contact information is listed below. Thank you for your time and consideration. We look forward to hearing from you.

RE: [REDACTED] & [REDACTED] Study

For the University of North Dakota Institutional Review Board,

The Rocky Mountain ADA Center is willing to distribute survey information for Sara [REDACTED] and Rebecca [REDACTED]'s research study at the University of North Dakota to our electronic newsletter subscribers (approximately 1200 individual email contacts). We understand that this study will be supervised by the students' advisor, Anne [REDACTED].

We understand that no persons will be contacted until the Institutional Review Board at the University of North Dakota has approved the research study. We understand that each recipient will have the opportunity to choose to participate and will be asked to provide consent before participating.

Sincerely,

Sara [REDACTED] and Rebecca [REDACTED], MOTS
Occupational Therapy Program
University of North Dakota
School of Medicine & Health Sciences

Sara [REDACTED], MOTS / 701.[REDACTED] / [REDACTED]@my.und.edu

Rebecca [REDACTED], MOTS / 701.[REDACTED] / [REDACTED]@my.und.edu

Anne [REDACTED], PhD, OTR/L / 701.[REDACTED] / [REDACTED]@med.und.edu

Sara

Our contact information for parents must remain confidential. However we can put a short blurb about your project in our enews which reaches many ND families and then they could contact you if they are interested. Would that work?

Cathy [REDACTED]

Executive Director
Pathfinder Parent Center
1600 2nd Avenue SW Ste 30
Minot, ND 58701

1. [REDACTED]

We don't charge anything for the service -

Cathy [REDACTED]

Executive Director
Pathfinder Parent Center
1600 2nd Avenue SW Ste 30
Minot, ND 58701

1. [REDACTED]

Appendix F

Official IRB Approval Letter

U N I V E R S I T Y O F  N O R T H D A K O T A

INSTITUTIONAL REVIEW BOARD
c/o RESEARCH DEVELOPMENT AND COMPLIANCE
DIVISION OF RESEARCH
TWAMLEY HALL ROOM 106
264 CENTENNIAL DRIVE STOP 7134
GRAND FORKS ND 58202-7134
(701) 777-4279
FAX (701) 777-6708

November 29, 2012

Sara Joersz and Rebecca Polansky
c/o Sara Joersz
910 North Mandan Street
Bismarck, ND 58501

Dear Ms. Joersz and Ms. Polansky:

We are pleased to inform you that your project titled, "Parents of Children with Disabilities: An Exploratory Study of Factors Influencing Occupational Therapy Home Program Engagement" (IRB-201211-141) has been reviewed and approved by the University of North Dakota Institutional Review Board (IRB). The expiration date of this approval is May 1, 2013.

As principal investigator for a study involving human participants, you assume certain responsibilities to the University of North Dakota and the UND IRB. Specifically, any adverse events or departures from the protocol that occur must be reported to the IRB immediately. It is your obligation to inform the IRB in writing if you would like to change aspects of your approved project, prior to implementing such changes.

When your research, including data analysis, is completed, you must submit a Research Project Termination form to the IRB office so your file can be closed. A Termination Form has been enclosed and is also available on the IRB website.

If you have any questions or concerns, please feel free to call me at (701) 777-4279 or e-mail michelle.bowles@research.und.edu.

Sincerely,



Michelle L. Bowles, M.P.A., CIP
IRB Coordinator

MLB/jle

Enclosures

Appendix G

Informed Consent

TITLE: Caregivers of children with disabilities: An exploratory study of factors influencing occupational therapy home programming engagement

PROJECT DIRECTOR: Sara [REDACTED], occupational therapy student (MOTS); Rebecca [REDACTED], (MOTS); Dr. Anne [REDACTED], PhD, OTR/L.

PHONE #: Sara (701) [REDACTED]; Rebecca (701) [REDACTED]; Dr. Anne [REDACTED] (701) [REDACTED]

DEPARTMENT: University of North Dakota: Department of Occupational Therapy

We would like to invite you to take part in this research study which is titled, “Caregivers of children with disabilities: An exploratory study of factors influencing occupational therapy home programming engagement”.

You are invited to take part in this research study because you are a parent or caregiver of a child (birth through 17 years old) who has a disability and receives occupational therapy services. Specifically, you are invited to participate if your child and family are currently carrying out a home program that was given to you by an occupational therapists or if you have done so in the past.

This study is being done by Rebecca [REDACTED] and Sara [REDACTED]. We are students at the University of North Dakota. Anne [REDACTED] (our advisor) is also assisting with this research. The results of this research will be used to complete our degrees and provide information to the occupational therapy profession.

This research is being done to learn about things that make it easy or hard for families to complete home programs that are provided by therapists. We hope the information we learn can be used to improve occupational therapy services for families.

This message has been sent to parents of children who have disabilities in different parts of the U.S. We hope that more than 100 people may complete this study.

This research study involves completing a survey. It will take about 15-20 minutes to do this survey. The survey has questions about your ideas about the home program, what could be done to make the home program better, how confident you feel carrying out the home program, things that make it difficult to do home program, and if you feel the program helps your child. There are also demographic questions.

Taking part in this research study is completely voluntary. You are free to skip any questions that you do not want to answer. You can also stop taking the survey at any

time. Once you are done with the survey, you can click “submit” and the survey results will be automatically be sent to a secure database.

There may be some risks from being in this study. You may feel frustrated or uncomfortable when completing the survey. Such risks are not viewed as being in excess of what many people feel during daily life. You do not have to answer any questions you do not want to answer. You can also choose to stop filling out the survey at any time and exit the survey. There is no penalty for choosing not to participate or exit the survey before it is completed.

You may not benefit personally from being in this study. However, we hope that, in the future, other people may benefit from this study. We hope to gain information that can be used by occupational therapists to design home programs that work best for all children and their families.

There are no costs for you to participate in this research study.

You will not be paid for being in this study.

The University of North Dakota and the research team are receiving no payments from other agencies, organizations, or companies to conduct this research study.

No data that can identify you will be collected and individual surveys will remain confidential. We will not track internet provider addresses. The information that is gathered will be presented in a form of a summary if published. Only the researchers and the people who audit research studies will have access to the data. After 3 years, the data will be destroyed.

Completing this study is voluntary and you can skip any questions. If you decide to participate, you can exit the survey at any time without penalty.

Thank you for your time and consideration. If you have any questions, you can contact the student researchers or their advisor:

Rebecca [REDACTED]

(701) [REDACTED] or [REDACTED]@my.und.edu

Sara [REDACTED]

(701) [REDACTED] or [REDACTED]@my.und.edu

Anne [REDACTED], PhD, OTR/L (Advisor) at

(701) [REDACTED] or [REDACTED]@med.und.edu

University of North Dakota

Department of Occupational Therapy

2751 2nd Ave. N Stop 7126

Grand Forks, ND 58202

If you have any questions regarding your rights as a research subject, or if you have any concerns or complaints about the research, you may contact the University of North Dakota Institutional Review Board at (701) 777-4270. Please call this number if you cannot reach the research staff or if you wish to talk with someone else.

Please feel free to print a copy of this consent form for further reference.

By choosing the item marked “I understand this study and would like to participate. I understand I can stop completing the study at any time by closing the internet window.” you are giving your consent to participate in this research. This also means that you understand the study and that you can exit the study at any time.

If you choose not to participate, you can exit from this page now.

Thank you for your time and consideration.

____ I understand this study and would like to participate. I understand I can stop completing the study at any time by closing the internet window.

Appendix H

Multi-dimensional Occupational Therapy Home Programming Engagement Survey

Q1-6 This section is about your child's response to the home program. Please read the statement in the column on the left and mark the circle in the column that best describes how much you agree or disagree with the statement.

	Strongly Disagree (1)	Disagree (2)	Neither Agree nor Disagree (3)	Agree (4)	Strongly Agree (5)
My child's mood is better after doing the home program. (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My child feels better physically if we do the home program. (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My child likes doing therapy at home. (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The home program causes my child discomfort. (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The home program activities give my child just the right challenge (not too hard, not too easy). (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My child can do more for himself or herself after doing the home program. (6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q7-10 This section is about how you feel about the home program. Please read the statement in the column on the left and mark the circle that best describes how much you agree or disagree with the statement.

	Strongly Disagree (1)	Disagree (2)	Neither Agree nor Disagree (3)	Agree (4)	Strongly Agree (5)
My child's home program is important to me. (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am motivated to complete the home program with my child. (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am hopeful that the home program will help my child. (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I do not understand the importance of the home program. (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q11-16 Please read the statement in the column on the left and mark the circle that best describes how much you agree or disagree with the statement.

	Strongly Disagree (1)	Disagree (2)	Neither Agree nor Disagree (3)	Agree (4)	Strongly Agree (5)
My child's home program takes too much time. (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am stressed about doing the home program. (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Carrying out my child's home program is part of our daily routine. (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My child's home program is difficult to fit into my family's schedule. (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The home program has activities my child would do anyway. (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My child's home program has to be done too often. (6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q17 Please mark the items that make it hard to carry out your child's home program (check all that apply).

- Lack of directions by the therapist (1)
- Budget (financial concerns) (2)
- Busy family life (3)
- Busy work or school schedule (4)
- The program is too long (5)
- The home program is confusing (6)
- The therapist does not understand my family's needs (7)
- The activities do not focus on my child (8)
- The activities are too hard for my child (9)
- I don't understand how the activities are helping. (10)

Q18 Please mark the items that make carrying out your child's home program easy.

- The therapist provides good education (1)
- Instructions are clearly written (2)
- Photographs are provided to help us remember how to do the activities (3)
- Practicing the program with my child and the therapist (4)
- Using everyday activities for the home program (5)
- My child enjoys the home program (6)
- The therapist is motivating (7)
- My child's therapist checks in with us to monitor progress (8)
- We were involved in the goal-setting process (9)

Q19 How many times per week is your child's home program recommended?

- 1 time per week (1)
- 2 times per week (2)
- 3 times per week (3)
- 4 times per week (4)
- 5 times per week (5)
- 6 times per week (6)
- daily (7)

Q20 How often are you able to complete the home program?

- 0-25% of the recommended time (1)
- 25-50% of the recommended time (2)
- 50-75% of the recommended time (3)
- 75%-100% of the recommended time (4)

Q21 Which option best describes your child's ability to do everyday tasks? (such as brushing his or her teeth, getting dressed, etc.)

- The same as others his or her age (1)
- Less than others his or her age (2)
- Much less than others his or her age (3)

Q22 Which option best describes your child's ability in the school setting?

- The same as others his or her age (1)
- Less than others his or her age (2)
- Much less than others his or her age (3)

Q23 Which option best describes how your child interacts with other children?

- As much as others his or her age (1)
- Less than others his or her age (2)
- Much less than others his or her age (3)

Q24 Who helped design your child's home program? (Mark all that apply)

- Me (1)
- My child (2)
- Occupational Therapists (3)
- Teachers (4)
- Doctors (5)
- Other (6) _____

Q25-27 Please read the column on the left and mark the circle that matches how much you agree.

	Strongly Disagree (1)	Disagree (2)	Neither Agree nor Disagree (3)	Agree (4)	Strongly Agree (5)
I feel confident carrying out my child's home program (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am able to help my child do the activities as well as anyone else. (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am able to change my child's home program with ease. (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q28-33 The next questions deal with aspects of the environment that impact your home program. Please read the statement on the left and mark the circle in the column that best describes how much you agree.

	Strongly Disagree (1)	Disagree (2)	Neither Agree nor Disagree (3)	Agree (4)	
We have enough space in our home to carry out the home program. (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
We have the right equipment to carry out the home program. (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My child and I are not able to do the activities in our home. (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
There is too much going on in our home to do the suggested activities. (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Doing the home program activities negatively affects other family members. (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Family support helps us do the activities at home. (6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q34 Where does (or did) your child receive occupational therapy services? (Check all that apply)

- School (1)
- Hospital (2)
- Clinic (3)
- In my home with a therapist (4)

Q35 How long have you and your child carried out an occupational therapy home program?

- Less than 1 month (1)
- 1-2 months (2)
- 3-4 months (3)
- 5-6 months (4)
- 7 months to a year (5)
- More than 1 year (6)

Q36 What is your gender?

- Male (1)
- Female (2)
- Other (3)

Q37 Which of the following best describes your marital or partnership status?

- Single (1)
- Married (2)
- In a partnership (3)
- Separated (4)
- Divorced (5)
- Widowed (6)
- Never Married (7)

Q38 What is the age of your child who receives or has received occupational therapy services?

- 1 day to 2 years (1)
- 3-4 years old (2)
- 5-8 years old (3)
- 9-12 years old (4)
- 13-17 years old (5)

Q39 What is the gender of your child who receives or has received occupational therapy services?

- Male (1)
- Female (2)

Q40 What best describes your employment status?

- Employed full time outside of the home (1)
- Employed part time outside of the home (2)
- Employed full time but work from home (3)
- Employed part time but work from home (4)
- Not employed in a job outside of the home (5)

Q41 5. How many children (under the age of 18) are currently living in your house?

- 0 (1)
- 1 (2)
- 2 (3)
- 3 (4)
- 4 (5)
- 5 + (6)

Q42 What is your total annual household income? (in U.S. Dollars)

- Less than 30,000 (1)
- 30,000 – 39,999 (2)
- 40,000 – 49,999 (3)
- 50,000 – 59,999 (4)
- 60,000 – 69,999 (5)
- 70,000 – 79,999 (6)
- 80,000 – 89,999 (7)
- 90,000 – 99,999 (8)
- 100,000 or more (9)

Q43 Who is your child's primary caregiver?

- Mother (1)
- Father (2)
- Two parents (3)
- Other Caregiver (4) _____

Q44 Which of the following items best describes your child's condition? (Check all that apply)

- Autism (1)
- Attention Deficit Hyperactivity Disorder (ADHD) (2)
- Cerebral Palsy (3)
- Developmental Delay (4)
- Down's Syndrome (5)
- Genetic Condition (6)
- Anxiety (7)
- Depression (8)
- Oppositional Defiant Disorder (9)
- Bipolar Disorder (10)
- Other (11) _____

Q45 In which state do you currently reside?

- Alabama (1)
- Alaska (2)
- Arizona (3)
- Arkansas (4)
- California (5)
- Colorado (6)
- Connecticut (7)
- Delaware (8)
- District of Columbia (9)
- Florida (10)
- Georgia (11)
- Hawaii (12)
- Idaho (13)
- Illinois (14)
- Indiana (15)
- Iowa (16)
- Kansas (17)
- Kentucky (18)
- Louisiana (19)
- Maine (20)
- Maryland (21)
- Massachusetts (22)
- Michigan (23)
- Minnesota (24)
- Mississippi (25)
- Missouri (26)
- Montana (27)
- Nebraska (28)
- Nevada (29)
- New Hampshire (30)
- New Jersey (31)
- New Mexico (32)
- New York (33)
- North Carolina (34)
- North Dakota (35)
- Ohio (36)
- Oklahoma (37)
- Oregon (38)
- Pennsylvania (39)

- Rhode Island (40)
- South Carolina (41)
- South Dakota (42)
- Tennessee (43)
- Texas (44)
- Utah (45)
- Vermont (46)
- Virginia (47)
- Washington (48)
- West Virginia (49)
- Wisconsin (50)
- Wyoming (51)
- I do not live in the continental United States (52)

Thank you for taking the time to share your ideas and complete this survey. It is greatly appreciated. Have a good day and thank you again for your participation and assistance.

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